SENSORY PROCESSING PATTERNS IN HIGH-ABILITY ADULTS WITH AUTISM SPECTRUM DISORDERS IN THE WORKPLACE

by

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Abstract

Rationale: Previous studies have reported low employment rates for adults with autism spectrum disorders (ASD). The challenges to finding and maintaining work have been attributed to their social, communication, behavioural and sensory processing difficulties. Numerous studies report that children with ASD experience abnormal responses to sensory stimuli, whereas estimates for adults remain unclear. Furthermore, little is known about how sensory processing patterns affect employment.

Objectives: The purposes of this study were a) to describe the self-reported sensory processing patterns in high-ability adults with ASD and compare them to adults without ASD; and b) to explore the role that sensory processing patterns play in the workplace for high-ability adults with ASD.

Methods: A sequential mixed methods approach was used. In Phase I, 20 participants with and 20 without ASD completed the Adolescent/Adult Sensory Profile (AASP) and employment details. In Phase II, 10 of the 20 participants with ASD described their work experiences during phone interviews. Participants with ASD were recruited from autism societies in Ontario and Québec.

Results: Significant differences were found in all four subscales of the AASP between the high-ability adults with ASD and those without ASD. The adults with ASD obtained significantly higher scores on the Low Registration, Sensation Avoiding and Sensory Sensitivity subscales than the comparison group, and significantly lower scores on Sensation Seeking. Approximately half of the adults with ASD were employed, but few were experiencing sustained employment. Participants described using avoidant, replacement and preventative coping strategies to overcome overwhelming sensations at work. Enhanced sensory processing had the potential to improve work performance. Participants chose alternative work environments based on their
sensory preferences and challenges. Disclosing their ASD diagnosis proved to be a delicate process, resulting in differential consequences on accommodations and workplace relationships.

**Conclusions:** High-ability adults with ASD displayed different sensory processing patterns compared to individuals without ASD. Most of these adults showed an awareness of their sensory needs. Sensory processing patterns impacted on work choice, performance and satisfaction. Accommodations that modified the physical environment and occupational tasks promoted an optimal work fit for individuals with sensory issues. Self-employment offered a means of self-accommodation.
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List of Abbreviations

AASP  Adolescent/Adult Sensory Profile
ADHD  Attention Deficit Hyperactivity Disorder
AD    Autistic Disorder
AS    Asperger Syndrome
ASD   Autism Spectrum Disorder
ASD-CARC Autism Spectrum Disorders-Canadian American Research Consortium
DSM-IV-TR Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision
HFA   High-Functioning Autism
JAN   Job Accommodation Network
NAS   National Autistic Society
NOC   National Occupational Classification
NYLS  New York Longitudinal Study (NYLS) Adult Temperament Questionnaire
OAARSN Ontario Adult Autism Research and Support Network
PDD   Pervasive Developmental Disorder
PDD-NOS Pervasive Developmental Disorder-Not Otherwise Specified
PEO   Person-Environment-Occupation
SP    Sensory Profile
TAAP  The Autism Acceptance Project
ToM   Theory of Mind
Chapter 1

Introduction

1.1 General Introduction

The deinstitutionalization movement signaled a shift toward community integration for individuals with disabilities in terms of housing, education and employment (Minnes, Nachshen, & Woodford, 1999; Radford & Park, 1999). Work programs for persons with developmental disabilities that were once managed in institutions began to develop in local communities in North America circa 1950, largely spearheaded by families (Sandys, 1999). However, a lag in community services accompanied the rather quick discharge of patients from psychiatric hospitals in Canada from the 1960s through to the new millennium (Sealy & Whitehead, 2004). The complexities of this shift in paradigm continue to have implications today in service provision for both children and adults with developmental disabilities, including those with Autism Spectrum Disorders (ASD) (Orentlicher & Olson, 2004). Unfortunately, many service providers do not have specialized training to deal with the complex needs of adults with ASD (Autism Ontario, 2008).

Furthermore, full participation and equal access to opportunities in the community is limited in individuals with ASD compared to persons without disabilities (Orentlicer & Olson, 2004). The medical model has traditionally viewed impairment within the individual as the primary obstacle to participation in society (Michailakis, 2003). The social model, in contrast, views disability as a socially constructed phenomenon with the lack of opportunities being the result of social, physical, and legal barriers (Michailakis). The obstacles in the environment, as opposed to the person, are seen as disabling, and thus, intervention focuses on adapting the
environment. In the workplace, accommodations are often required to help integrate persons with disabilities (Davis, 2005; Martz, 2007).

1.2 Background Information

1.2.1 Autism Spectrum Disorders

ASD is “the common clinical term for the pervasive developmental disorders (PDD) described in the classification systems” (Baird et al., 2006, p. 210). The Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR) includes five distinct disorders under the broad category of PDDs: Autistic Disorder, Rett’s Disorder, Childhood Disintegrative Disorder, Asperger’s Disorder (AS), and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) (APA, 2000). Each of these disorders has specific criteria for diagnosis, however, difficulties in social interaction, communication and restricted, repetitive behaviour are common to all ASDs (Huebner & Dunn, 2001), which are considered a class of neuro-developmental disorders (Gillberg & Billstedt, 2000). Given that a wide range of abilities and deficits are seen across the autism spectrum, the terms low- and high-functioning autism are often used. Individuals with normal or above normal intellectual ability, that is, an IQ level of 70+ are considered to be ‘higher functioning’ or have ‘higher ability’ (Howlin, 2004).

In fact, there is confusion as to what differentiates individuals with AS from those with high-functioning autism (HFA) (Hill & Frith, 2003). AS became an official diagnosis when it was included in the DSM IV in 1994 (Fombonne, 2005b). This subgroup includes individuals who display the core features required for an ASD diagnosis but exclude individuals with delays in language and cognitive development. What is not clear is the designation of those individuals who had significant delays when first diagnosed but later on became fluent and more socially engaged. Although it is not a diagnosis in the classification systems, these individuals are now
typically termed individuals with HFA (Hill & Frith). A review of the literature by Howlin (2004) suggests that the differences in presentation between HFA and AS diminish in adulthood. Despite their high IQ scores, a poor prognosis is often seen in both of these individuals.

The term *autism* is being used in the literature to describe all the conditions seen across the spectrum (Garcia-Villamisar & Hughes, 2007; Ganz, 2007; Howlin, 2004; Huebner & Dunn, 2001). While some study authors use the term autism as a collective term, others differentiate among the various forms of autism. Given the inconsistent uses of the terms in the literature, this thesis attempted to include the original terminology used by the various study authors, otherwise the encompassing term of ASD was used. In addition, the term ‘high-ability adults with ASD’ will be used to collectively delineate all the study participants in this study who were diagnosed with a form of ASD and were able to self-report without the need for assistance.

Prevalence rates for all PDDs have increased to an estimated 0.6% of the population; however, Fombonne (2005b) cautions that this rise in prevalence may not necessarily imply an increase in the incidence of new cases. Based on reviews of published epidemiological studies, current global estimates for the prevalence of PDDs are as follows: autism at approximately 13 per 10,000, AS at 2.6 per 10,000, and PDD-NOS at 20.8 per 10,000 of the population (Fombonne, 2005a; 2005b). Overall, exact prevalence figures are difficult to ascertain due to the changed diagnostic criteria for PDDs over time and the different methodologies used across survey studies (Fombonne, 2005b).

The financial implications of caring for autism are substantial on families and society, particularly in health care and social costs (Autism Ontario, 2008). In the United States, societal costs for caring for all individuals with autism is over $35 billion per year and $3.2 million for each individual with autism over their lifetime (Ganz, 2007). In Canada, Autism Ontario (2008)
translates these costs to average anywhere from $1.4 to 8.4 billion for one generation. Ganz argues that the largest expenses are not incurred in childhood, but rather in adulthood. Adult care and lost productivity (in terms of unemployment or reduced work in both the adult with autism and their family members) contributes the most loss to personal income and societal costs.

Recent epidemiological and economic studies on individuals with ASD suggest an increase in prevalence rates and substantial costs related to ASDs. The need for additional financial and social support becomes clear, especially considering the changing needs as children with ASD become adults.

1.2.2 Employment and Support Needs for Adults with ASD

Studies have estimated the employment rate for adults with autism to be at approximately 20% and those with higher functioning autism to be at about 30% (Howlin, 2004). The challenges to finding and maintaining work for these individuals have been attributed to their social, communication and behavioural difficulties (Capo, 2001; Nesbitt, 2000), including difficulties in processing sensory information (Capo, 2001; Hurlbutt & Chalmers, 2004; Orentlicher & Olson, 2004).

Most individuals with autism require some type of ongoing support, but few resources and services are available (Autism Ontario, 2008; Howlin, Alcock & Burkin, 2005). In adulthood, support is needed in the areas of employment, living arrangements and social interactions (Howlin, 2004). Current adult services in Canada focus on individuals with intellectual disabilities, neglecting a group of individuals with ASD (Autism Ontario, 2008). Despite their need for support, individuals with AS have also been denied assistance based on average or above average intelligence levels (Frith, 2004; Howlin).
The repercussions of unemployed adults with ASD are felt by society and family members (Howlin, 2004). Many are dependent on families, government or charity sources for financial assistance (Howlin). Medical care, including treatment for the psychological effects of unemployment is costly. Funding specialized education and training programs are also expensive, with many having failed to transfer the skills they learned at school into concrete vocations (Mawhood & Howlin, 1999). A change to the current education and vocational systems becomes necessary.

The economic consequences are not limited to adults with lower abilities, but also extend to the higher functioning adults, with lack of supported employment as a contributing factor. The average annual cost for young adults with HFA, including AS, was calculated to be 31,604€ (approximately $49,559.50 CAD) in Western Sweden, with large productivity losses at 45% of total societal costs (Jarbrink, McCrone, Fombonne, Zanden & Knapp, 2007).

With a dismal employment outlook and increasing reliance on external sources for assistance, many adults with ASD remain dependent, regardless of abilities. Predicting a successful and satisfactory future for individuals on the spectrum is not a simple feat. Many factors need to be considered in ensuring quality outcomes.

1.2.3 Outcome Measures

Academic achievement and IQ levels have traditionally been the benchmarks for predicting successful outcomes in individuals with autism (Burgess & Gustein, 2007); however, IQ scores alone may not be adequate indicators for success in this population (Mawhood & Howlin, 1999). Burgess and Gutstein argue that these outcome measures are poor predictors of quality of life for individuals with autism. They recommend ‘real-world predictors’ such as
employability, social support, family life and self-determination as better outcome measures for individuals with autism.

Despite employment being central to the quality of life for adults with ASD, limited research exists in this area (Hurlbutt & Chalmers, 2004). Wehman (2003) maintains that integration at work is not the only point to consider, but level of integration, or inclusion, is also essential for job satisfaction and quality of life. Workplace inclusion is an important outcome of supported employment programs for persons with disabilities (Wehman). Job satisfaction is an important factor that predicts quality of life for employees, including individuals with ASD (Burgess & Gutstein, 2007). Unfortunately, quality of life indicators in the area of employment have not been sufficiently explored in the autism literature (Garcia-Villamisar, Wehman & Navarro, 2002).

Other important employment outcomes for individuals with ASD are work performance, social integration, and level of satisfaction with vocational support programs. In addition, income level, hours worked, job retention, job placement and length of time to placement are also important considerations for successful work outcomes (Hillier et al., 2007). A vital component to employment longevity is the presence of a job coach, who helps to facilitate work integration, including establishing natural supports in the workplace (Hawkins, 2004). Chiocchio and Frigon (2006) found that job tenure or length of time in a job increases for individuals with developmental disabilities such as mental retardation when both the employee and work environments are satisfied; consequently, work integration must include a good fit between the person and the environment.
Thus, important employment outcome measures include areas such as workplace inclusion, job satisfaction, duration and performance. Individuals with ASD may need to overcome personal challenges or barriers in the workplace in order to perform maximally at the workplace. One area of difficulty may be related to the sensory processing abilities within the adult with ASD.

1.2.4 Sensory Processing Functioning and ASD

The challenges facing persons with ASD are often attributed to social, communication and restricted patterns of interest; however, many persons with ASD also have sensory processing difficulties, which have an effect on behaviour and performance in daily activities (Dunn, Saiter, & Rinner, 2002; Dunn, Smith-Myles, & Orr, 2002). A growing number of studies are uncovering the prevalence of sensory processing problems in children and adults. An estimated 30 to 100% of children with ASD experience abnormal responses to sensory stimuli (Dawson & Watling, 2000), whereas estimates for adults remain unclear.

Kanner’s first description of autism included children with atypical communication, behaviour and sensory sensitivities (Ruble & Sears, 2001). The children first studied by Hans Asperger also demonstrated different sensitivities to taste, touch, and sound. Despite these early observations, sensory processing difficulties are not considered as main criteria for diagnosis of ASD in the present DSM-IV (Dunn, Smith-Myles, et al., 2002). There have also been many autobiographical accounts of persons with ASD such as Grandin, White and Jolliffe who have described their sensory sensitivities (Attwood, 1998). Given the prevalence of sensory abnormalities and several autobiographical reports, researchers argue for the inclusion of a sensory processing component to the criteria in the DSM-IV for an autism diagnosis (Chamak, Bonniau, Jaunay & Cohen, 2008; Dunn, Saiter, et al., 2002; Dunn, Smith-Myles, et al., 2002).
1.2.5 Research Methodology

Few studies have used qualitative methods to elicit the viewpoints of persons with autism (Chamak et al., 2008; Mercier, Mottron & Belleville, 2000). Areas explored within qualitative research include, but are not limited to, explorations on life experiences (Hurlbutt & Chalmers, 2002), restricted interests (Mercier, Mottron & Belleville), perceptual, cognitive and emotional information processing (Chamak et al.), sensory, motor and communication issues (Shoener, Kinnealey, Koenig, 2008) as well as employment needs (Hurlbutt & Chalmers, 2004; Muller, Schuler, Burton & Yates, 2003).

Fewer still are published articles on autism using mixed method research designs. Mixed methods research uses a practical, outcome-oriented approach to answer complex research questions (Johnson & Onwuegbuzie, 2004). Combining qualitative and quantitative methods can reveal information not otherwise obtained from research with either method alone. Strengths of mixed methodologies include the ability to generate and then test theory, confirm findings, and obtain greater breadth and depth on a research topic; however, drawbacks may include prolonged time, funding and the need for knowledge in both qualitative and quantitative methods (Johnson & Onwuegbuzie, 2004). Different types of designs are possible by varying combinations of data collection and analysis. Qualitative and quantitative data collection can occur sequentially or concurrently (Creswell, 2008) and several procedures exist for data analysis (Johnson & Onwuegbuzie, 2004).

Forthofer (2003) argues that health problems involve multi-layered systems including social, behavioural, biological and environmental causes. Furthermore, she contends that health sciences and mixed methodology are both applied sciences; as such, new trends including patient-centered care and health promotion can be incorporated within this methodology. Given the complexity and variability seen in ASD, mixed methods research is a natural option.
**1.3 Problem Statement**

Most studies on autism disorders focus on children, while research with adults is limited (Brereton & Tonge, 2002; Howlin, 2004). Consequently, adults in this population remain underserved across Canada (Autism Ontario, 2008). Various individuals with autism have described the phenomenon of ‘sensory overload’, or an intense reaction to sensory input (Orentlicher & Olsen, 2004); however, little is known about the sensory processing difficulties experienced by adults with ASD and their effect on employment. Consequently, suitable employment accommodations related to sensory processing issues have not been empirically studied in this population. Furthermore, limited published qualitative research on ASDs means that in-depth information about the experiences lived by this population is lacking. In order to increase our understanding of this particularly personal phenomenon, it is beneficial to seek the meaning of sensory experience from the individuals themselves.

**1.3.1 Purpose Statement**

The purposes of this two-phase study were to:

a. Describe the self-reported sensory processing patterns in high-ability adults with ASD and compare them to adults without ASD.

b. Explore the role that sensory processing patterns play in the workplace for high-ability adults with ASD.

**1.3.2 Research Questions**

The following research questions and sub-questions were posed:
I. Do high-ability adults with ASD present with unique sensory processing patterns, as measured through self-report?
   a. Is there a common sensory processing profile in high-ability adults with ASD?
   b. Is there a significant difference in sensory processing patterns between high-ability adults with ASD and those without ASD?

II. What are the experiences of high-ability individuals with ASD with intense sensory processing patterns in the workplace?
   a. What is the nature of their employment?
   b. What are their challenges at work?
   c. How do they cope with their sensory challenges at work?
   d. How do sensory processing patterns affect job choice, performance, and satisfaction?
   e. What accommodations help to facilitate workplace inclusion?

1.4 Overview of Thesis

The general aim of this thesis was to explore the sensory processing experiences of high-ability adults with ASD at work. This thesis is organized into five chapters. Chapter 1 has provided background information on ASD, challenges in employment, outcome measures and research methodology. The second chapter provides a review of the literature related to employment, accommodations and sensory processing in individuals with ASD. Chapter 3 describes the methodology used in this mixed methods study. The fourth chapter reveals the quantitative and qualitative findings of the study. The final chapter discusses the results in light of the current literature as well as the research and workplace implications.
Chapter 2
Literature Review

2.1 Process of Review

The initial goal of the literature review was to explore the employment challenges for adults with ASD; this led to a search on the evidence to date on sensory processing dysfunction within this population, specifically in adults.

Questions posed during the literature search included: what are the challenges to finding and maintaining employment for adults with ASD?; how many adults with ASD are employed and what type of work do they engage in?; what is the prevalence of sensory processing dysfunction in individuals with ASD?; what assessment tools are available to evaluate sensory processing in adults?; what supports help them to work?; and what are the personal views of individuals with autism regarding work and sensory experiences?

Several literature searches were conducted using databases such as PsychInfo, AMED, CINAHL, EMBASE, and Health and Psychosocial Instruments. Search terms included autism, autism spectrum disorder, Asperger syndrome, adult, sensory processing, sensory processing dysfunction, sensory processing patterns, employment, work, workplace, occupation, accommodations, supports, qualitative research and mixed methods.

2.2 Employment and ASD

Work has been shown in the literature to have several psychosocial benefits, such as structuring days, creating meaningful lives, providing social connections, and improving self-identity (Sandys, 1999). Individuals with autism have much value to offer at work; many are reputed to be hard-workers, reliable and motivated (The National Autistic Society, 2008).
Hawkins (2004), an expert in employment for individuals with AS describes this population as having qualities that employers seek, such as trustworthiness, honesty, a strong work ethic, and many have exceptional analytical skills.

Unfortunately, employment rates for individuals with ASD are low. Jobs found are often poorly remunerated, menial and incongruent with their qualifications (Howlin, 2004). These poor employment opportunities also affect high functioning adolescents and adults (Howlin et al., 2005). In a study on the long term outcome of adults with autism with higher IQs, Howlin, Goode, Hutton and Rutter (2004) found that the majority were found to be very dependent on the support of family or others for financial assistance and for independent living. Those that found jobs mainly did so through family contacts. Higher functioning adults frequently experienced long periods of unemployment (Mawhood & Howlin, 1999), with low self-esteem and depression often following (Nesbitt, 2000). These psychological consequences often occur in individuals with ASD with higher ability, likely because of their increased insight compared to individuals with severe autism (Autism Ontario 2008; Nesbitt).

Challenges to work have been identified by individuals with autism in the literature. In a study by Muller, Schuler, Burton and Yates (2003), adults with AS and HFA identified the following obstacles to successful employment: difficulties in navigating through the job application process, adjusting to the new job routine, and communicating and socializing with coworkers and employers. This study sought individuals who self-reported problems with social cognition, and therefore, their results highlighted social difficulties in particular. The participants in Hurlbutt and Chalmer’s (2004) study expressed difficulty with the social, communication and sensory aspects of work. One participant in particular expressed the potential for employers to
unknowingly cause further stress to individuals with AS who experience ‘sensory overload’, or the inability to manage the excessive amounts of sensory input received.

Individuals with ASD vary in terms of their ability to work and where they work. Four models of service in employment exist and are available to individuals with developmental disabilities: competitive employment, sheltered workshops, supported employment (Capo, 2001; Sandys, 1999) and self-employment as a newer service model (Sandys). Competitive employment refers to regular work that offers above minimum wage salaries and benefits (Capo). Sheltered workshops are segregated programs that aim to train skills for use in community employment; however, critics have argued that wages are often low and skills may not be transferrable to other settings (Sandys). In supported employment programs, individuals work in regular settings and are facilitated by job coaches who offer training and support to the individual as well as the employer or coworkers (Sandys). Self-employment refers to an individual working for himself independently; whereas supported self-employment offers additional support (Sandys).

Common types of employment for individuals with ASD have been in sheltered workshops, supported employment programs (Garcia-Villamisar, Ross & Wehman, 2000; Garcia-Villamisar et al., 2002; Howlin, 2004) and in competitive employment (Schaller & Yang, 2005). Adults with lower functioning ASD have often worked in sheltered workshops, whereas individuals with mild or moderate forms of autism have had better outcomes in supported employment (Garcia-Villamisar, 2000 [Spanish] as cited in Garcia-Villamisar & Hughes, 2007). Supported employment programs designed for persons with autism have been few (Garcia-Villamisar et al., 2000), especially those with higher functioning autism (Howlin et al., 2005). Nevertheless, Howlin suggests that the majority will require some form of support and can even be successful given the right type of support (Mawhood & Howlin, 1996).
The supported employment model has been found to increase job satisfaction, quality of life (Garcia-Villamisar et al., 2002; Howlin et al., 2005; Mawhood & Howlin, 1999), self-confidence, self-worth and independence in persons with ASD (Rideley & Hunter, 2006). Cognitive impairments seen in ASD can be a challenge to finding gainful employment; however, supported employment programs can improve executive functioning in adults with low educational levels (Garcia-Villamisar & Hughes, 2007). Howlin et al. (2005) concluded that the type of supported employment for adults with HFA or AS needed to be appropriate to the individual’s intellectual abilities in order to be satisfying to the individual and cost effective for governments. In a study on competitive employment (Schaller & Yang, 2005), individuals with autism earned higher wages and worked longer hours per week compared to supported employment; however, the authors suggest that people who work in supported employment may choose to earn less in order to keep their Supplemental Security Income (SSI) benefits, a US federal income supplement program.

2.2.1 Supports and Accommodations

Barriers to inclusive employment vary by the type of disability and can include physical, attitudinal or social limitations (Martz, 2007). Contributing to the lack of job opportunities and supports for individuals with autism is a poor understanding of this disorder (Nesbitt, 2000). Accommodations at work allow individuals to complete their job tasks with the help of additional support (Hawkins, 2004). Employers may be willing to accommodate employees for a variety of reasons, such as receiving government subsidies, maintaining stability of positions, or for humanitarian reasons (Hawkins). Employers may also extend these modifications to all workers in order to improve productivity and perhaps to avoid possible lawsuits (Ontario March of Dimes & Partners, 2007).
‘Reasonable accommodation’ is a legal requirement found in various federal laws in the United States of America for employers to follow “unless it would cause [employers] undue hardship” (U.S. Department of Labor, 2009). It includes “any change in the work environment or in the way a job is performed that enables a person with a disability to enjoy equal employment opportunities” (U.S. Department of Labor, 2009). In Canada, the Canadian Charter of Rights and Freedoms stipulates that every person has the right to equal protection and benefit of the law, regardless of physical or mental disability (Department of Justice Canada, 1982). Accommodations are required under the Canadian Human Rights Act (Canadian Human Rights Commission, 2007). These federal laws were made to protect persons with a disability against discrimination; provincial laws such as the Ontario Human Rights Code (Ontario Human Rights Commission, 2008) and the Quebec Charter of Human Rights and Freedoms further state the rights of all individuals (Commission des Droits de la Personne et des Droits de la Jeunesse, 2009).

The most common work accommodations found for individuals with disabilities are physical accessibility, modified work environments, task modification, and flexible scheduling (Davis, 2005). Persons with ASDs may benefit from accommodations such as the provision of concrete examples on acceptable behaviour, advance notice of meetings, written instructions, or a break down of assignments (Hawkins, 2004; Job Accommodation Network [JAN], 2009; Kitchen, 2007). Mawhood and Howlin (1999) found that if supports in the workplace matched the needs of high-ability adults with autism, there was greater chance for success in the workforce. This view points to a need for individuals to become better advocates for themselves.

There is limited information in the literature about how persons with disabilities view accommodations at work. According to Schartz, Hendricks and Blanck (2006), individuals with
disabilities that have knowledge of their accommodation needs have an increased likelihood of obtaining employment. In a study done by Muller, Schuler, Burton and Yates (2003), the employment supports for individuals within the autism spectrum differed from those with other developmental disorders. The participants in this qualitative study reported their needs as including social, communication and attitudinal supports as well as autism awareness training at the work site. Similarly, following a qualitative study on the views of adults with AS, Hurlbutt and Chalmers (2004) concluded that job flexibility in terms of hours, breaks, amount of work or work location is an important accommodation. Employer needs, however, were assessed in a study by Nesbitt (2000) and it was found that organizations employing individuals with AS were more receptive to information regarding support, whereas those not employing them focused on expected behaviours at work. Systematic studies dedicated to determining accommodation needs specifically for sensory processing difficulties in individuals with ASD were not found in the literature.

The results of a study on the quality of life of men with AS showed that these individuals were not satisfied with their social and physical functioning (Jennes-Coussens, Magill-Evans & Koning, 2006). The authors suggest that the physical domain of quality of life may be related to the motor or sensory issues present in these individuals. They believe that assessments of physical functioning may assist individuals in choosing suitable jobs.

2.3 Autism Spectrum Disorders and Sensory Processing Functioning

Sensory processing is defined as the “ability to register, decode, comprehend, and differentiate sensory input, sensory sequences, and sensory patterns” (Huebner & Dunn, 2001, p. 13). Sensory abnormalities across all the senses have been documented for individuals with autism (Harrison & Hare, 2004). In Baranek’s (2002) extensive review of sensory and motor
interventions in children with autism, 42 to 88% of older children with ASD were found to have unusual sensory responses. Specifically, children with ASD between the ages of three and six were found to have sensory processing differences compared to children without ASD (Watling, Deitz & White, 2001).

In a critical review of sensory dysfunction in autism, Rogers and Ozonoff (2005) did not find clear evidence that children with autism have more sensory problems than those with other developmental disorders. On the other hand, there was evidence to support that they have more sensory symptoms than typically developing children, as reported by parent questionnaires. In studies following, Baranek, David, Poe and Watson (2006) found that 69% of children with Autistic Disorder had a higher prevalence of unusual sensory experiences when compared to children with other ASDs (such AS and PDD-NOS), developmental delay and typically developing children. Distinct sensory patterns have been observed in children and adults with a variety of conditions such as developmental disorders, pre-term infants, and regulatory disorders (see Dunn, 2001 for a detailed bibliography).

A study on the patterns of sensory abnormality in individuals with autism revealed that more than 90% of children with autism are affected across different sensory domains; in addition, sensory abnormalities continued to be seen with increasing age and different IQ levels (Leekam, Nieto, Libby, Wing & Gould, 2007). In contrast, a study by Kern et al. (2006) found that sensory dysfunction lessened with age in individuals with autism. This study included a sample of children and adults from 3 to 56 years old using the Sensory Profile (Dunn, 1999); this tool is aimed at uncovering different sensory processing patterns in children from 3 to 10 years old and is completed by a caregiver (Dunn). At the time of designing this study and during data collection, no other published study had previously researched self-reported sensory processing
patterns in adults with ASD. In a very recent study by Crane, Goddard and Pring (2009), adults with ASD self-reported more extreme sensory processing patterns compared to adults without ASD.

2.3.1 An Overview of Assessments used in Sensory Processing for Adults

Most published assessments measuring sensory processing were developed for children; researched and published tools designed specifically to measure sensory processing in the adult population are few (Brown, Tollefson, Dunn, Cromwell, & Filion, 2001). In Kinnealey, Oliver and Wilbarger’s (1995) study on the coping strategies of adults with sensory defensiveness, an over-reaction to harmless stimuli, the authors created the Adult Sensory History Interview in order to screen cases, given the lack of available instruments at the time. Harrison and Hare (2004) also developed the Sensory Behaviour Schedule and applied it to caregivers of adults with autism with the goal of planning interventions such as maximizing suitable environments.

The Adolescent/Adult Sensory Profile (AASP) is a published instrument designed to evaluate how individuals respond to different sensory experiences in their environment (Brown & Dunn, 2002). It is a 60-item self-report questionnaire using a five-point Likert scale indicating the frequency of responses to different sensory experiences that results in four different scores; these scores reflect the four different sensory processing patterns, based on Dunn’s (1997) Model of Sensory Processing (see section 2.3.2). Each quadrant reflects multiple sensory systems; that is, items in the questionnaire for each quadrant include auditory, visual, touch, activity level, taste/smell, and movement processes (Pohl, Dunn, & Brown, 2003). Typical examples include: “I find it difficult to work with background noise (for example, fan, radio)” in the auditory processing category, “I limit distractions when I am working (for example, I close the door, or turn off the TV)” in the visual processing category, and “I avoid elevators and/or escalators
because I dislike the movement” in the movement processing category. Classifications within the AASP are available and were based on testing individuals without disabilities (n=496). Cut-off scores for each quadrant allow for comparisons to be made between the population to be tested and this normative base (Brown & Dunn).

A series of studies was conducted by a group of researchers, including the developers, to determine the reliability and validity of the AASP tool. In order to verify whether items in the questionnaire represented the intended quadrant, face validity was determined by an expert panel of eight judges who attained full agreement after the revision of one item. Item reliability using Pearson product-moment correlations were also acceptable after revisions were made to the sensation avoiding subscale, with values ranging from $r = 0.26$ to 0.56. This tool showed acceptable internal consistency, a measure of how well the different items in the same test correlate with each other, with Cronbach’s alpha values ranging from 0.60 to 0.78. Construct validity, the degree to which the tool measures what it purports to measure, was verified physiologically by observing responses to auditory stimuli obtained via skin conductance.

Responsivity differed significantly across the four groups \(F (3, 17) = 8.38, p=0.001\), as did habituation to the stimulation, as defined by no response twice consecutively \(F (3, 17) = 46.85, p<0.001\) (Brown, Tollefson, Dunn, Cromwell & Filion, 2001). The AASP was compared to another tool, the New York Longitudinal Study (NYLS) Adult Temperament Questionnaire, to determine the convergent and discriminant validity. Moderate correlations ranging from 0.30 to 0.46 were found between some of the subscales of the two tests (Harcourt Assessment, 2005).

Thus far, this tool has been used in research studies with different populations in order to understand differences in sensory processing. In a study by Brown, Cromwell, Filion, Dunn and Tollefson (2002), adults with schizophrenia and adults with bipolar disorder were found to score
higher on the sensation avoiding subscale compared to mentally healthy adults. Adults with schizophrenia also scored higher on low registration and lower on sensation seeking than the mentally healthy controls. Age-related differences in sensory processing patterns are also seen in older adults (Pohl et al., 2003). Crane et al. (2009) have also used this tool in their study on adults with ASD.

The AASP (Brown & Dunn, 2002) is among the few published tools used to evaluate sensory processing uniquely in adults. The AASP allows the researcher or clinician to assess the impact of sensory processing on performance and satisfaction in daily activities (Harcourt Assessment, 2005). Completing a sensory questionnaire may offer the participant different benefits: it allows for active participation by the participant to identify personal sensory preferences (Brown et al., 2001), it increases the participant’s awareness of how they respond to their sensory environment and it can also be empowering for the individual, by leading them to organize their routines or choosing work environments (Pohl et al., 2003). Obtaining a sensory history through a questionnaire provides information on contextually-based behaviour that may not be apparent in a clinical observation (Brown et al.). This tool was judged by this study’s principal investigator (TB) to be an age-appropriate tool that would reveal information more pertinent to adults aged 18 and over, such as behaviours used to cope in social or work-related situations.

2.3.2 Dunn’s Model of Sensory Processing

Both the Sensory Profile (Dunn, 1999) and the AASP (Brown & Dunn, 2002) tools were designed based on Dunn’s (1997) Model of Sensory Processing, which describes the process on two continua: neurological thresholds and self-regulation strategies (see Appendix A). The low to
high continuum of neurological thresholds describes the amount of stimuli needed by the nervous system to produce a response. A high threshold suggests an individual requires a large amount of stimuli from the environment in order for the nervous system to detect them in contrast to the small amount needed for an individual with a low threshold. The self-regulation strategies are the behaviours used by individuals to respond to the demands of the task and environment. An active behavioural response occurs when an individual responds to the stimuli, while a passive response means a lack of acknowledgment of the stimuli by the individual. The two continua intersect, resulting in four distinct patterns of sensory processing: low registration, sensation seeking, sensory sensitivity and sensation avoiding. Individuals with low registration typically exhibit flat affect, appear unmotivated, and do not notice the happenings in their environment. Those with sensation seeking characteristics show engagement and excitement in their surroundings. Sensory sensitivity refers to persons who are more aware of their surroundings and consequently are more distracted. Individuals within the sensation avoiding quadrant avoid unfamiliar and difficult to modulate stimulation; as such, they prefer predictable environments and rituals (Dunn, Saiter et al., 2002).

These four sensory processing patterns are theorized to occur in all individuals, with some showing more intensity than others (Dunn, 2007). This model has been applied to children and adolescents with AS (Dunn, Saiter, et al., 2002). Common characteristics displayed by these youth have been described within each of the four sensory processing patterns (see Appendix B). According to Dunn, Saiter, et al., knowledge of these patterns can assist service providers in planning specific interventions in areas such as home, school and other community activities for individuals with AS.
2.3.3 Sensory Processing and Activities of Daily Living

“Sensory integration theory refers to constructs that discuss how the brain processes sensation and the resulting motor, behavior, emotion, and attention responses” (Miller, Anzalone, Lane, Cermak & Osten, 2007, p. 135). In this vein, it is hypothesized that the stereotypic behaviours associated with individuals with autism may relate to problems in modulating sensory information (Baker et al, 2008; Dunn, Myles, et al., 2002). Likewise, difficulties in socialization seen in ASD may also be attributed to sensory processing difficulties (Dunn, Smith-Myles, et al.; Hilton, Graver & LaVesser, 2007; Leekam et al., 2007). Significant relationships were found between sensory processing patterns and social, emotional and behavioural functioning in children with Autistic Disorder (Baker, Lane, Angley & Young, 2008). The resultant increase in anxiety, aggression or stereotypic behaviours can interfere with performance in daily skills and completion of life roles (Orentlicher & Olsen, 2004).

Sensory processing functioning becomes important when it affects participation in daily life (Dunn, 2007). Studies on sensory processing and ‘occupation’ defined by occupational therapists as the engagement in daily life pursuits (Huebner & Dunn, 2001), are limited in the literature. In an effort to study the relationship between sensory processing and the ‘occupation’ of play in children with sensory processing dysfunction, Bundy, Shia, Qi and Miller (2007) were not able to find an increase in playfulness after intervention; however, a relationship between sensory processing and performance in daily life activities such as leisure, work and social relations has been reported by researchers, professionals (Dunn, Saier, et al., 2002) and individuals with ASD (Hurlbutt & Chalmers, 2004), including Grandin, Shore and Willey (Dunn, Smith-Myles, et al., 2002).
The environment can inhibit or facilitate maladaptive behaviours by offering supportive or challenging environments (Mailloux & Roley, 2004). Information on sensory processing can be used to match the task or context to a person’s strengths and challenges in daily living activities and can ensure more productive and satisfying work (Dunn, 1997). Published studies focusing exclusively on sensory processing and the ‘occupation’ of adults such as work in the ASD population were not found in the literature. Contextual information becomes vital to consider in the workplace in order to assess how the environment can enable function.

2.4 Occupational Therapy: Knowledge in Sensory Processing and in Employment

Capo (2001) argues that employment in autism is not sufficiently researched in the occupational therapy literature, despite the fact that productivity is one of the core features addressed by the profession. Occupational therapists are qualified to assess and treat sensory issues and to adapt environments; therefore, they are well suited to assist individuals with autism in work integration (Capo; Orentlicher & Olsen, 2004). In addition, occupational therapists have the ability to help individuals translate their sensory preferences to succeed in everyday functioning; for instance, knowledge in sensory processing patterns can help guide daily choices that will impact on satisfaction (Dunn, 2001).

2.5 Summary of the Literature Review

In summary, employment outcomes for individuals with ASD are poor, with many adults being financially dependent on family and government assistance, including high functioning individuals. Although individuals with ASD may be great assets to a workplace, many require some form of support to accommodate for challenges in the social, communication, behavioural
and sensory spheres. Unusual sensory processing patterns in children with ASD have been well researched. Studies on the sensory processing abilities in adults with ASD are only recently emerging. Occupational therapists have long been interested in the effects of sensory processing on daily life activities. How these sensory processing patterns affect the social participation of adults with ASD has been given little attention in the literature.
Chapter 3
Methods

3.1 Research Design

The purposes of this study were to describe the sensory processing patterns in high-ability adults with ASD and to explore the influence of these patterns on their work experiences. In order to do this, a mixed methods procedure involving a sequential design was used (Creswell, 2009). In this two-phase study, Phase I involved quantitative data collection and analysis followed by Phase II qualitative data collection and analysis (see Figure 1). The objectives of Phase I were to describe sensory processing patterns in high-ability adults with ASD, test the hypothesis that these adults report different sensory processing patterns compared to a group without ASD, and to select cases for Phase II. The objective of Phase II was to explore how the sensory processing patterns found in the high-ability adults with ASD relate to their work experiences. This chapter will first describe Phase I in its entirety, including participant selection, inclusion/exclusion criteria, as well as assessment and analysis procedures, followed with the same information for Phase II.

Figure 1: Study Design using a Sequential Mixed Methods Approach
3.1.1 Research Paradigm

Mixed methodology follows a pragmatic worldview or belief that research should focus on understanding a given problem through a multitude of approaches. Unlike the post-positivists or constructivists who subscribe to specific views, researchers who use mixed methods are not concerned with a particular philosophy or methodology (Creswell, 2009). Within the pragmatic view, multiple perspectives are recognized and the use of quantitative and qualitative methods are seen as compatible (Johnson & Onwuegbuzie, 2004).

3.2 Description of Phase I: Sensory Processing Patterns and Employment Characteristics

Information on general demographics, employment details, and sensory processing patterns was gathered from the participants with ASD through mail and those without ASD in person. The data collected was used primarily to compare the two groups on their sensory profiles and employment information and then used to inform the next phase of the study.

3.2.1 Hypothesis

For Phase I, the following non-directional hypothesis was tested, based on anecdotal accounts and previous research: There will be a significant difference between the scores of high-ability adults with ASD and those without ASD on each of four subscales of the Adolescent/Adult Sensory Profile.

3.2.2 Participant Selection

Recruitment for Phase I took place from August 2008 to March 2009. Convenience sampling was used to locate participants with high-ability ASD. Several community autism organizations were approached via email or telephone, including: Geneva Centre for Autism, Kerry’s Place Autism Services, Miriam Foundation, The Autism Acceptance Project (TAAP),
Autisme Montréal, employment agencies specializing in vocational rehabilitation and provincial Autism and Asperger’s Societies. In addition, research groups such as the ASD studies at Queen’s University and the Autism Spectrum Disorders-Canadian American Research Consortium (ASD-CARC) programs were approached. Finally, organizations that include Listerv memberships such as the Ontario Adult Autism Research and Support Network (OAARSN) and the Ottawa Directory of Services for Children and Adults with ASD were asked for assistance in recruitment. Sample size was not predetermined given the anticipated difficulty in recruitment. Participants who were recruited were then selected for the study based on the inclusion/exclusion criteria (see section 3.2.3).

After initial contact with the various community agencies, a recruitment letter (see Appendix C) was sent out along with copies of the recruitment flyer (see Appendix D). For those organizations who requested it, the original research proposal and the Queen’s University ethics approval (see Appendix E) were also sent.

A comparison group was included in the protocol in March 2009 as this was deemed beneficial to the interpretation of the results. These participants were recruited during the month of March 2009 in Kingston through convenience and snowball sampling. Twenty individuals were recruited in order to match the number in the ASD group.

3.2.3 Inclusion and Exclusion Criteria

The inclusion criteria for the group of participants with ASD included the following: adult age (18-64 years old), a confirmed ASD diagnosis (name of physician or psychologist who gave ASD diagnosis and age of diagnosis required), verbal communication, fluent in English (reading comprehension and speech), the ability to self-report and the ability to give written informed consent to participate in the study. Inclusion criteria for the comparison group included the following: adult age (18-64 years old), fluent in English and the ability to self-report.
The exclusion criteria for the group of participants with ASD were as follows: blindness or deafness, requires assistance in completing forms and the use of facilitated communication. Persons using facilitated communication were excluded as there is evidence that output of facilitated communication may be influenced by the facilitators (Chamak et al., 2008) and therefore not a true representation of self-report. Also, the presence of blindness or deafness was excluded as in other sensory studies on autism (Kern et al., 2006; 2007) because these individuals are thought to process sensory information differently. Participants in the comparison group were excluded if they: were blind or deaf, had an ASD diagnosis, a family history of ASD, or an intellectual disability. Persons with a family member with autism were excluded given that close relatives may exhibit some characteristics related to autism as per genetic studies (Howlin, 2004).

### 3.2.4 Assessment Procedure

Once participants agreed to participate in Phase I of the study, a package containing the AASP tool (Brown & Dunn, 2002), a demographics form for participants with ASD (see Appendix F) or another for the comparison group (see Appendix G), a Phase I study information letter for the participants with ASD (see Appendix H) or one for the comparison group (see Appendix I), a Phase I consent form (see Appendices J and K) and a postage-paid return self-addressed envelope were mailed out to them. All participants were at liberty to tabulate the scores themselves if they wanted to know the results of their sensory profiles. For all who returned the AASP, the scores and sensory classifications were verified by the primary investigator in order to ensure accurate scoring.

### 3.2.5 Analysis Procedure

The goal of analysis for Phase I was twofold. An initial descriptive analysis was performed to display and contrast the general and employment characteristics of the ASD and comparison groups. The second goal of analysis was to test the hypothesis that high-ability adults
with ASD would report different sensory processing patterns compared to adults without ASD. A one-way MANOVA was conducted on the two groups within the four subscales. To further examine the sensory processing differences between the two groups, univariate follow up tests were calculated on the results of the four separate subscales using individual one-way ANOVAs. Statistical analysis was performed with SPSS 17.0.

3.2.6 Statistical Assumptions

The three assumptions underlying the one-way MANOVA were examined. To ensure normal distribution of the data (Green & Salkind, 2005), the subscale scores for each group were examined using the Shapiro-Wilk’s test. All subscales revealed significance values above p=0.05, except for low registration for the comparison group. The subscales with significance were thus considered to originate from a normally distributed population; however, additional investigation was done to ensure normality especially within the low registration subscale. Upon visual examination of the histograms and probability plots (or P-P plots, used to map out how closely the data deviate from normal), the data were considered sufficiently normal to allow for parametric testing.

The second assumption entails equal population variances between the two samples (Green & Salkind, 2005). Box's test of equality of covariance was not significant, suggesting no reason to believe heterogeneity of variance. The last assumption concerns the cases being independent of each other (Green & Salkind). The two groups were independent of each other. Thus, it was determined that the requirements for use of the MANOVA had been satisfied. The statistical method used was verified with the statistician involved with Queen’s University School of Rehabilitation Therapy.
3.3 Description of Phase II: Interviews

This part of the study involved a qualitative research design using the tradition of phenomenology. The objective of this phase was to explore the experiences of high-ability adults with ASD with intense sensory processing patterns in their workplaces through in-depth interviews. “Intense” was defined as high scores obtained on the AASP, that is, scores ranging in the “much more than most people” or “more than most people” classification (as defined by the tool) in at least one subscale.

3.3.1 Phenomenology Tradition

Creswell (1998) classifies phenomenology as one of the five main research traditions within the qualitative paradigm. A fundamental assumption of phenomenology described by the philosopher Edmund H. Husserl is that ‘we can only know what we experience’ (Patton, 2002, p. 105); that is, our initial understanding of an experience comes about through the senses that then permeate our consciousness (Patton). Phenomenology aims to describe the meanings behind the ‘lived experience’ of a particular phenomenon by seeking meanings from the individuals themselves (Creswell; Patton; Van Manen, 1997). It aims to describe what a person experienced and how it was experienced in an effort to obtain the essence of the phenomenon, or ‘what makes a thing what it is (and without which it would not be what it is); that what makes a thing what it is rather than its being or becoming something else’ (Van Manen, 2002).

3.3.2 Interviews

Various research methods can be used to elicit meanings; interviews with persons that experience the phenomenon in question can generate rich, in-depth information. Patton (2002) states that sensory, feeling, knowledge and behavioural questions have the capacity to reveal great breadth and depth of information in the individual interview; also, when extreme or unusual views are sought, individual interviews help to better illuminate the experience. In this study,
individuals with more intense sensory processing patterns were sought for the interview because they were thought to experience the phenomenon in question more profoundly.

Dunn (2001) has argued that “sensory processing is a deeply personal experience” (p. 618). Thus, only the individual themselves can truly describe how they experience sensory information from the environment. It was therefore deduced that sensory experience was best uncovered through a qualitative design, using a phenomenological approach.

**3.3.3 Participant Selection**

Sampling of participants for Phase II was purposive. Purposeful sampling is a strategy used in qualitative research, whereby participants are chosen because they are “information-rich cases” and yield information that is central to the study (Patton, 2002, p. 46). Individuals are selected because they have indeed experienced the phenomenon (Creswell, 1998). Once the analysis from Phase I was complete, participant selection began for the second phase, based on sensory processing and employment characteristics. The selected participants from Phase I described their work experiences during individual phone interviews lasting from 20 to 50 minutes.

Criterion sampling is a type of sampling strategy used to identify cases that meet predetermined criteria; the use of standardized questionnaires is one method that can yield selected cases to be followed up by interview (Creswell, 1998; Patton, 2002). Criterion sampling is well suited to a phenomenological study, as it serves as a quality check that individuals have experienced the phenomenon (Creswell). In this study, the information gained through the AASP tool was used in part for the selection of cases. Those participants with ASD who obtained the highest scores in at least one of the four subscales were considered for the interview; that is, those scores falling within the “more than most people” and “much more than most people” categories set by the AASP classifications. Individuals in this study whose scores fell in the “similar to most
people” classification in all four subscales were not considered for the interview as they were not considered to be a case representative of the phenomenon.

Those eligible for the interview were further stratified into one of two groups, based on employment stability: stable or unstable. Employment status was chosen as a second criterion in order to verify whether a relationship between length of time at a job and sensory processing pattern existed. The criteria for “sustained employment” outlined in Russinova’s (1997) study on patterns of employment in persons with mental illness were applied to this study. To be considered in sustained employment, participants in that study had to have all three criteria met:

- At least ten hours per week of current, competitive employment
- At least six months of continuous competitive employment in the past year
- At least twelve months of employment in the past 24 months, with six months of work in each of the two years.

These criteria were applied to this study because they clearly captured employment status over a set period of time, whereas a clear definition for stable and unstable employment criteria was difficult to find in the literature search. Following these criteria, six individuals were considered to have sustained stable employment and 14 individuals had unstable employment. Three were excluded based on their sensory profiles being in the “similar to most people” classification in the AASP tool, thus not representing intense sensory profiles. Ultimately, five individuals with stable employment were chosen for the interview, along with five from the unstable employment category who had higher scores on at least one subscale of the AASP tool.

As per Morse (1994), the recruitment of six participants is considered an adequate sample to capture the essence of a particular phenomenon, whereas Creswell (1998) recommends ten individuals. With a total of ten participants interviewed in this study, the sample was considered
within the guidelines that allow for a clear description of meaning attributable to an experience. Recruitment within qualitative methods occurs until redundancy of information is achieved; that is, further information is no longer obtained through additional data collection (Lincoln & Guba, 1985). For a study this size, it would be difficult to achieve saturation. In addition, given the variability seen in ASD as well as the varied sensory processing patterns and workplaces, saturation was not met in all themes. Additional research would need to be done to verify whether similar patterns would be seen.

3.3.4 Interview Protocol and Procedure

The interviews took place in February and March 2009. Due to geographic reasons, all interviews were conducted over the telephone by the principal investigator. To ensure privacy, calls were made from a private office in a hospital located in Kingston. The selected participants were contacted to confirm their willingness to be interviewed as they had indicated on the Phase I consent form; an additional consent form was mailed out to those participants for Phase II (see Appendix L). Interviews were digitally recorded for ease of transcription by a professional transcriber.

The interviewer followed a semi-structured interview guide (see Appendix M). Questions were based on the Person-Environment-Occupation (PEO) framework (see Appendix N), one that is widely used in occupational therapy research and practice (Strong, Rigby, Stewart, Law, Letts, & Cooper, 1999). In the employment context, this framework helps to examine the employee’s needs in relation to the work tasks and the environment. The person’s skills, capacities and resources are analyzed; the multidimensional nature of the environment in the work setting is considered; and the physical, cognitive and behavioural demands of work are examined. The result of the complex relationships among these three factors is known as occupational
performance. Difficulties in occupational performance are the result of the complex relationships among these three factors. The PEO framework also allows for a client-centered and holistic approach (Shaw & Strong, 2008), which is congruent with research methods that involve direct interviews with participants to uncover their personal views.

Therefore, interview questions focused on the participant’s job tasks, work environment and sensory experiences at work. Other issues explored were personal coping strategies, work supports received or those deemed important to have, as well as the participant’s perception of an ideal job situation.

### 3.3.5 Qualitative Analysis Procedure

Data analysis in qualitative methods is done concurrently during and after data collection (Patton, 2002). The objective of data analysis in phenomenology is to seek meanings of the lived experience within an individual or shared among persons (Patton). Various forms and procedures have evolved within phenomenology. The VanKaaam method of phenomenological analysis, modified by Moustakas (1994), has been known to offer systematic and rigorous procedures for data analysis (Patton). The following steps outline the procedure used to analyze the data in this method:

1. *Epoche* (a Greek word meaning “to refrain from judgment”): the researcher sets aside any preconceived notions prior to data collection in order to facilitate fresh insights and new knowledge (Moustakas, 1994). This step attempts to eliminate any personal bias, or at least bring these prejudices to a level of awareness (Patton, 2002).

2. *Transcendental-Phenomenological Reduction*: Once judgments have been suspended, information is approached with a fresh perspective in order to come to the original meaning by bracketing the research topic (Moustakas). Through a process of horizontalization, every
statement is treated with equal value. Significant statements relevant to the experience are extracted from the verbatim transcript and irrelevant or overlapping topics are eliminated. These statements are clustered into meaning units and themes. The themes are organized into constituents of the phenomenon, called textural descriptions; that is, “what” was experienced (Moustakas; Patton).

3. Imaginative Variation: The textural descriptions are considered from different perspectives. They are thus considered according to structural descriptions; that is, “how” it was experienced, and in what context (Moustakas).

4. Synthesis of Meanings and Essences: The textural and structural descriptions are combined in order to obtain the essential structures of the experience (Moustakas).

This approach was used to analyze the transcribed interviews in this study. The principal investigator engaged in the process of *epoche* prior to commencing data collection. A conscious attempt was made to set aside personal opinions about the phenomenon of sensory experiences in the workplace for adults with ASD and written out through a Statement of Subjectivity (see Appendix O). Significant statements were initially extracted through a colour-coding system with notes made in the margins on each verbatim transcript. The significant statements were then transferred into a word processing document, from which meaning units were created, and duplications deleted, as per the *phenomenological reduction* step (Moustakas, 1994). For instance, the units coded as “values” or “interests” were grouped into the thematic headings of “employment choice”. Each meaning unit with its associated meaning statements was further subdivided to consider the context. The final theme was the result of a combination of the textural and structural descriptions; for example, “employment choice as a result of personal factors”.

This process occurred after the completion of each interview as a method of verifying whether saturation of themes occurred, whereby no new information is obtained (Creswell, 1998).
and at the end in order to combine the experiences of all ten participants. The themes were then placed into a matrix that divided the stable versus unstable employment group in order to explore qualitative differences. Coding of qualitative themes was done solely by the principal investigator; the findings were then presented to the research team.

3.3.6 Trustworthiness

Trustworthiness is a process that aims to limit bias in interpretation by increasing the credibility and validity of the data analysis (Patton, 2002). According to Patton, quality research depends on a set of criteria, from which judgments about credibility emanate. Rigorous methods exist to enhance the quality and credibility of qualitative research. Creswell (1998) recommends the use of at least two of the eight following procedures in order to ensure trustworthiness of findings:

- Prolonged engagement in the field and persistent observation of the participants
- Triangulation, or using various sources of data, methods, investigators and theories
- Peer review or debriefing with a colleague regarding the findings
- Negative case analysis, in which initial patterns of data are revisited if contradictory patterns are found
- Clarifying researcher bias includes the positioning of the researcher’s preconceived notions or experiences from the beginning of the study
- Member checking the findings with participants to ensure credibility
- Rich and thick description of quotes provides the reader with the ability to make judgments as to whether the findings are transferrable to another situation
- External audits include an independent person evaluating the accuracy of the findings.
In this study, different procedures were used to ensure trustworthy findings. At the outset, the principal investigator clarified any biases through the explicit subjectivity statement (see Appendix O). After each interview, memoing was done to record initial thoughts for analysis and preparation for the next interview.

Triangulation of different methods and analyst reviews were used. Methods triangulation involves the use of a combination of quantitative and qualitative methods as “a form of comparative analysis” (Patton, 2002, p. 558). This mixed methods study used the published AASP tool to ensure that the interviewed participants experienced the sensory phenomenon in question. Primary analysis of interview data was performed by the principal investigator and themes were later verified by the thesis advisor. Additional review came from the supervisory committee, including an expert in qualitative methods. Audience review (Patton) served as an additional peer-review check; the preliminary results were presented and discussed at seminar in the Rehabilitation Sciences department at Queen’s University as well as at a conference for developmental disabilities, in which an audience member and researcher with AS stated that the findings were “bang on”.

An effort was made to clarify meanings during the interviews; some participants emailed the principal investigator after the interview in order to clarify statements made. Several participants provided rich, thick quotes, describing their experiences articulately, which enhanced the credibility of the themes found. An audit trail of all decisions made during research planning, data collection and analysis was kept by the principal investigator.

3.4 Ethical Considerations

Ethical approval for this study was received from the Queen’s University Research Ethics Board (REH-438-08) (see Appendix E). Additional amendments to the study were sought for changes in recruitment procedures. In an effort to recruit more participants, ethics approval was
required for a modification to the study recruitment procedures. The study was advertised through the Autism Connects website belonging to the ASD-CARC program, and required an additional consent form (see Appendix P). The inclusion of a comparison group without ASD was thought to be beneficial to the study in order to have a point of reference from which to compare the AASP results of the ASD group (see Appendix Q for amendment approval).

Confidentiality was maintained by substituting participant names from the AASP tool, the demographics form and verbatim transcripts with numeric codes. The electronic audio-taped interview and verbatim transcripts were uploaded into the principal investigator’s personal computer and secured by a password. All paper and audio materials saved onto CDs were locked in a filing cabinet and held in a locked room.

Potential risks to the study participants were deemed minimal but may have included difficulties in divulging information regarding employment conditions; however, these were anticipated to be a low risk given that all participants live in the community and were presumed competent to consent at the outset. If the participant experienced any form of distress, the principal investigator would be able to recognize symptoms, being an experienced occupational therapist, and refer them to the appropriate resource. Potential benefits were minimal and may have included an increased awareness of the participant’s sensory preferences. Informed consent regarding the purposes, risks and benefits in participating in the study was received from all study participants.
Chapter 4

Results

In this chapter, results obtained from Phase I will first be discussed, including participant characteristics, sensory processing patterns, and employment characteristics. The qualitative findings obtained from the Phase II interviews regarding sensory experiences at work will then follow.

4.1 Phase I: Sensory Processing Patterns and Employment Characteristics

4.1.1 Participation

In total, 40 adults gave signed consent and participated in Phase I of the study. Initially, 32 participants with high-ability ASD were recruited, but three dropped out for personal reasons before the start of the study, one was not reachable and eight were excluded as they did not fulfill the inclusion requirements. Those excluded did not have a definitive ASD diagnosis, they did not supply the name of a physician or psychologist who diagnosed them, or they required assistance to fill out the AASP, and therefore did not truly self-report. In all, 20 individuals with high-ability ASD were included in this phase. The participants included in the study came from two Canadian provinces, Ontario (70%) and Quebec (30%). They were recruited with the assistance of Autism Ontario, OAARSN, ASD-CARC, Queen’s University Autism Research lab and through personal contacts.

Twenty participants without ASD were recruited within Kingston, Ontario through convenience sampling through the principal investigator’s community contacts. An effort was made to match the participants on age and gender. It was difficult to find exact matches, however, closely related matches were found.
4.2 Participant Characteristics

4.2.1 General Demographics

Descriptive statistics were used to calculate the general characteristics of both the ASD and comparison groups. The groups were relatively similar in terms of age, averaging in the mid thirties and ranging between 19 and 63; gender ratios were equivalent. The largest difference was in terms of education, where the comparison group had attained a higher rate of post-secondary and post-graduate education (see Table 1 for details).

Table 1: General Characteristics of Study Participants

<table>
<thead>
<tr>
<th></th>
<th>ASD (N= 20)</th>
<th>Comparison (N=20)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age (years)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>36.9 (11.2)</td>
<td>35.6 (11.3)</td>
</tr>
<tr>
<td>Range</td>
<td>19-63</td>
<td>19-60</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>9</td>
<td>9</td>
</tr>
<tr>
<td>Female</td>
<td>11</td>
<td>11</td>
</tr>
<tr>
<td><strong>Highest Level of Education Attained</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No diploma</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>High School</td>
<td>7</td>
<td>1</td>
</tr>
<tr>
<td>College/CEGEP</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>Bachelor’s Degree</td>
<td>6</td>
<td>10</td>
</tr>
<tr>
<td>Master’s Degree</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>PhD</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Currently pursuing education</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td><strong>ASD Dx</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AS</td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>HFA</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>PDD-NOS</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td><strong>Age of ASD Dx</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>29.4 (13.2)</td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>4-50</td>
<td></td>
</tr>
<tr>
<td>Diagnosed as adults</td>
<td>15/20</td>
<td></td>
</tr>
</tbody>
</table>
Seventy five percent of the individuals with ASD were diagnosed as adults, with age at diagnosis ranging from four to 50 years old (Mean=29.4, SD=13.2). The ASD subgroups recruited were AS (n=12), HFA (n=5) and PDD-NOS (n=3). In terms of co-morbidities, 40% of the ASD sample self-reported diagnosed depression, 35% anxiety and/or panic disorder, 25% ADHD, and 20% learning disability. Only one individual in the comparison group reported depression.

### 4.2.2 Employment Characteristics

At the time of data collection, a higher proportion of individuals in the comparison group were currently employed (85%) compared to those with ASD (55%) (see Table 2).

<table>
<thead>
<tr>
<th>Table 2: Current Employment Characteristics of Study Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Status</strong></td>
</tr>
<tr>
<td>-----------</td>
</tr>
<tr>
<td>Unemployed</td>
</tr>
<tr>
<td>Employed</td>
</tr>
<tr>
<td>Full-time</td>
</tr>
<tr>
<td>Part-time</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Company Size (# workers)</strong></th>
<th>ASD (n=20)</th>
<th>Comparison (n=20)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Small (0-49)</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Medium (50-99)</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Large (100+)</td>
<td>5</td>
<td>14</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Method of Job Procurement</strong></th>
<th>ASD (n=20)</th>
<th>Comparison (n=20)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advertisement</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>Agency</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Contacts</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Self-employed</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Other</td>
<td>5</td>
<td>3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Length of time</strong></th>
<th>ASD (n=20)</th>
<th>Comparison (n=20)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-3 mos.</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>4-6 mos.</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>7-12 mos.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>13-24 mos. (1-2 years)</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>25-60 mos. (2-5 years)</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>61-120 mos. (5-10 years)</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>121+ (10+ years)</td>
<td>4</td>
<td>3</td>
</tr>
</tbody>
</table>
A high unemployment rate was seen in the high-ability individuals with ASD (45%); however, of those employed, more individuals were working full-time (64%) as opposed to part-time (36%). Compared to the adults with ASD who were employed, the comparison group was working fewer hours, with 53% working less than 40 hours/week, compared to 27% of the individuals with ASD. Within the group of adults with ASD, 30% were currently experiencing sustained employment, and thus placed in the stable employment category in this study. Within the unstable employment category, 10% of individuals with ASD were found to be self-employed.

Participants with ASD who were employed at the time of data collection held various job titles (see Table 3). In an effort to standardize job descriptions in Canada, the National Occupational Classification (NOC) was created, classifying occupations according to skill type and skill level of work (Human Resources & Skills Development Canada, 2009).

Table 3: Job Titles of Currently Employed High-Ability Adults with ASD

<table>
<thead>
<tr>
<th>Job Title</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1  Contract worker (cleaning, clerical duties)</td>
</tr>
<tr>
<td>P4  Digital Imager</td>
</tr>
<tr>
<td>P5  Desk Supervisor/Day Camp Counsellor/Gymnastics Teacher</td>
</tr>
<tr>
<td>P7  Compliance Technician</td>
</tr>
<tr>
<td>P8  Industrial Cleaner</td>
</tr>
<tr>
<td>P11 Desktop Product Developer</td>
</tr>
<tr>
<td>P14 Translator</td>
</tr>
<tr>
<td>P16 Research Scientist</td>
</tr>
<tr>
<td>P18 Musician/Composer/Photographer/Astrologer</td>
</tr>
<tr>
<td>P19 Research Assistant</td>
</tr>
<tr>
<td>P20 Educational Assistant</td>
</tr>
</tbody>
</table>

Applied to this study, the two groups showed variations in employment type. Participants in the ASD group were working equally in the areas of natural/applied science, art/culture/recreation/sport and sales/service at the time of data collection, whereas the individuals
in the comparison group worked in areas not seen in the ASD group such as social, health, and business occupations (see Figure 2).

**Figure 2: Areas of Current Employment in High-Ability Adults with ASD and Adults without ASD**

The majority of individuals in the comparison group (82%) were working in large-sized companies compared to 45% of the high-ability adults with ASD. The groups also differed in how they obtained their jobs. The comparison group found their current jobs mainly through advertisements and contacts, whereas the individuals with ASD found their job through different channels; that is, through initial volunteering, dropping off their résumé or working collaboratively with their health care providers. The two groups were relatively similar in terms
of long term job tenure, with 46% of individuals in the comparison group spending more than one year at the same job location compared to 35% of the individuals with ASD.

4.3 Analysis of Sensory Processing Patterns

A one-way multivariate analysis of variance (MANOVA) was conducted to determine the effect of the four sensory subscales on the independent variables (ASD group and the comparison group). Significant differences between the two groups were found among the four subscales, Wilks’s $\Lambda = 0.575$, $F (4, 35) = 6.474$, $p<0.01$. A moderately significant effect size between the two groups was seen with the multivariate $\eta^2=0.425$.

Analyses of variance (ANOVA) on each dependent variable (subscale scores) were conducted as follow-up tests to the significant MANOVA in order to verify how much of an effect was seen within each dependent variable. Significant differences were found in each of the four subscales (see Table 4 for details).

Table 4: Statistics of Subscale Scores on the Adult Sensory Profile*

<table>
<thead>
<tr>
<th></th>
<th>Mean (SD)</th>
<th>Range</th>
<th>F-test</th>
<th>df</th>
<th>p-value</th>
<th>$\eta^2$</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Low Registration</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ASD Group</td>
<td>40.05 (10.56)</td>
<td>24-55</td>
<td>10.89</td>
<td>1, 38</td>
<td>0.002**</td>
<td>0.22</td>
</tr>
<tr>
<td>Control Group</td>
<td>30.25 (8.05)</td>
<td>16-40</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Sensation Seeking</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ASD Group</td>
<td>40.95 (10.03)</td>
<td>25-68</td>
<td>9.67</td>
<td>1, 38</td>
<td>0.004**</td>
<td>0.20</td>
</tr>
<tr>
<td>Control Group</td>
<td>49.65 (7.49)</td>
<td>36-62</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Sensory Sensitivity</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ASD Group</td>
<td>49.85 (10.59)</td>
<td>32-66</td>
<td>25.77</td>
<td>1, 38</td>
<td>0.000**</td>
<td>0.40</td>
</tr>
<tr>
<td>Control Group</td>
<td>35.45 (6.98)</td>
<td>18-44</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Sensation Avoiding</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ASD Group</td>
<td>49.95 (12.30)</td>
<td>30-68</td>
<td>22.20</td>
<td>1, 38</td>
<td>0.000**</td>
<td>0.37</td>
</tr>
<tr>
<td>Control Group</td>
<td>34.65 (7.72)</td>
<td>18-50</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*= scores on the AASP are classified such that mid-range scores reflect similarity to most people and either high or low scores reflect atypical sensory processing

**= significant at $p<0.05$
Moderate effect sizes were seen in the sensory sensitivity ($\eta^2 = 0.40$) and sensation-avoiding ($\eta^2 = 0.37$) subscales, while weaker effect sizes were seen in the low registration ($\eta^2 = 0.22$) and sensation seeking ($\eta^2 = 0.20$) subscales. As seen in Table 4, the high-ability adults with ASD collectively scored higher on the sensory sensitivity, sensation avoiding and low registration subscales compared to the comparison group and lower on the sensation seeking subscale.

Greater variability was observed in the scores of the high-ability adults with ASD than of those in the comparison group. Larger standard deviations were seen in the scores of the ASD group. When the scores of both groups were compared to the normative base provided by the AASP tool, different patterns were seen. In the group involving the high-ability adults with ASD, more individuals responded in the “much more than most people” classification for all subscales except sensation seeking (see Figure 3).

Figure 3: Frequency of Classification Responses for High-Ability Adults with ASD
The frequency of responses for the sensation avoiding and sensory sensitivity were almost equal with low registration following closely. Three high-ability adults with ASD had sensory profiles that were clustered in the “similar to most people” classification; however, in the comparison group, a greater frequency of scores was clustered in the “similar to most people” classification on most subscales. Slightly more scores in the low registration subscale were seen in the “more than most people” classification (see Figure 4).

**Figure 4: Frequency of Classification Responses for Adults without ASD**

![Figure 4](image)

In terms of gender differences, scores for the males (n=9) with ASD were clustered in the “similar to most people” classification (see Figure 5); however, the females’ (n=11) responses were clustered in the “much more than most people” classification for the low registration, sensory sensitivity and sensation avoiding subscales (see Figure 6). Both males and females showed fairly equal responses in the sensory seeking subscale, tending towards the “similar to most people” and “less than most people” classifications.
Figure 5: Frequency of Classification Responses for High-Ability Males with ASD

Figure 6: Frequency of Classification Responses for High-Ability Females with ASD
With regards to employment stability in the ASD group, the sensory profiles did not reveal great differences among the stable employment group (n=6) and unstable employment group (n=14). The stable employment group did, however, show higher scores within the “much more than most” classification, especially in the sensation avoiding subscale (see Figure 7). Meanwhile, the unstable employment group showed more of a broad profile (see Figure 8).

**Figure 7: Frequency of Classification Responses for High-Ability Adults with ASD with Stable Employment**

![Classification of Responses According to the Adult Sensory Profile](image-url)
In summary, results from Phase I demonstrate that high-ability adults with ASD in this study showed different sensory processing patterns compared to adults of similar age and gender without ASD. Significant differences were found in all four subscales for the two groups. High-ability adults with ASD scored higher in the sensation avoiding, sensory sensitivity and low registration subscales than the comparison group, but lower in the sensory seeking subscale. Responses by males in the ASD group tended towards the “similar to most people” classification whereas the females’ scores were skewed towards the “much more than most people” classification. Also, approximately half of the adults with ASD in this study were employed, but few were experiencing sustained employment. Those adults with ASD with stable employment...
tended to have sensory profiles with scores slightly skewed to the “much more than most people” classification than those with unstable employment, who showed more of a broad profile.

4.4 Phase II: Participant Interviews

Participants for Phase II were selected from the group of high-ability adults with ASD from Phase I. Participants were chosen based on intense sensory processing patterns and employment stability.

4.4.1 Participant Characteristics

Ten high-ability adults with ASD from Phase I were interviewed about their work experiences. Five participants were chosen from the “stable employment” group and five from the “unstable employment” group to verify whether employment stability had any influence on the challenges experienced, coping strategies used or accommodations received. No qualitative differences were found between the stable and unstable employment groups.

Demographically, the two groups differed in terms of age, gender and ASD diagnosis. The stable employment group included mostly females within a lower age group and all having reported an AS diagnosis. They all had post-secondary education and were currently employed. The unstable employment group included mostly males who were older and reported a variety of ASD diagnoses. Only 40% had post-secondary education and 40% were self-employed. In terms of sensory profiles, more variability in scores is seen in the stable employment group than the unstable group. The stable group held higher scores in the sensation avoiding and sensory seeking subscales. Alternately, the unstable group scored higher in the low registration and sensory sensitivity scores (see Table 5 for details). Of the ten participants with ASD interviewed, 60% reported depression, 50% anxiety and/or panic disorder, 30% ADHD, 30% learning disability and 20% obsessive compulsive disorder (OCD).
Table 5: Characteristics of Interviewed Participants with ASD (n=10)

<table>
<thead>
<tr>
<th></th>
<th>Stable Employment (n=5)</th>
<th>Unstable Employment (n=5)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (years)</td>
<td>39</td>
<td>46</td>
</tr>
<tr>
<td>Age Range</td>
<td>26-51</td>
<td>37-63</td>
</tr>
<tr>
<td><strong>Gender Ratio</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Male: Female)</td>
<td>1:4</td>
<td>4:1</td>
</tr>
<tr>
<td><strong>ASD Diagnosis Given</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>100% AS</td>
<td>40% AS</td>
</tr>
<tr>
<td></td>
<td></td>
<td>40% PDD-NOS</td>
</tr>
<tr>
<td></td>
<td></td>
<td>20% HFA</td>
</tr>
<tr>
<td><strong>Diagnosed as adults</strong></td>
<td>100%</td>
<td>100%</td>
</tr>
<tr>
<td><strong>Post-Secondary Education completed</strong></td>
<td>100%</td>
<td>40%</td>
</tr>
<tr>
<td><strong>Current employment</strong></td>
<td>100%</td>
<td>40% (all self-employed)</td>
</tr>
<tr>
<td><strong>Mean scores on Adult Sensory Profile (SD)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low Registration</td>
<td>39.20 (12.40)</td>
<td>47.80 (6.98)</td>
</tr>
<tr>
<td>Sensation Seeking</td>
<td>39.80 (17.34)</td>
<td>37.00 (6.89)</td>
</tr>
<tr>
<td>Sensory Sensitivity</td>
<td>51.80 (13.39)</td>
<td>54.80 (8.58)</td>
</tr>
<tr>
<td>Sensation Avoiding</td>
<td>58.00 (10.12)</td>
<td>53.80 (6.65)</td>
</tr>
</tbody>
</table>

4.4.2 Phase II: Qualitative Findings

Interviews with the ten high-ability participants with ASD revealed commonalities and differences regarding sensory experiences at the workplace. Overall, seven major themes emerged from the interviews with the participants with ASD (see Table 6 for details). Participants portrayed the challenges but also the benefits that intense sensory processing abilities posed at work. They described personal strategies used in order to produce more satisfying and productive work, but also identified the need for more understanding and support at the workplace.
Table 6: Clusters of Common Themes and Meaning Units (n=10)

<table>
<thead>
<tr>
<th>Cluster</th>
<th>Description</th>
</tr>
</thead>
</table>
| 1. Sensory processing patterns present challenges to work | a) Individual & multiple sensory domains affected  
b) Different environments as the source  
c) Physical, cognitive & emotional effects on the body  
d) Work performance and satisfaction affected |
| 2. Use of active coping strategies to overcome sensory challenges | a) Resourcing various types of strategies (Avoiding, Replacement, Preventative)  
b) Influence of work task and environment on coping strategy accessed |
| 3. Positive contributions of enhanced sensory processing | a) Superior technical skills  
b) Complexity in replacing sensory irritation with sensory pleasure |
| 4. Employment choice as a result of personal factors | a) Sensory processing patterns guiding choice of career  
b) Value of work overriding sensory challenges  
c) Interests guiding career path  
d) Unconscious reasons to lessen anxieties |
| 5. Implications of disclosing ASD diagnosis at work | a) Ambiguous & individual process surrounding decision to disclose  
b) Selective disclosure to employer and/or coworkers  
c) Disclosure depending on timing of diagnosis  
d) Positive and negative consequences of disclosure on accommodations  
e) Initiating accommodations without disclosure |
| 6. Importance of awareness of needs in acquiring accommodations | a) Importance of self-awareness of needs  
b) Importance of others’ awareness of their needs  
c) Self-awareness as a combination of personal experiences and help from others |
| 7. Optimal work fit | a) Environment & job tasks affording the possibility of control, predictability, flexibility & balance |

Some participants were more forthcoming and articulate than others in sharing their experiences. In addition, some participants spoke about their experiences in different job situations and one participant in particular held several jobs at once; therefore, verbatim quotes of some participants are used more frequently than others in this thesis. Full saturation of themes was
not achieved in all areas; however, this is reasonable given a combination of factors, namely, the small sample size, variability in sensory profiles and diversity of workplaces. The qualitative themes with supporting quotes are described:

1. Sensory processing patterns present challenges to work

Sensory-related challenges at work were reported by the adults with ASD. The affected sensory domains, including visual, tactile, auditory and olfactory, had consequences to their physical (nausea, fatigue and accumulated stress), cognitive (concentration) and emotional (well-being) functioning. These issues ultimately affected their work performance (productivity).

The high physical demand of processing multiple external stimuli at once was reported by the participants. The gymnastics teacher, who is also a medical student, described her experience in the hospital environment:

“You’re there and a lot of the hospitals use fluorescent lighting and they’re painted high gloss to promote as much light as possible, but that kills me. By noon you want to go to sleep but you have to be there until five or six at night. It’s not good. There are a lot of people around, there are a lot of distractions, there’s different smells, there’s all different noises. It’s very draining (P5).”

Similarly, another participant also described difficulties processing auditory and movement stimulation in his work as a research assistant. He discriminated between the different sources affecting his level of tolerance:

“Well lots of things, sensory stuff. Too many people. Too many noises. Voices and stuff like that. That gets to be too much. I can listen to a radio. But it’s when you have a bunch of people talking at once, all over the place (P16).”

Other reported difficulties were the cognitive and emotional results of processing sensory information, which ultimately affected work performance. Conscious efforts were made to overcome the resultant disruptions, as described by this participant:

“I kind of control my space, I have to live an orderly life as much as I can. I used to work as a research associate and my supervisor was a mess. Piles of papers, were all over the place. That caused me a lot of chaos, confusion and made me far less productive. I also
had to share an office with someone when I was a research associate, and that was
distracting (P16).”

Different environments can be sources for different challenges. One participant
juxtaposed her sensory experiences in her gymnastics and office jobs, which she held
simultaneously, “You don’t have the same issues like the lighting and echoing of the gym but
you’re dealing with computers that are flickering and fluorescent lighting and constant phones
ringing and people coming (P5).”

An additional difficulty described was the lingering effects of having to process difficult
sensory information. The notion of having to recover after work was also described by a couple
of participants. The educational assistant spoke about having to endure a highly sensory-
demanding situation, habituating to the source of the problem:

“It bothered me the whole afternoon… I basically just sat there in the dark and I had my
hands over my ears and every once in a while I would take them off and start getting used
to the noise and when I couldn’t stand it I’d put them back on and then gradually I was
just able to handle more and more. And I went back to work; it was hard (P20).”

Even prior to entering the workplace, individuals described sensory processing
difficulties while on the road. The multisensory environment inherent in public transport, driving
or even walking to work took a toll on them. Some individuals actively came up with alternatives
to avoid driving altogether, as in this case: “I walk or bike. I avoid driving. I don’t drive because I
can’t deal with the lights and reflections of cars and buses are noisy and too many people
touching (P5).” The sensory input of driving wreaked havoc within this educational assistant,
affecting her cognitive faculties, to the point of not knowing what to do:

“If I’m stressed and overtired then it can affect me more. If I—this is not so much at
work, but I’ve had situations where I’ve been really upset. I’m afraid to cross the street
because of the movement. I can’t figure out the movement. I can’t figure out when it’s
safe: the lights, cars, people will be really—and I’ll basically have a major shutdown.
Like, I won’t know how to get home. I basically won’t know how to get home. So I carry
a cell phone with me so that I can call if I feel like I’m going to shut down. I have had a
major shutdown at school before but I don’t usually get myself to that point. I usually go
home or get some medication into me before that happens...No, I don’t drive. I have my license. I did get it, but I hate driving, just because of the movement, and my reactions aren’t always quick enough and I find, even as a pedestrian, if I come up to a stop light sometimes it takes me a while to figure out whether the green means go, the green means stop, and I don’t feel I’m safe as a driver, especially if there’s many things going on around me. I can’t sort out all the different things and be able to make a decision of what to do. I don’t feel I’m safe (P20).”

2. Use of active coping strategies to overcome sensory-related challenges at work

Various forms of active coping strategies to overcome the sensory-related problems at work were reported. Avoidant and replacement strategies, but also preventative approaches, were taken depending on the ability to remove the self from the situation and the intensity of the stimulation for that particular situation. One participant, P18, described the regular use of natural supplements as a preventative measure to prepare himself for the unavoidable stresses prior to his musical performances. A majority of participants described avoidance of a situation or an environment as a usual strategy to avoid an assault to their senses: “I try not to go into the back part of the centre where their kitchen is during that time or I go outside for my lunch hour (P5)”; however, in the event of difficulty in leaving a sensory-provoking situation, some individuals reported taking medication to calm nerves and in one case, a cellular phone to call friends or family for immediate emotional support. A review of the individual sensory profiles of those interviewed revealed that a majority scored highest in the sensation avoiding and sensory sensitivity subscales respectively; these results corroborate the findings in the interview regarding the use of active coping strategies, especially avoidant, to deal with the sensory challenges.

Depending on the work environment and sensory pattern, various behaviours resulted from trying to process the surrounding sensory input. One participant, who rated many items in the touch processing section of the AASP as ‘almost always’ bothersome, described her response to tactile stimuli as a gymnastics teacher, one of her many part-time jobs:
“...kind of a burning sensation if people tend to touch my skin. It’s weird. I have a very exaggerated startle response, so I’ve accidentally punched people who have come up behind me before to pat me on the shoulder. So I tend to avoid physical contact, but in gymnastics you can’t avoid it entirely so it’s just kind of like you know you’re going to be touched, so you try to initiate it if you can (P5).”

Sometimes, trying to avoid areas of work may be difficult to do if it is an intrinsic part of the work environment. Participants have to sometimes resort to making uncomfortable adjustments to the stimuli. This water compliance technician describes her ability to adjust to certain stimuli, but not others:

“Just odd sounds bothered me. It’s hard because it’s a waste water plant. There were things that made me sick, like smells and stuff. I find with smells I can block it out. With visual, it’s not as easy (P7).”

Some participants described replacement strategies that relieved stresses related to sensory processing difficulties. The educational assistant revealed her use of occupation or meaningful activities in order to replace the activity that caused initial stress:

“We had an assembly with all the children...they were supposed to sing as loud as they could, and it set me off. I had a major meltdown because of that...after it was done I left the gym. It was really hard to look at anything and it was even hard to hear anything, so I asked the principal to find me a spot that was dark and quiet...I had my hands over my ears and every once in a while I would take them off and start getting used to the noise and when I couldn’t stand it I’d put them back on and then gradually I was just able to handle more and more...One of the things that I find is really helpful for me when I’m really upset is photography...so I got my camera out and took a lot of pictures and that seemed to calm me down because I’m focused on something else...and with the medication it just helps (P20).”

Some participants engaged in soothing activities that involved other senses in order to override overwhelming feelings. This same participant described rocking, a vestibular activity, as a method to release the sensory ‘overload’:

“...lots of people, lots of stuff in the class. You know if there’s a lot of stuff around. I can get kind of overloaded with just all the visual stuff and so there’s not much I can do with that in my particular job; I mean, a kindergarten classroom is full of stuff, so like I say I will often end up with headaches but I’ve just learned that that’s part of my job and often when I work at home often I have a quiet time in my chair rocking or I’ll lie down or things like that. I’ve just learned to do things. I basically cope throughout the day. It’s
often when I leave school that things kind of hit me and I can have a meltdown sort of in
the evening (P20)."

Where feasible, some individuals modified their own personal environment proactively
and in turn, self-accommodated to the sensory-related issues. Personal offices were thought to be
places relatively easy to change:

“I override their computer system and use my own computer which has a higher
refresh so it’s better and I shut the lights off, and my manager is never there so she
doesn’t mind. The outside part where the public is well lit so you don’t need the lights on.
I turn down the ringer on the phone. It’s easier to make it an accommodating
environment (P5).”

3. Positive contributions of enhanced sensory processing

Although acute sensory processing can be challenging in the workplace, participants also
described positive influences on work performance. Individuals reported how their technical skill
sets as scientists or artists helped them excel in their line of work. One participant, a digital
imager, described how his keen visual sense helped him with his trade:

“I don’t know if I’m bothered by it but I pick up on it…and people say that’s what makes
me a photographer, because I see things that others don’t and it seems to be quite
working to my advantage. I mean I’m always picking up on things that others don’t see
(P4).”

Another participant described the same phenomenon in her work as a compliance
technician. She noted her attention to detail in her sensory profile and elaborated on this during
the interview:

“I notice everything. I’m very bright, and I’m a visual thinker and I never thought there
was a difference. When it comes to water and waste water treatment you’re thinking of
hydraulic load or how a pump turns on or how things knit. I’m just very good at looking
at schematic or troubleshooting in that way because I can visualize it, because I’m very
technical I just pick up on all the stuff (P7).”

Enhanced visual processing was reported to be beneficial in other skill sets such as
driving. This participant who scored fairly high in the visual processing section of the AASP
described his cautious driving:
“I’m more in tune with what’s going on. Again, visually, with seeing things that other people don’t. I have an excellent record. I haven’t had an accident in years and years. Not many tickets. I’m acutely aware of what’s going on around me (P4).”

Furthermore, one participant articulately described how the same sense that causes him irritation in some situations, is also peculiarly responsible for helping him in his work. This musician, whose scores were highest in the auditory processing section of the AASP, described this complex experience:

“The same thing that would make me disturbed by sounds also makes me very good at hearing them….On one hand, I hear so much in the sounds that people never hear they call me a perfectionist. To me it’s just so big I can’t ignore it. On the other hand, I have to pick things out and get one thing at a time. So if I see something I’m not really seeing and if I hear something I’m not really listening. Sometimes that can be very tricky in the process. If I’ve been working on a bass track in the song, and all I hear then is that bass track and everything disappears, it’s hard for me to put it back in and reorient myself in hearing it all in one again. So I have to trick my brain somehow to do that. Sometimes I have to leave it a few days and then go back to it (P18).”

4. Employment choice as a result of personal factors

The participants described their decision to work and their choice of work as the result of several personal factors, including sensory preferences, values and interests, with some on an unconscious level. One musician described his choice of employment as a method of replacing certain auditory processing challenges with his preferences. The type of music he chose to create was:

“…mostly music for meditation, healing that sort of stuff. I started doing the music in a way because I was so disturbed by outer sounds; I wanted to create other sounds that would block out all the other disturbing sounds (P18).”

Despite the sensory-related challenges inherent in the job tasks and environment, these individuals expressed a readiness to endure them based on vocational interests and values. One participant described how she chose to pursue teaching gymnastics based on her values:

“I love teaching. I love the kids and it keeps me active and it’s a good sport and I do well…Gymnastics is satisfying. I go in there, teach some kids some skills. I get to leave without getting kicked in the head (P5).”
In addition to valuing the teaching profession, the sense of naturally understanding the needs of another person with autism was described by this educational assistant:

“On those days I’m in a kindergarten and I work specifically with two five-year-old girls who are on the autism spectrum. So I am with them throughout the day helping them to cope and teaching them and basically being their educational assistant in the classroom. So that can get really stressful at times. Often I’ll have a headache by about two o’clock in the afternoon, but I’ve learned that that’s just what happens and I’ve learned to deal with that. I love my job; I absolutely love it, and I wouldn’t think of doing anything else. In the kindergarten, they come in, I’m responsible for helping them throughout the day with transitions, with their teaching, helping them deal with everything I kind of deal with, because I mean, we’re similar, and all sorts of other things (P20).”

She continued to describe her desire to continue working, with the overall benefits of work outweighing the challenges. The resilience and tenacity within this individual is clear:

“It’s really hard for me to work. It’s a struggle, but I am really stubborn and I’ve always wanted to work. I never wanted to go on disability or you know anything like that. And I’ve been told that maybe it might be a good idea at times of my life when I was really having a hard time that maybe it was time to go on disability but there’s just no way. I will work until there’s absolutely no way I could work. I have a very strong work ethic. I really feel that’s a need for my self-esteem to be making my own money and to providing my own way and so work is hard—it’s not easy for me, but I choose to do it because it helps me with my self-esteem and I just want to be a regular person of society, a valuable person, somebody that’s doing something. And so work does provide for my needs in that way. It provides financial needs; it provides self-esteem needs for me (P20).”

The sense of accomplishment and altruism are also reasons to pursue employment. This research scientist described areas of satisfaction for him:

“I like accomplishing technical, and getting through technical barriers. And two, I have a good working relationship with a few of my coworkers and if I can help them with something technical or statistical I get a great deal of satisfaction out of that. If I can help operationally, because of my skill there, I like that very much. So those are good days (P16).”

Several participants described their work choices as a result of their particular area of interest. One participant described her reasons for choosing medicine, “Medical is kind of my obsession. I started reading medicine books in Grade 2 and so it just kind of happened naturally.
(P5).” Adults who were diagnosed later in life retrospectively came to conclusions for their vocational choices. The participant who was a surveyor also described his love for a subject matter, in this case geography, as a reason for choosing his line of work, “Back in elementary school I came across these maps about to be thrown out. When I pulled out the atlas I couldn’t seem to let go of it. Maps, time and stuff seemed to lead on to surveyor work (P3).” Also diagnosed later in life was the research scientist, who felt he chose his career path unconsciously to avoid stress-provoking situations:

“I had no idea about my diagnosis I just was gifted in certain things, and in those days one would have thought if they were gifted in one thing they were gifted in everything. I kind of stumbled through life and unconsciously made choices that kept me away from people and kept me away from the difficulties of work. For example, after my undergraduate degree, instead of working, which would be difficult and scary I stayed in graduate school. I stayed in graduate school for a long time and worked as a research associate that is not really the real world compared to people in private sector. Then I went into my consulting business at home, which is also not the real world. I realized later that I unconsciously made many decisions to accommodate my stresses and anxieties (P16).”

5. Implications of disclosing ASD diagnosis at work

Participants described the intricacies involved in disclosing their ASD diagnosis, including timing of disclosure, people informed, and consequences of disclosure. The decision to disclose their ASD diagnosis to employers or coworkers was an ambiguous process for many of the participants. The deliberation process, in which they carefully weighed the pros and cons of such an action, resulted in a difficult choice. Disclosure was dependent on several factors: a fear of job loss, distrust of what may be done with the sensitive information, or learning from past experiences:

“Being experienced with other coworkers who approached her for accommodations, they ended up fired….Well that particular coworker had a visual impairment. She was having issues using the computer screens, she really needed a magnified thing to work in the office and the manager decided it was too much effort to go through it….Depends on whether I’m going to lose my job over it. I’ve told preceptors during my clerkship and I have two be ok with it and one be very anti. I told people in undergrad when I needed accommodations in their classroom or for testing. I had one professor that if I needed
accommodations that I wasn’t mentally capable to be in the University environment and I should seek education elsewhere. I would consider telling them but I would pick who I told \( \text{(P5)} \).”

Trust in the person told was an essential ingredient in the decision to disclose. A certain amount of empathy was described by one participant as she reasoned her colleagues’ behaviour, “They’re just looking at me from the perspective as a person without Asperger’s, so they don’t understand. I don’t know if I can trust them to deal with the information appropriately \( \text{(P7)} \).” Distrust in an employer, colleague or the greater system at large can be the result of past experiences and become a compelling reason to refrain from divulging this information:

“I found I have to get the job, and then tell them at some point, if there becomes a problem. My experience is not to say anything until something comes up…Even then sometimes it’s difficult and sometimes I think maybe I shouldn’t have said anything. There’s all sorts of laws, anti discriminatory but that’s just something that’s not reality. Well that’s been my experience \( \text{(P4)} \).”

However, disclosing the ASD diagnosis at work was beneficial to some participants. For those individuals, disclosure only came after their continued struggles at work became apparent. The initial fear of divulging or being ‘found out’ at work can become a relief. After having recently disclosed to her boss and coworkers, the educational assistant had a positive experience:

“… [laughing] I just did today. One of them I told today because this particular school it was Monday when I cried for an hour and a half; and that was the first time that I really had a meltdown there this year. It’s a new school so nobody knew about my background. And it’s really lonely; you feel that you have a secret or something and you’re afraid somebody’s going to find out. So it was really hard because I knew I was crying and I didn’t think I could tell anybody. So my doctor and I talked and we agreed that maybe it was time that I talk to the principal. So I did talk to her today. My other school, at the library, when I had the meltdown when I was in the gym, which was about two or three weeks ago, I told the principal just so that she knew I wasn’t going nuts on her, and actually she asked me if I would speak to the whole staff. So on the PA day I spoke to the whole staff about what it was like to have Asperger’s. And that went really well, so I was really pleased. I guess I was really scared about the kindergarten school because I have this fear that if they know that I have Asperger’s they’ll say, “Well, you’re not fit to work with autistic kids.” And I just kept having this fear in me so I was afraid to tell her. But she was really good today; she was really positive with me and she said that I would be the right one to work with the kids. So that was encouraging. And she was very supportive and she was willing to, if I needed anything, to let her know, and she just
likened it to somebody with a broken leg or somebody with diabetes or something. So she was really good. It was better than I thought it was going to be…I think it’s important that somebody knows, somebody that the person would trust, so that if they are having a hard time that there’s somebody that they can go to who will understand a bit. I don’t know whether it has to be your boss or whether it could be somebody else, a co-worker or whatever (P20).”

Adding to the complexity is the fact that some individuals received late diagnoses, only after being hired at a particular place of work. The decision to tell afterwards was a delicate process and became a question of timing. Retrospectively, this participant who is currently unemployed, described his opinion on why disclosing would be beneficial:

“Yes I’d rather be straight forward at the beginning, even at the interview, so nothing comes up afterwards and regardless of if people say that might hurt my chance getting the job, then I would say if the employer bases their decision on that then I don’t think I’d like to have that employer anyways. That’s why I’d rather be straight forward with people, because if they do know, they are more understanding and I then I have a fair chance at getting a job (P3).”

When to disclose and to whom became relevant. Selective disclosure within the workplace had varying consequences on acceptance and accommodations. In the case of one participant, her disclosure was late and resulted in disbelief, “I’ve only ever told one person. Never my boss. The person I told I don’t think believed me (P7).” However, others had positive results with disclosure being restricted to coworkers and not the employer:

“I get along very well with my coworkers, and most of them are fairly accommodating to me. They’re willing to have lights off in the conference room when we have staff meetings, they print out notes for me so I don’t have to use the screen if I don’t want too. They don’t yell and they make an effort not to randomly hug me (P5).”

Others had experienced mixed emotions about receiving accommodations. Negative coworker reactions occurred in some cases as they perceived the supports as threatening, giving the worker with ASD an added advantage. The research scientist described his experience:

“…so I work at home as much as I think I can get away with. This kind of annoys my coworkers, for me to be able to do that. It’s a bit of a compromise. So working at home is great, so I can work in isolation. I guess I paint a picture of what my characteristics are,
strengths and weaknesses and kind of get my managers to accommodate that on a friendly personal level. Well I remind them that I have Asperger’s, I work that into discussions (P16).”

Disclosing was not always deemed necessary. One participant stated that she obtained accommodations simply by asking for specific changes as a means of being able to complete her duties:

“With accommodations, I do not ask with or under the premise of having Asperger’s. I just ask as if it was something that I need...He’s been very accommodating. Knowing that you have Asperger’s is a huge relief because in the past I couldn’t figure out why certain things bothered me and not other people or that I wasn’t able to handle things, certain deficiencies (P7).”

6. Importance of awareness of needs in acquiring accommodations

The majority of participants in this study expressed the view that it is important for others to understand their needs at work, including their sensory needs. Employers, coworkers and vocational counselors may not fully comprehend their challenges. Knowing what they require, they feel results in the ability to complete their jobs. In addition, the participants felt that coming to an understanding of their own needs was a personal journey.

When some study participants took the initiative to ask for accommodations at their workplaces, it resulted in negative consequences. Employers or colleagues were not open to the requests of their sensory sensitivities. One participant had this opinion to give, “That when people describe sensitivity to something, their comments be taken seriously. People shouldn’t shove the problem back on the autistic person; they make the autistic person solve their own problems. Insensitivity I’d call it (P3).” Anger was expressed in the lack of understanding and the resultant treatment given by the employers when another participant initiated his requests:

“We’re not stupid; we’re not lazy; we’re capable of doing quality work and being employed. We would just like a little understanding and that unfortunately our abilities to process noises and distractions and others can deal with, we can’t deal with it in the same way. We need a little understanding and accommodation and not to be belittled or chastised because we ask for it (P4).”
Not only was an understanding from their employers vital, but so was self-awareness of their own needs important. Being an active agent was deemed necessary to get the needed supports, especially in the absence of understanding or services:

“Self awareness is extremely important. If someone is being bothered by something and consciously they don’t know why so they’ll get agitated or anxious about it, that’s a problem. So self awareness, find out what causes the difficulties. You have to do something about it. They have to take specific steps to prevent or block what causes the problem (P16).”

Coming to an awareness of personal needs was not always straightforward. It was a process that resulted from a combination of personal experience and help acquired from others. One participant was only now coming to an awareness of her visual sensitivities:

“I’m pretty aware, personally. I wasn’t always. People have educated me as I’ve gone along. When I was in high school and even early undergrad, especially in grade school people would say you’re squinting or stuff. I’m just starting to really figure out what bothers me (P5).”

Knowing his needs was a subjective experience that came subconsciously but also from working at it for this musician:

“I have to say now I’m becoming aware but it took years of work to get me to this point…In some ways I did, because I created a perfect environment for myself at home…its subconscious, I just certain things suit me and I surrounded myself in the things that suit me…A lot of it was just self awareness. Spiritual work that I’ve done. I have yoga type disciplines too and pretty in-depth therapy (P18).”

Participants expressed the view that responsibility in supporting adults with ASD lies in both the person and society. Dual awareness was felt to be essential in helping to acquire accommodations that fit each person’s needs. One participant had an interesting analogy to this effect:

“That it’s extremely important for not just the autistic person but for everybody, recognizing their needs and make it better… It’s almost like a canary in a coma… might be really disturbed by the lights for instance and they might act up so maybe calm the lighting and they might calm down…The onus has to be on the individual to some point because it’s going to be different from individual to individual. Certainly modern society
doesn’t get how much these things are affecting us. Especially sound, we are very visually cultured so we can’t handle sound as much (P18).”

7. Optimal work fit for sensory needs

The participants in this study held the view that the optimal work situation for their sensory needs had to offer them a certain amount of control, predictability and flexibility. For many, this type of environment was considered to be ideal. The home as a permanent workplace was described as a dream for this participant:

“I would love to work at home, where I have a nice view out the window, nice and sunny, quiet and controlled. No distractions, where I can work for hours at a time, where I know people wouldn’t come in and talk to me at random. That would be ideal. So a home office would be ideal (P16).”

In addition to a quiet atmosphere, having time away from the source that instigates the sensory disturbance was also reported as a necessary component to regaining focus. This medical student described her ideal job:

“My ideal job: anesthesiology in a nice rural town with low lighting and a very quiet operating room in a nice conveniently packed time span. Have everything in the day and then have a large portion of the day to decompress. Minimal people involved…I did a bit of anesthesiology in a small town and it was very quiet. The operating room is quiet. It was just you and the patient. Here there’s like 12 people, it’s busy, people are talking, other patients are trying to get your attention. It’s different (P5).”

Other participants were able to make adjustments to their personal workspaces in order to improve productivity and satisfaction in their current jobs. Participants described the changes they made in order to achieve this sense of predictability, as described by the water compliance technician:

“I rearranged my desk. I reorganized my desk, so I’m further away from the door. Before it was wide open. I’m closed off you can’t really see me; I have more privacy I guess. Most of the stuff on my desk is gone, it’s all put away. I’m all organized and I know where everything is and how I can find it…It’s better now. It’s predictable. I know where everything is and where I keep things. As an operator, I could be at a different plant every day and then because the plants aren’t the same I have to find out where supplies are and things. When I worked at the plant I had to carry my things with me because they’re different. So now things are much better now because I have my own space and it’s regular (P7).”
Two participants who were self-employed were able to self-accommodate to their unique sensory patterns with more ease. This participant described how he modified his own environment in order to support his tactile sensitivities:

“I’ve created an environment for myself where there is relatively very little stuff like that… I keep it really simple; I’m clean with lots of soft fabrics everywhere, and soft lighting… in terms of touch I always have to wear certain fabrics. I covered my office chair with a softer fabric because I found the fabric on it too harsh. That makes me feel better and helps me sit there all day. I get a certain calming response just by touching it (P18).”

The nature of self-employment offered another study participant the flexibility in managing his time in order to accommodate to his sensory experiences. By changing the environment regularly, he was able to successfully manage certain unavoidable environments, until the recession of the 1990s obliged him to return to school and eventually on disability income. He explains how his last job as a self-employed electrician was more suitable than the previous job he held as a surveyor:

“Well as an electrician I didn’t seem to be exposed to one environment day after day for very long. I was always moving from one job site to another and one job might have lasted up to a week. I wasn’t exposed to one environment, noise or anything for too long. By changing back and forth seemed to be more refreshing for me. As an electrician I have been all over and I hardly ever had a reaction like I did in that survey office… As an electrician, because of the changes, I wasn’t subject to one environment for too long. Even if I worked in a small commercial place, sure there were customers and doors banging, but I knew that once I had done by job there fixing the problem, I knew I’d be out of there… but because I was self employed I was able to leave the site when I chose because if there was too much noise I couldn’t stand it… Where if I was working for an employer and I’d have to stay until I finished and the noise was there I don’t think I’d be able to keep a job (P3).”

Alternating job tasks or two different jobs entirely was another ideal that was reported. Balanced periods of focused work with periods of rest may be a compromise that could work for this educational assistant:
“This year I have two different schools I’m at. So at one school I’m in a library, so at that school I go in and I put books away. I have classes that come in during the day and I’m responsible for helping them exchange their books and helping them throughout the library and I do everything sort of connected with the library. So that’s kind of my down job. It helps me regroup from the day that I’m in the kindergarten, which is my other half-time job…I like the library but I miss being in a classroom. I’ve never been in a library; this is the first year that I’ve been an EA in the library and I find it a nice change. It’s sort of a time when I can de-stress a bit but still be working and then get back into the heavier load when I’m with the girls on the other days. …So I’m hoping that maybe I can sort of wrangle something for next year and the next couple years where I can combine a half-time library with a half-time in the classroom ’cause that seems to be a nice fit that allows me to work full-time better (P20).”

All participants expressed the view that individuals with autism with higher abilities are able to succeed at work, given the right fit between their sensory needs and the appropriate environment. This participant described the delicate balance that persons like him need to do in order to participate in society:

“So the understanding of an environment and the sensitivities and what the individual needs, I think, from my own experience in the autism spectrum, can take somebody from really being below their functioning to excelling in some area. The intelligence is there. It’s just the interface that isn’t. To the world, things are really there. It’s the interface between understanding what the world is wanting and having the world understand how you’re trying to put it across (P18).”

In summary, the findings from Phase II indicate that the high-ability individuals with ASD who were interviewed shared common struggles in the workplace, including sensory problems. Given the obstacles, most were able to find suitable active strategies to overcome their sensory sensitivities. Disclosing their ASD diagnosis resulted in differential consequences on accommodations and work relationships. Understanding their sensory needs was considered an important piece to improving job opportunities and retention. Little difference was seen in the sensory profiles between the stable and unstable employment groups. As well, little difference was seen between these employment groups within the qualitative themes.
Chapter 5
Discussion

5.1 Discussion of Findings

5.1.1 Adults with ASD with Higher Ability and Services in Canada

This study aimed to describe the sensory experiences of high-ability adults with ASD in order to understand how human, environment and job factors contributed to the challenges and solutions in the workplace. The majority of the high-ability adults with ASD recruited in this study were from the province of Ontario (70%). In recent efforts to add to the epidemiological studies on PDDs in Canada, Ouellette-Kuntz et al. (2006) estimated prevalence rates to be at 28.4 per 10,000 in the province of Manitoba and 35.2 per 10,000 in Prince Edward Island for children aged 1 to 14 years old. Meanwhile, prevalence rates increased from 12.3 per 10,000 in 1996 to 43.1 per 10,000 in 2004 in children aged 4 to 9 years in British Columbia, based on autism codes provided by the province’s education data base (Ouellette-Kuntz, Coo, Lloyd, Kasmara, Holden & Lewis, 2007). It remains unclear as to how many adults with ASD are living in different provinces in Canada and what proportion are high-ability individuals.

Based on the selection criteria of this study, namely, the ability to self-report independently, the sample included persons within the higher functioning end of the spectrum. Given their normal levels of intelligence, individuals with higher functioning autism, including AS, are often denied the supports they need (Frith, 2004; Howlin, 2004). In an epidemiological review of 21 studies, nearly 29.6% of children with ASD did not have an intellectual disability while 29.3% had mild to moderate intellectual disabilities (Fombonne, 2005a). According to Autism Ontario (2008), adult developmental services in Ontario are largely aimed at persons with an intellectual disability. Consequently, a large proportion of adults without an intellectual...
disability remain underserved in terms of disability-related health care and social services as well as community supports. Although they are considered high functioning individuals, many require ongoing support (Howlin, 2004).

Despite a recruitment strategy targeting agencies across Canada, only 32 participants with ASD were recruited over a six month period, with 20 fulfilling the inclusion criteria. Fear of exposure and stigma as a person with autism may have discouraged the participation of some individuals in a study on employment. In fact, one father tried to enroll his son in this study but his son refused on the basis of a potentially harmful impact on future job prospects.

In addition, more females (n=11) than males (n=9) with ASD were recruited in this study. This is surprising as many studies on autism report gender ratios reflecting higher numbers of males with the condition. In an epidemiological review of studies on autism, male to female ratios were found to be 4.3:1. The difference is greater when intellectual functioning is considered normal, where the male to female ratio is at 5.5:1 than when an intellectual disability is present, 1.95:1 (Fombonne, 2005a).

5.1.2 Sensory Processing Patterns in High-Ability Adults with ASD

The findings of this study gave support to the hypothesis in Phase I that high-ability adults with ASD show differences in sensory processing patterns compared to adults without ASD. The adults with ASD in this study tended to be more sensitive to stimuli in the environment and avoided these situations more than the comparison group. They also did not actively seek out stimulation in their environment. These results are in line with the latest findings of a study by Crane et al. (2009), where adults with AS and HFA scored higher in the low registration, sensory sensitivity and sensation avoiding quadrants and lower in the sensation seeking quadrant than the comparison group without ASD using the AASP tool. In fact, 94.44% reported extreme sensory
processing on at least one quadrant, in which “the extreme 5 percent of these quadrants represented the highest 5 percent of scores in the comparison group” (p.221) and a wide variability of patterns were seen within the ASD group (Crane, Goddard & Pring, 2009). In contrast to this study and Crane et al.’s study, Kern et al. (2007) found that individuals with autism scored higher in the sensation seeking quadrant, compared to the control group without autism. Kern et al.’s study, however, used the Sensory Profile and relied on caregiver report which may not accurately represent how individuals with ASD truly respond to sensory input.

In addition, even within the different ASD subgroups in this study, adults showed variability in their sensory processing profiles, as was also seen in Crane et al.’s (2009) study. Curiously, the adults with ASD in this present study scored higher in the low neurological threshold quadrants (sensory sensitivity and sensation avoiding subscales) but also in the low registration subscale, which is considered to belong to the high neurological threshold quadrant. The results seem counter-intuitive at first glance: how can an individual be so sensitive to sensory stimuli but not register stimuli at the same time? Possible reasons could include that they can be so overwhelmed by the environment that they miss some information; alternatively, they may be so in tune with one particular sense that they disregard their surroundings or cues from other sensory sources; finally, their responses may vary in different environments, for instance, work as compared to home. In Rogers and Ozonoff’s (2005) review of sensory dysfunction in autism, more evidence was found to support the hypo-responsive theory, where individuals with autism are less sensorially aroused, than the hyper-arousal theory. Although their review focused on children, this may explain the findings of elevated low registration scores in the adults with ASD in this study.

Sensory processing differences in adults with ASD have also been found in other studies (Crane et al., 2009; Leekam et al., 2007) and in personal reports of individuals with ASD such as
Grandin, White and Jolliffe (Attwood, 1998). Sensory symptoms in persons with ASD were seen to persist with age in a study done by Leekam at al. In contrast, Kern et al. (2007) found that such symptoms were seen to potentially ameliorate with age. Although the present study was not a longitudinal study, the high-ability adults with ASD did present intense sensory symptoms when compared to adults without ASD.

Documented differences in sensory processing patterns are not only seen in individuals with ASD but also in other disabilities such as attention deficit hyperactivity disorder (ADHD), learning disability, Fragile X syndrome, and schizophrenia when compared with persons without disabilities (see Dunn, 2007, for an extensive review). In a study by Brown, Cromwell, Filion, Dunn and Tollefson (2002), adults with schizophrenia and bipolar disorder also showed differences in sensory processing patterns compared to a mentally healthy group. Although no significant differences were found to account for the variability found within the adults with schizophrenia, the authors suggest that phase of illness or different subtypes may be the reason. Perhaps individuals within the different ASD subgroups would also show differences in sensory profiles. Given the small sample size, this conclusion could not be made.

Overall, a broad range of sensory profiles were observed in the high-ability adults with ASD. The variability in sensory processing patterns also made it difficult to identify clear differences based on sex and employment stability.

5.1.3 Employment Characteristics in the ASD group

The employment rate in this study (55%) was higher than previously reported (20-30%) in Howlin’s (2004) review of the literature. The nature of this study, focusing on employment, and its advertisement as a study on the relationship between sensory processing and employment may have contributed to attracting those that are employed as opposed to unemployed. Geographically, 30% of the sample was recruited from Quebec; only 10% of the Quebecers were
currently working compared to 45% of the Ontarians. In 2006, the province of Quebec had the largest unemployment rate for persons with disabilities at 14.7%, compared to the other provinces (Ministry of Industry, 2008). The current global economic recession that is also affecting Canada (Bank of Canada, 2009) may also have been a contributing factor in the unemployment figures seen in this study. It is encouraging that of those individuals with ASD who were employed in this study, more worked full time hours (55%) than part time hours (27%), where 30 hours or more per week represented full time status and less than 30 hours per week, part-time status (Hawkins, 2004).

Job duration in terms of being at their current place of work for more than 2 years was moderately high for the adults with ASD compared to the comparison group, 64% and 41% respectively (see Table 2). However, when applying Russinova’s (2007) more stringent criteria for ‘sustained employment’, 70% of the individuals with ASD were found to have ‘unstable employment’. This rate is consistent with a review of the reported employment outcomes from the last 40 years provided by Howlin (2004), where individuals with ASD held long periods of unemployment. Little difference was seen in the qualitative themes emerging from the individuals with ‘stable’ and ‘unstable employment’. Perhaps interviewing more individuals would have revealed greater differences, if any.

The types of employment seen in the participants in this study were mainly in the natural/applied sciences, art/culture/recreation/sport, and sales/service, as per the NOC classification (Human Resources & Skills Development Canada, 2009). As per Hawkins (2004), a vocational specialist specializing in ASD, employment trends over the last couple of decades indicate that the service industry, such as finance, government, and wholesale, is overtaking the goods industry. Given the current global economic situation (Bank of Canada, 2009), these trends may change. Individuals in this study were not employed in the business nor government sectors;
however, some were employed in the sales area. Nonetheless, individuals with ASD, including AS, are encouraged by Hawkins to look for jobs that reflect the current labour market.

5.1.4 Sensory Challenges and Coping Strategies in the Workplace

The difficulties in visual, auditory, olfactory, tactile, and movement processing reported by the participants in this study have also been documented for individuals with ASD across these different sensory domains (Harrison & Hare, 2004). Furthermore, many of the participants in this study used active coping strategies such as avoidance, preparation, and replacement strategies. This is consistent with adults with ‘sensory defensiveness’ who have described coping strategies such as avoidance, predictability, mental preparation, talking through, counteracting and confrontation (Kinnealy et al., 1994). Accounts from adults with autism have described coping strategies used for noise and visual sensitivity, such as tuning out sounds or replacing them with pleasant ones or using sunglasses for brightness (Attwood, 1998).

Participants also described the physical, cognitive and emotional effects that sensory processing have on them at work, leading to interference with productivity and satisfaction. Very few studies involving adults with ASD describe the implication of sensory processing at work (Hurlbutt & Chalmers, 2004).

5.1.5 Employment Choices

The high-ability adults with ASD in this study chose their area of work for various reasons, among which sensory preferences and unconsciously avoiding stressors were identified. Knowledge of sensory processing patterns can assist individuals in choosing appropriate work environments (Brown et al., 2000). In a study by Muntaner, Pulver, McGrath and Eaton (1993), adults with schizophrenia tended to choose work environments with a low potential for physiological arousal, including low complexity jobs and less social interaction. Furthermore,
responses from questionnaires such as the Sensory Profile and the AASP have the ability to reflect activity of the nervous system (Dunn, 2007). Employment choice for high-ability adults with ASD may therefore be linked with their neurological make up.

Other participants in this study spoke of their employment choice as a result of particular interests. This may reflect the ‘repetitive, restricted interests’ symptom required for an ASD diagnosis (APA, 2000). These ‘special interests’ may have the potential to guide an individual’s career path (Attwood, 1998; Hawkins, 2004); for instance, Temple Grandin’s ‘fixation’ on livestock led her to a career as an agricultural scientist (Attwood). Although these restricted interests have the ability to provide a sense of well-being, their overwhelming qualities can negatively affect them socially (Mercier et al., 2000). Nonetheless, resiliency was seen in many of the participants of this study as they continually endured sensory-disturbing environments because of a genuine vocational interest.

Sensory processing abilities may not always be a challenge to overcome at the workplace. Some participants in this study described a positive influence of enhanced sensory processing on their work skills as artists or technicians. Their ability to pick out details or hear sounds that others could not was considered an advantage. Individuals with AS are often described as detailed-oriented and meticulous workers in the areas of art or science (Frith, 2004). This excellence in perception (Frith) can also be attributed to the enhanced sensory processing functioning in the visual or auditory domains in certain individuals with ASD. Theories such as the Enhanced Perceptual Functioning (EPF) model may explain the superior visual and auditory discrimination associated with individuals with autism (Mottron, Dawson, Soulières, Hubert & Burack, 2006). Temple Grandin (2008) has discussed how her “visual thinking”, or the ability to think in pictures as opposed to words, has helped her career as a livestock equipment designer.
Other adults with ASD have also shared with her their positive experiences in their work as computer programmers, composers and accountants.

5.1.6 Disclosure of Diagnosis and Resultant Accommodations

A majority of the interviewed participants struggled with the decision to disclose their ASD diagnosis at work, stating fears of job loss or differential treatment from employers or coworkers. Varying opinions about disclosure exist in the literature. Meyer (2001) and Shore (2002), both adults with ASD, do not offer definitive recommendations, stating that every situation is unique and that this dilemma stays within the individual throughout their lifetime. The risk of losing a relationship, job, or being stigmatized needs to be weighed against improving understanding and work relationships (Shore, 2008). They do recommend others to consider who, what, where, when, why and how prior to disclosure at the workplace.

Hawkins (2004) recommends disclosure in the early stages of the job search in order to promote job success; however, she also agrees that it is a personal decision as it is not obliged by law. The participants in Hurlbutt and Chalmers’ (2004) study felt disclosure was a personal issue; the authors also conclude that legal protection exists if accommodation needs are stated at the outset of the job. As per the Americans with Disabilities Act (ADA) in the U.S., individuals are required to disclose their disability in order to obtain accommodations; however, only certain diagnoses are recognized (Goldberg, Killeen & O’Day, 2005). For instance, individuals with AS have been denied assistance due to their normal to high IQ scores (Howlin, 2004). Furthermore, sensory processing dysfunction may not even be considered as a proper diagnosis requiring accommodation. Individuals with mental illness have also struggled with the decision of whether or not to disclose to their employer, despite the encouragement to do so by mental health professionals and vocational consultants (Goldberg et al.). While supported employment
programs usually accompany an explicit or implicit disclosure of the diagnosis (Goldberg et al.) this may not happen in competitive employment and so the decision to disclose rests on the individual.

Participants in this study also described disclosing to certain people within their workplace. Some participants in this study had positive experiences with coworkers after disclosure. Of those that had negative experiences, coworkers did not always know of the ASD diagnosis. In a study by Belcher and Smith (1994), coworkers reported positive attitudes towards fellow employees with autistic disorder with varying ranges of cognitive and behavioural challenges. However, individuals with higher-ability ASD may be more prone to workplace bullying due to their difficulties in social situations (Howlin, 2004). Goldberg et al. (2005) suggest that complete, selective or nondisclosure of a diagnosis may work for some but not for others. The decision to disclose in individuals with mental illness rested on several factors such as legal, policy and other factors including knowledge in policies and phase of recovery (Goldberg et al.).

Rendering the issue more complex is the high incidence of dual diagnosis or co-morbidity with a mental illness. In a review of co-morbid conditions in autism and AS, Gillberg and Billstedt (2000) state that the coexistence of autism with other medical or behavioural conditions is the rule rather than the exception. Depression is very common in individuals with autism and AS and very high rates of ADHD and Tourette’s syndrome are seen. In fact, 70% of the participants with ASD in this study reported a secondary mental health condition such as depression, anxiety and ADHD. The disclosure question then becomes more complex, as do the needs.
Timing of disclosure may also need to be factored in the decision. A number of participants in this study were diagnosed as adults, after they were already hired at their current job. Unlike many physical disabilities, mental illness or higher ability ASDs may not be apparent to the general public. However, in a study by Roberts and Macan (2006), individuals with a non-visible physical ability who disclosed early in the interview process were rated as more qualified and more likeable. For some individuals with ASD, self employment may offer a way out of this disclosure dilemma as well as social difficulties. These benefits must be weighed against possible disadvantages related to self-employment such as lower income, longer hours and higher stress. The literature search on self-employment and ASD did not reveal any study focusing exclusively on this group.

5.1.7 Awareness of Needs and Resultant Accommodations

All the participants with ASD included in this study were able to report their sensory preferences through the AASP without assistance. However, they expressed varying levels of self-awareness of needs in the qualitative portion of the study. The literature states that individuals with autism have decreased levels of insight into their emotions and those of others (VanBergeijk, Klin & Volkmar, 2008); they lack Theory of Mind (ToM) or the ability to ascribe mental states to the self and others (Frith & Happé, 1999). It is a widely held assumption that children with autism have difficulty with social interactions due to the lack of intuitive ability to understand their minds and those of others (Hill & Frith, 2003). One study found that adults with HFA lack self-consciousness, or the ability to self-reference (Toichi, Kamio, Okada et al., 2002). Frith and Happé suggest that having an intact ToM may be an ingredient for an intact self-consciousness. Since individuals with AS pass tests of mental states, they add that some adults with HFA or AS may arrive at a ToM and self-consciousness through a long and difficult process.
Little research in the area of introspection and self-consciousness in adults with autism means this is an area not readily understood (Frith & Happé).

Participants in this study described a process of self-awareness achieved through a combination of self-discovery and external assistance. According to Frith (2004), analysis of autobiographies from individuals with AS demonstrate that there may be higher degrees of self-awareness in adulthood. Many researchers and professionals feel that autobiographical accounts may be flawed (Frith & Happé, 1999) given the level of egocentricity and lack of insight associated with ASD (Frith, 2004). Despite this unresolved issue, researchers such as Hurlbut and Chalmers (2004) state that “adults with AS have strong opinions about what works and does not work for them” (p. 215). Participants in this study were also quite articulate about their sensory preferences and challenges as well as what environments would suit them best.

The optimal working conditions discussed by most of the participants included quiet, controlled and predictable environments with balanced periods of work and rest. This is consistent with accommodations for individuals with ASD in the literature (JAN, 2009; Kitchen, 2007; Hawkins, 2004). Tsatsanis, Foley and Donehower (2004) recommend the following environmental interventions for individuals with AS and HFA, “permitting choices, brief breaks from work, a quiet space, transition statements or warnings before changing activities” (p. 254).

A number of participants also described their frustrations with employers and health professionals who are not aware of their needs. Hawkins (2005) agrees that limited specialized employment resources exist for these individuals. Even within other disabilities, many professionals who work with students with learning disabilities lack knowledge in the selection of appropriate accommodations and often use a cookie-cutter approach (Lindstrom, 2007). With internet resources provided by the UK-based The National Autistic Society (NAS) (NAS, 2008)
and JAN (2009), employers have access to possible accommodation ideas to help mitigate the sensory sensitivities often associated with ASD. With increased public awareness of the abilities of persons with AS, more work opportunities can be found (Hawkins). Awareness of specific ASD needs from employers and vocational counselors is critical in order to tailor appropriate interventions and accommodations.

Interestingly, two participants in this study were currently self-employed, while another recently hired a job coach in order to pursue self-employment. Studies focusing only on self-employed individuals with ASD were not found; however, one study identified one individual who was a self-employed fabric designer (Howlin et al., 2004). Self-directed employment, or ‘microenterprise’, is a more recent model that is springing out of the supported employment model, and is in line with the concepts of person-centered planning and self-determination (Ridley & Hunter, 2006). Individualized disability funding is another approach in which funds for the acquisition of supports are allocated directly to the individual with a disability and not to an agency. Individuals benefit by gaining capacity, choice and control, concepts compatible with the new emphasis on person-centered planning and self-determination (Lord & Hutchison, 2003). The individualized funding model also supports the vocational needs of persons with developmental disabilities, usually in the areas of supported employment or self-employment (Sandys, 1999).

Wehmeyer (1992) defined self-determined behavior as “the attitudes and abilities necessary to act as the primary causal agent in one's life and to make choices and decisions regarding one's quality of life, free from undue external influences or interference” (p.305). Self-determination can be improved within the individual through learning from life experiences but also through environmental supports and accommodations (Wehmeyer, 1999). The components
of self-determined behaviour include: choice making, decision-making, problem solving, goal setting, self-observation, self-evaluation, self-reinforcement, self-instruction, self-advocacy, and self-awareness (Wehmeyer, Agran & Hughes, 1998). Community programs can help foster self-determination in people with autism, as seen in a study by Fullerton (1995), where parents observed improvements in self-awareness and self-directed behaviour in their high school children with autism. Self-determination does not necessarily mean developing absolute control over one’s life, but recognizing when it is essential to ask for help (Wehmeyer, 1995), such as professionals or counselors.

5.1.8 Optimal Combination of Person-Environment-Occupation

Just as ‘goodness of fit’ needs to be evaluated between an adolescent with ASD and a post secondary institution (VanBergeijk et al., 2008), so is this fit important when transitioning from school to employment or from job to job. According to Nuehring and Sitlington (2003), individuals with autism who are transitioning from high school to an adult vocational service provider benefit from having choices, increased communication among all parties involved and a thorough assessment to verify whether there is a good ‘match’ between the individual and the environment. Certain jobs may inherently supply the sensory input an individual with ASD requires or enjoys (Orentlicher & Olson, 2004). Matching a person’s sensory preferences or challenges against the job tasks and environment becomes an important consideration.

‘Goodness of fit’ for work can be examined using the Person-Environment-Occupation (PEO) framework (Law et al., 1996; see Appendix N). In applying the PEO framework to this study, complex relationships between each of the dimensions of person, environment, and occupation can be examined. For instance, within the person-occupation transaction (P-O), choice of employment for the participants in this study was linked with interests, values and sensory
challenges and preferences. Some participants found a good match between their enhanced sensory processing skill and their jobs as technicians or artists. Person-environment (P-E) analysis revealed that processing challenging sensory information from the physical environment was often accompanied by active coping strategies internal to the individual. Issues of disclosure and accommodations can also be examined between the person and the social environment comprising of the employer and coworkers, whereas the occupation-environment (O-E) transaction involves the workplace layout and availability of job support. Integrating these pairs of dimensions together reveals the resultant occupational performance and satisfaction issues unique to each individual, or the degree of ‘fit’ between the individual and work. Once the obstacles and enablers of work are revealed, intervention or guidelines can be developed in conjunction with all employees at a given location that aim to increase the occupational performance of the worker (Shaw & Strong, 2008). Intervention will be discussed in the implications for social participation in section 5.4 below.

5.2 Limitations Associated with the Research Study

A number of methodological limitations were associated with this study, despite efforts made to minimize them. The main objective for Phase I was to describe sensory processing patterns within high-ability adults with ASD as compared to adults without ASD. An attempt was made to match the two groups on demographic characteristics such as gender and age in order to ascertain that the differences were due to sensory processing patterns alone. Exact matches were difficult to find, but closely-related matches were sought.

Sampling procedures within Phase I attempted to be random, but given logistical and time constraints, convenience sampling was used. While attempts were made to recruit individuals with ASD from across Canada, participants were recruited from two provinces. Also,
adults who are not online or affiliated with a particular autism agency may have been missed. The comparison group as well may have been biased given that Kingston is a university town, producing an unbalanced sample. While a sample size of 20 high-ability individuals with ASD may be considered small, significance was still found between the two groups. A larger sample size may further confirm these findings.

In addition, the diagnosis of ASD was self-reported by the participants and not confirmed by psychological testing. Efforts were made to improve identification by requesting the name of the diagnosing physician or psychologist and age of diagnosis. The reason for this selection method was the difficulty in locating adults with ASD in the community, given the geographical distance and the lack of a central database. Other studies have also relied on this selection method (Hurlbutt & Chalmers, 2002, 2004). A measure for the severity of ASD symptoms was not included in this study, however, individuals with ASD were required to report if they needed assistance to fill in the questionnaire. Ultimately, those that could not were excluded and considered individuals with lower ability. The results of this study cannot be generalized to lower ability adults with ASD.

A criticism may be made regarding the accuracy of self-report from persons with autism. The literature discusses the decreased levels of insight and self-awareness in these individuals (Frith, 2004; Frith & Happé, 1999); however, a number of studies have used qualitative methods with adults with ASD (Chamak et al., 2008; Hurlbutt & Chalmers, 2002, 2004; Mercier et al., 2000; Muller et al., 2003; Shoener et al., 2008). The purpose of this study and the selection of the AASP tool were purposely used to elicit the perspectives of persons with higher functioning ASD.
The qualitative portion of this study was designed with the tradition of phenomenology in mind. After interviews with ten individuals with ASD, it was difficult to articulate what was the true “essence” of sensory experiences at work. This is likely due to the variability seen in individuals with ASD, in addition to the different workplaces. In retrospect, perhaps another qualitative tradition such as hermeneutics may have been more appropriate as it focuses on the interpretation of people’s meanings within their specific contexts (Patton, 2002). In effect, this study evolved into a generic mixed methods study. Generic qualitative studies focus on understanding the experience, without prescribing to one particular qualitative tradition. These studies appear to be a growing trend, especially in the applied sciences (Caelli, Ray & Mill, 2003).

A final limitation reflects the method of interviews in Phase II of the study. The fact that the interviews were conducted over the telephone may seem unorthodox for a qualitative study. However, face-to-face interviews with individuals with ASD may have been more stressful given their difficulties with socialization, while the telephone may have provided a comfortable barrier. In addition, only one interview was done with the participants. Although follow-up interviews may have expanded on certain topics with some of the individuals, those who were less forthcoming would likely not have much more to add and those who were more verbose described their experiences in very great detail.

5.3 Implications for Future Research

Phase II of this study aimed at exploring the sensory experiences of adults with ASD in the workplace, an area that has not been systematically studied with this population before. This study solicited the views of high-ability adults as seen through their ability to self-report independently; however, exploring the views of individuals with ASD who are non-verbal
through augmentative communication or those with an intellectual disability through additional assistance would allow for a more complete representation of the whole spectrum.

An important area that has not been considered in this study is the inclusion of the employer’s viewpoints on accommodating individuals with ASD. In addition, interviews with colleagues and observations at the workplace would place the findings into context. Of course, these studies could only be done to the extent that the adult with ASD has disclosed to his colleagues and consented to the study. These additional studies would help corroborate the findings from the interviews with individuals with ASD, who may have varying levels of self-awareness.

A purposive sample targeting a particular group can reveal additional information on challenges and support needs at the workplace. For instance, self-employed individuals with ASD have not been sufficiently explored in the literature. Additionally, researching participants scoring high in only one quadrant of the AASP, such as the sensory seekers, who seem to be in the minority among individuals with ASD, would elicit information into their specific needs.

5.4 Implications for Social Participation

“Sensory processing patterns are reflections of who we are: these patterns are not a pathology that needs fixing” (Dunn, 2001, p. 617). One pattern is not necessarily better than another. Interventions are necessary when there are problems in performance and satisfaction (Dunn, 2001). Many participants in this study described challenges stemming from the physical and social environments at the workplace. Following the social model of disability, designing interventions targeting various forms of the environment (physical, social, cultural and institutional) will help accommodate individuals with ASD for these difficulties. By sharing their knowledge in sensory processing and employment, occupational therapists would be invaluable to teams assisting adults with ASD to maximize their potentials in the community.
To date, the studies on sensory processing in individuals with ASD discuss the implications relating to better diagnosis and treatment (Chamak et al., 2008; Crane et al., 2009). In fact, occupational therapists have been known to use ‘sensory diets’ as their intervention plans for children with sensory issues, whereby personalized activities are prescribed according to the needed sensory input (Aquilla, Yack & Sutton, 2005). It is also important to extend the discussion to include how these sensory processing patterns ultimately affect daily life (Dunn, 1997). The extent to which sensory processing difficulties affect the level of social participation in the community, quality of life, and in this case, work inclusion for individuals with ASD is critical to examine.

In keeping with person-centered philosophy, persons with ASD should be able to control the direction of their lives, choose meaningful work, and become self-advocates. Given the right tools and environmental supports, high-functioning adults with ASD have the potential to develop advocacy skills which will serve them in many life areas. Specific programs aimed at promoting self-determination in the employment area can provide adults with autism a means of learning the skills of self-advocacy, including asking for suitable supports either in competitive or supported employment arenas. Young adults with autism can develop self-determination in programs designed with their particular sensory, cognitive and social needs in mind (Fullerton, 1995). Developing skills in self-determination can be especially beneficial in situations where individuals with ASD do not disclose out of fear or late diagnosis.

At the workplace level, employers and coworkers can be sensitized to the legitimate sensory needs of adults with ASD and assist in providing a more inclusive work environment. Employers may realize the value that these individuals bring to their company and by accommodating appropriately, both can benefit.
At the systems level, informing the public, including employers and direct service providers can help reshape societal attitudes and decrease stigma associated with ASD. Service providers such as employment agents and vocational rehabilitation specialists who are not used to working with this population can come to an awareness through training in the unique features of autism in order to ensure competent care; this can be done through in-services or speeches given by adults with ASD themselves. However, interventions or accommodations still need to be individualized, as evidenced by the variability of sensory profiles and work environments. Knowledge that these individuals are able to work given specific accommodations can begin to help increase job opportunities for individuals with ASD, thereby decreasing costs to society.

5.5 Conclusions

This study was the first to focus exclusively on the impact of sensory processing patterns at the workplace in adults with ASD. Results of this study show that high-ability adults with ASD show different sensory processing patterns compared to individuals without ASD. The majority of the high-ability individuals with ASD in this study were highly sensitive to stimuli in their environment (sensory sensitivity), tended to avoid situations that provoked these sensitivities (sensation avoiding) and to a lesser degree, missed sensory information around them (low registration).

Despite commonalities, the variability in responses in the qualitative portion of the study likely reflects the variability seen in ASD (Howlin, 2004). Most of the adults with ASD who were interviewed showed an awareness of their sensory needs and have developed active coping strategies. Accommodations directed at modifying the physical environment and occupational tasks promote successful work fit for individuals with sensory issues. Both the environment and the job functions need to be considered against the individualized sensory processing pattern of
the individual with specific sensory needs in order to achieve an optimal work fit. By creating individualized environments that are either subdued or stimulating, work productivity and satisfaction can be capitalized. Sensory processing patterns can impact on choice, performance and satisfaction at work. Different sensory patterns do not need to be considered as disabling; they can enhance work productivity. Increasing public awareness of their abilities and challenges will improve job prospects for adults with ASD. The supported self-employment model needs to be evaluated as an alternative model as it may offer a means of self-accommodating to sensory differences by designing optimal environments.

Varying sensory processing patterns, different coping strategies, and different work environments mixed with the variability of ASD and additional co-morbidities demonstrate the complexity of this issue. It is important to note that sensory processing needs vary across the ASD population and are currently not being met at the workplace. Knowledge of sensory processing patterns in adults with ASD is necessary in order to improve work productivity, satisfaction and overall quality of life.
References


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Appendix A: Dunn’s (1997) Conceptual Model of Sensory Processing

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<tr>
<th>Neurological Threshold Continuum</th>
<th>Behavioral Response Continuum</th>
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<td>HIGH (habituation)</td>
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<td>LOW (sensitization)</td>
<td>Sensitivity to Stimuli</td>
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**Figure 1.** Relationships between behavioral responses and neurological thresholds.

Appendix B: Conceptual Model of Sensory Processing and Asperger Syndrome

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<th>Neurological thresholds</th>
<th>Low Registration</th>
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*Hypothesized relationships based on Dunn’s conceptual model of sensory processing.

FIGURE 2. Common characteristics of individuals with Asperger syndrome when considering Dunn’s conceptual model of sensory processing.

Appendix C: Recruitment Letter to Autism Community Agencies

Kingston, August 5, 2008

To Whom It May Concern:

I am writing to you to request your permission to advertise my research study in your centre or to your mailing list/membership.

I am a student enrolled at Queen’s University in Kingston, Ontario, in the Master of Rehabilitation Sciences program. I am also a practicing Occupational Therapist and I am interested in understanding the lives of adults with autism spectrum disorders (ASD). My research project, provisionally entitled “Sensory Processing Patterns in the Workplace in Adults with Autism Spectrum Disorders”, will be conducted in two phases.

Phase 1: will explore the relationship between sensory processing patterns in adults with ASD and participation in paid employment. A questionnaire, the Adolescent/Adult Sensory Profile Questionnaire will be mailed to the participants. It will take about 20-30 minutes to complete. Participants do NOT need to be working for this phase of the study.

Phase 2: will explore the impact of sensory processing patterns on the work experience of adults with ASD. One interview will take place with selected participants about their sensory experiences in the workplace. The interview will last approximately one hour and will be done either over the telephone or face-to-face at a location that will be determined together, but one where there will be privacy. Only selected participants will be contacted for the interview, particularly those who score on the extreme ends of the profile.

Participants will be considered for the study if they are 18 years and older with an ASD diagnosis, including autism, Asperger syndrome, or pervasive developmental disorder- not otherwise specified (PDD-NOS), and are fluent in English.

If you have any questions, please do not hesitate to contact any of the following:
Tiziana Bontempo, Principal Investigator at (613) 583-7743 or 6tb3@queensu.ca
Dr. Rosemary Lysaght, Graduate Supervisor at (613) 533-2134 or lysaght@queensu.ca

Thank you kindly,
Tiziana Bontempo
MSc Rehabilitation Sciences candidate
Appendix D: Recruitment Flyer

Participants needed for a research study:

“Sensory Processing Patterns in Adults with Autism Spectrum Disorders in the Workplace”

You are eligible to participate in part or all of this 2-phase study if you:

- are 18 years old and over
- are diagnosed with an Autism Spectrum Disorder (ASD)
- do not have a severe hearing/visual impairment

You do not need to be working at this time.

**Phase 1:**
- Find out your sensory patterns by taking a questionnaire! Questionnaire completion will take 20-30 minutes.

**Phase 2:**
- You may be asked to talk about your work experiences if you are currently working. Participate- all from your own home!

For more information, please contact:

Tiziana Bontempo  
MSc Rehabilitation Sciences candidate  
Queen’s University  
Kingston, Ontario  
Email: 6tb3@queensu.ca  
Tel.: 613-583-7743
Appendix E: Ethics Approval

QUEEN'S UNIVERSITY HEALTH SCIENCES & AFFILIATED TEACHING HOSPITALS RESEARCH ETHICS BOARD

July 22, 2008

Ms. Tiziana Bontempo
School of Rehabilitation Therapy
Louise D. Acton Building
Queen's University

Dear Ms. Bontempo,

Study Title: Sensory Processing Patterns in the Workplace in Adults With Autism Spectrum Disorders
Co-Investigators: Dr. R. Lysaght, Dr. T. Krupa, Dr. E. Kelley

I am writing to acknowledge receipt of your recent ethics submission. We have examined the protocol and consent forms for your project (as stated above) and consider it to be ethically acceptable. This approval is valid for one year from the date of the Chair’s signature below. This approval will be reported to the Research Ethics Board. Please attend carefully to the following list of ethics requirements you must fulfill over the course of your study:

► Reporting of Amendments: If there are any changes to your study (e.g. consent, protocol, study procedures, etc.), you must submit an amendment to the Research Ethics Board for approval. (see http://www.queensu.ca/vpr/reb.htm).

► Reporting of Serious Adverse Events: Any unexpected serious adverse event occurring locally must be reported within 2 working days or earlier if required by the study sponsor. All other serious adverse events must be reported within 15 days after becoming aware of the information.

► Reporting of Complaints: Any complaints made by participants or persons acting on behalf of participants must be reported to the Research Ethics Board within 7 days of becoming aware of the complaint. Note: All documents supplied to participants must have the contact information for the Research Ethics Board.

► Annual Renewal: Prior to the expiration of your approval (which is one year from the date of the Chair's signature below), you will be reminded to submit your renewal form along with any new changes or amendments you wish to make to your study. If there have been no major changes to your protocol, your approval may be renewed for another year.

Yours sincerely,

[Signature]
Chair, Research Ethics Board

Study Code: REH-438-08

► Investigators please note that if your trial is registered by the sponsor, you must take responsibility to ensure that the registration information is accurate and complete
Appendix F: Demographic Form for Comparison Group Participants

1. Name: ________________________
   Age: _______
   Gender: _____

2. Diagnoses (please check all that apply):
   □ Visual Impairment      If yes, describe: _______________________
   □ Hearing Impairment  If yes, describe: _______________________
   □ Attention-Deficit/Hyperactivity Disorder
   □ Obsessive Compulsive Disorder
   □ Anxiety/Panic Attack
   □ Depression
   □ Tics/Tourette syndrome
   □ Learning Disorder

3. Education:
   Final Grade completed: ________________
   □ Special Education
   □ High School Diploma
   □ College Diploma/ CEGEP degree (Area of Specialization): ____________________________
   □ University Bachelors Degree (Area of specialization): _______________________________
   □ University Graduate Degree (Area of specialization): _______________________________
   □ Other (Specify): ___________________________________________

4. Paid Employment History:
   □ Currently employed
   □ Employed within the last 6 months
   □ Currently a student
   □ Never been employed
   □ If not working, you would like to work given the optimal conditions

5. Current Paid Employment (if applicable):
   □ Full-time (indicate hours): ________________
   □ Part-time (indicate hours): ________________
   Start date: ___________________
   Job Title: _______________________________________

6. Type of Employment:
   Company Name: __________________________
   Company Size: _____________________________

   How you found this job:
   □ Advertisement
   □ Agency
   □ Contacts (family, friends)
   □ Other, please specify: _____________________________
7. Past Employment:

a) Start date of employment: _________ End date of employment: _________
   □ Full-time
   □ Part-time (indicate hours): ___________

   Job Title: ___________________________________________________________
   Company Name: _________________________________________
   Company Size: __________________________________________

   How you found your last job:
   □ Advertisement
   □ Agency
   □ Contacts (family, friends)
   □ Other, please specify: _________________________________________

b) Start date of employment: _________ End date of employment: _________
   □ Full-time
   □ Part-time (indicate hours): ___________

   Job Title: ___________________________________________________________
   Company Name: _________________________________________
   Company Size: __________________________________________

   How you found your last job:
   □ Advertisement
   □ Agency
   □ Contacts (family, friends)
   □ Other, please specify: _________________________________________

c) Start date of employment: _________ End date of employment: _________
   □ Full-time
   □ Part-time (indicate hours): ___________

   Job Title: ___________________________________________________________
   Company Name: _________________________________________
   Company Size: __________________________________________

   How you found your last job:
   □ Advertisement
   □ Agency
   □ Contacts (family, friends)
   □ Other, please specify: _________________________________________
Appendix G: Demographic Form for ASD Group Participants

1. Name: ________________________
   Age: _______
   Gender: _____

2. ASD Diagnosis (Please check one):
   □ Autism
   □ High Functioning Autism
   □ Asperger syndrome
   □ PDD-NOS

3. Name of Physician who diagnosed ASD: ____________________________________
   Age of diagnosis: ______

4. Other Diagnoses (please check all that apply):
   □ Visual Impairment   If yes, describe: _______________________
   □ Hearing Impairment If yes, describe: _______________________
   □ Attention-Deficit/Hyperactivity Disorder
   □ Obsessive Compulsive Disorder
   □ Anxiety/Panic Attack
   □ Depression
   □ Tics/Tourette syndrome
   □ Learning Disorder

5. Education:
   Final Grade completed: _____________
   □ Special Education
   □ High School Diploma
   □ College Diploma/CEGEP Degree (Area of Specialization): _______________________
   □ University Bachelors Degree (Area of specialization): _______________________
   □ University Graduate Degree (Area of specialization): _______________________
   □ Other (Specify): ___________________________________________

6. Paid Employment History:
   □ Currently employed
   □ Employed within the last 6 months
   □ Employed at one time
   □ Never been employed
   □ If not working, you would like to work given the optimal conditions

7. Current Paid Employment (if applicable):
   □ Full-time
   □ Part-time (indicate hours): ________________
   Start date: ___________________
   Job Title: _____________________
8. **Type of Employment:**
   Company Name: _________________________________________
   Company Size: __________________________________________

   How you found this job:
   □ Advertisement
   □ Agency
   □ Contacts (family, friends)
   □ Other, please specify: ________________________________

9. **Past Employment:**
   Start date of employment: _________   End date of employment: __________
   □ Full-time
   □ Part-time (indicate hours): __________

   Job Title: __________________________________________________________
   Company Name: _________________________________________
   Company Size: __________________________________________

10. **Sensory Processing**

    To your knowledge, have you ever had sensory integration treatment by an occupational therapist?
    □ Yes
    □ No

11. **Have you completed this form and the Adolescent/Adult Sensory Profile questionnaire independently?**
    □ Yes (on my own)
    □ No (needed help)
Appendix H: Phase I Study Information for Participants with ASD

**Title of Project:** “Sensory Processing Patterns in the Workplace in Adults with Autism Spectrum Disorders”

**Background Information:**
You are being invited to participate in the first phase of a research study conducted by Tiziana Bontempo, principal investigator in the Master’s of Rehabilitation Sciences program at Queen’s University and supervised by Dr. Rosemary Lysaght, to explore the sensory experiences of adults with Autism Spectrum Disorders (ASD) in the workplace. Please read through this consent form. If you have any questions, please do not hesitate to contact Tiziana or any other member of the research committee. This study has been reviewed for ethical compliance by the Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board.

**Purpose of the Study (Phase I):**
The goal of the first phase of this study is to explore the relationship between sensory processing patterns in adults with ASD and participation in paid employment. Recent studies have shown that four distinct sensory processing patterns exist according to the neurological make-up of a person and how they respond to their surroundings: Low Registration, Sensation Seeking, Sensory Sensitivity and Sensation Avoiding. Typically, persons with:

- Low Registration: do not notice the happenings in their environment.
- Sensation Seeking: show engagement and excitement in their surroundings
- Sensory Sensitivity: are more aware of their surroundings and are more distracted.
- Sensation Avoiding: avoid the unfamiliar and prefer predictable environments/rituals.

You will be considered for the study if you are 18 years and older with an ASD diagnosis, including autism, Asperger syndrome, or pervasive developmental disorder- not otherwise specified (PDD-NOS) and are fluent in English. You do not need to be working at this time in order to participate in the first phase of the study.

**Description of the study:**
The study will take place in two phases. In the first phase, a questionnaire on your sensory experiences will be mailed to you with an envelope with pre-paid postage. It will take about 20-30 minutes to complete. If you are willing, you may be asked to participate in the second phase of the study, which involves one interview to talk about your sensory experiences in the workplace.

**Potential Risks:**
There is no known risk to participating in Phase 1 of the research study.

**Benefits:**
Minimal benefits from completing the questionnaire may include an increase of your awareness on how you respond to your sensory environment.
**Exclusions:**
You will not be considered for this study if you are deaf and/or blind, as this may influence the sensory experiences.

**Confidentiality:**
All information obtained during the course of this study is strictly confidential and your anonymity will be protected at all times. Your name will be coded to protect your identity. Your name will not appear in any reports (published or unpublished) as a result of this study. The results of the questionnaire will be kept in a locked file cabinet and will be available only to Tiziana Bontempo and her research team at Queen’s University.

**Voluntary nature of the Study/Freedom to Withdraw or Participate:**
Your participation in this study is voluntary. You may withdraw from this study at any time.

**Liability:**
In the event that you are injured as a result of the study procedures, medical care will be provided to you until resolution of the medical problem. By signing this consent form, you do not waive your legal rights nor release the investigator(s) from their legal and professional responsibilities.

**Contacts (Please retain this information sheet):**
If you have any questions or concerns at any time, you may contact any of the following:
Tiziana Bontempo, Principal Investigator (613) 583-7743
Dr. Rosemary Lysaght, Graduate Supervisor (613) 533-2134
Dr. Elsie Culham, Director of the School of Rehabilitation Therapy (613) 533-6727

If I have questions regarding my rights as a research participant I can contact:
Dr. Albert Clark, Chair, Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board (613) 533-6081
Appendix I: Phase I Study Information for Comparison Group

**Title of Project:** “Sensory Processing Patterns in Adults with Autism Spectrum Disorders in the Workplace”

**Background Information:**
You are being invited to participate in the first phase of a research study conducted by Tiziana Bontempo, student investigator in the Master’s of Rehabilitation Sciences program at Queen’s University and supervised by Dr. Rosemary Lysaght, to explore the sensory experiences of adults with Autism Spectrum Disorders (ASD) in the workplace. Please read through this consent form. If you have any questions, please do not hesitate to contact Tiziana or any other member of the research committee. This study has been reviewed for ethical compliance by the Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board.

**Purpose of the Study (Phase I):**
The goal of the first phase of this study is to explore the relationship between sensory processing patterns in adults with ASD and compare them with adults without ASD. Recent studies have shown that four distinct sensory processing patterns exist according to the neurological make-up of a person and how they respond to their surroundings: Low Registration, Sensation Seeking, Sensory Sensitivity and Sensation Avoiding.

Typically, persons with:

- Low Registration: do not notice the happenings in their environment.
- Sensation Seeking: show engagement and excitement in their surroundings
- Sensory Sensitivity: are more aware of their surroundings and are more distracted.
- Sensation Avoiding: avoid the unfamiliar and prefer predictable environments/rituals.

We are currently seeking control subjects for this study who do not have an autism spectrum diagnosis.

You will be considered for this study if you are:
1. between 18 and 64 years old
2. are fluent in English

You do not need to be working at this time in order to participate in this study.

**Description of the study:**
The study will take place in two phases. In the first phase, a questionnaire on your sensory experiences will be mailed to you with an envelope with pre-paid postage. It will take about 20-30 minutes to complete.

**Potential Risks:**
There is no known risk to participating in Phase 1 of the research study.

**Benefits:**
There is no direct benefit to you as a participant in this research study.
**Exclusions:**
You will not be considered for this study if you or a family member has an ASD diagnosis. You will also not be considered if you have a significant hearing or visual impairments, an intellectual or learning disability.

**Confidentiality:**
All information obtained during the course of this study is strictly confidential and your anonymity will be protected at all times. Your name will be coded to protect your identity. Your name will not appear in any reports (published or unpublished) as a result of this study. The results of the questionnaire will be kept in a locked file cabinet and will be available only to Tiziana Bontempo and her research team at Queen’s University.

**Voluntary nature of the Study/Freedom to Withdraw or Participate:**
Your participation in this study is voluntary. You may withdraw from this study at any time.

**Liability:**
In the event that you are injured as a result of the study procedures, medical care will be provided to you until resolution of the medical problem. By signing this consent form, you do not waive your legal rights nor release the investigator(s) from their legal and professional responsibilities.

**Contacts (Please retain this information sheet):**
If you have any questions or concerns at any time, you may contact any of the following:
Tiziana Bontempo, Principal Investigator (613) 583-7743
Dr. Rosemary Lysaght, Graduate Supervisor (613) 533-2134
Dr. Elsie Culham, Director of the School of Rehabilitation Therapy (613) 533-6727

If I have questions regarding my rights as a research participant I can contact:
Dr. Albert Clark, Chair, Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board (613) 533-6081
Appendix J: Phase I Consent Form

**Please return this sheet** with your Adolescent/Adult Sensory Profile Questionnaire and demographics form.

**Participant Statement and Signature Section:**
I have read and understood the consent form for this study. I have had the purposes, procedures and technical language of this study explained to me. I have been given sufficient time to consider the above information and to seek advice if I chose to do so. I have had the opportunity to ask questions which have been answered to my satisfaction. I am voluntarily signing this form. I will receive a copy of this consent form for my information. I am aware that I can contact the student investigator, her supervisors or the chair of the Research Ethics Board at Queen’s University and I have been provided with their contact information.

☐ I agree to participate in Phase I of the study (complete the Questionnaire and demographics form)
☐ I am willing to be contacted by the principal investigator to participate in an interview of about one hour.

By signing this consent form, I am indicating that I agree to participate in Phase I of the study.

_________________________________________              _______________________
SIGNATURE OF PRINCIPAL INVESTIGATOR  DATE

_________________________________________              _______________________
SIGNATURE OF WITNESS     DATE

**Statement of Investigator:**
I, or one of my colleagues, have carefully explained to the participant the nature of the above research study. I certify that, to the best of my knowledge, the participant understands clearly the nature of the study and demands, benefits, and risks involved to participants in this study.

_________________________________________              _______________________
SIGNATURE OF PRINCIPAL INVESTIGATOR  DATE
Appendix K: Phase I Additional Consent Form

**Please return this sheet in the envelope with pre-paid postage.**

**Participant Statement and Signature Section:**
I have read and understood the consent form for this study. I have had the purposes, procedures and technical language of this study explained to me. I have been given sufficient time to consider the above information and to seek advice if I chose to do so. I have had the opportunity to ask questions which have been answered to my satisfaction. I am voluntarily signing this form. I will receive a copy of this consent form for my information. I am aware that I can contact the student investigator, her supervisors or the chair of the Research Ethics Board at Queen’s University and I have been provided with their contact information.

Please check off the boxes with which you agree:
□ I agree to participate in Phase I of the study (complete the Questionnaire and demographics form).

□ I agree to have the results from the Questionnaire and demographics form added to the ASD-CARC research registry data set, which may be used in future studies.

□ I am willing to be contacted by the principal investigator to participate in an interview of about one hour for Phase II of the study.

By signing this consent form, I am indicating that I agree to participate in Phase I of the study.

____________________________    ________________________
SIGNATURE OF PARTICIPANT    DATE

**Statement of Investigator:**
I, or one of my colleagues, have carefully explained to the participant the nature of the above research study. I certify that, to the best of my knowledge, the participant understands clearly the nature of the study and demands, benefits, and risks involved to participants in this study.

____________________________    ________________________
SIGNATURE OF PRINCIPAL INVESTIGATOR    DATE
Appendix L: Phase II Consent Form

**Please return this sheet in the envelope with pre-paid postage.**

By signing this consent form, I am indicating that I agree to:

- ☐ participate in Phase II of the study (participate in a one hour interview with the principal investigator).
- ☐ be audio-taped during the interview to facilitate accuracy.

_________________________________________              _______________________
SIGNATURE OF PRINCIPAL INVESTIGATOR  DATE

Statement of Investigator:
I, or one of my colleagues, have carefully explained to the participant the nature of the above research study. I certify that, to the best of my knowledge, the participant understands clearly the nature of the study and demands, benefits, and risks involved to participants in this study.

_________________________________________              _______________________
SIGNATURE OF PRINCIPAL INVESTIGATOR  DATE
Appendix M: Interview Guide

Thank you for participating in Phase II of my study on Sensory Processing Patterns in Adults with ASD in the Workplace. This part of the study involves a phone interview lasting approximately 30 minutes to one hour. I am interested in gathering information about your experiences in the workplace with respect to your sensory processing. As written in the consent form, the interview will be recorded for ease of analysis. Be assured that your responses to this interview will remain confidential; your name will not appear on any oral or written accounts that will be prepared. Please be reminded that you have the right to not answer any questions during the interview and at any time, you may terminate the interview. You also have the right to withdraw from the study at any time.

1. [General sensory processing]
   Some people say that people with ASD have sensory processing problems. What is your opinion?
   Probes: Can you give an example?
   In your opinion, are they drawn to sensory experiences or do they try to avoid them?

2. [Work History]
   Describe your current work situation. What have been your work patterns in the past?
   Probes: What was your longest job held? Did you have many periods of unemployment?

3. **If not currently working: past employment
   [Occupation]
   Describe your typical day at work.
   Probes: What are/were your tasks?

4. [Person]
   How do you think that sensory differences relate/d to your work?
   Probes: Tell me about anything that gets/got you anxious/overwhelmed at work.
   How do certain types of smells/movement/noise/touch/visual things affect you?
   What distracts/ed you? How do you deal/did you deal with it?
   How long does it take to recover from it?

5. [Environment-physical]
   Describe your work area.
   Probes: What is/was the physical layout of your workspace? How do you/did you find your work environment?

6. [Environment-social]
   Describe your relationship with your boss and with your coworkers.
   Probes: How have they supported you at work?

7. [Disclosure/accommodations]
   Has your employer made any changes to help you complete your job?
   Probes: Have you disclosed your ASD diagnosis to your employer? Coworkers?
8. **[Personal strategies]**
Describe any changes *you have made* to make your work easier for you.
*Probes:* What strategies do/did you use to help with the sensory issues?

9. **[Needs]**
How can your needs be better met at work?

10. **[Job Fit]**
Do you feel like your job is/was a ‘good fit’ for you? How so?
*Probes:* How does it compare with previous jobs?

11. **[Satisfaction]**
What makes a day satisfying at work?
*Probes:* Tell me what makes you happy at work. Unhappy?

12. **[Choice]**
What got you interested in your job?
*Probes:* How did you choose your current job? Your last job?

13. **[Self-awareness]**
Some people say that people with ASD are not aware of their needs or what bothers them. What is your opinion?
*Probes:* Can you give a personal example?

14. **[Ideal work]**
What would your ideal job look like, taking into account your sensory preferences?
*Probes:* task, environment, scheduling, working from home, sick leaves, frequent breaks

15. **[Advice on sensory & work]**
What would you like others with ASD to know about dealing with sensory issues at work?
Appendix N: Person-Environment-Occupation (PEO) Framework

Identify occupational performance strengths and problems

Assess performance components

Assess occupation, activities, tasks

Assess environmental conditions

Bring this information together in a transactional framework to develop intervention plan with client. Outcome is evaluated by measuring occupational performance.

person

environment

Occupational Performance

occupation

Appendix O: Statement of Subjectivity

- I believe that as an occupational therapist, I am knowledgeable in the areas of disability, sensory processing, and employment.
- I believe that some individuals within the autism spectrum can work, want to work and may benefit from work.
- I feel that the difficulties that may prevent them from finding and keeping a job occur at different parts of the employment process, including difficulties with initiating the job search, succeeding at the interview, and maintaining the job.
- I feel that they can work with help from outside sources (within the workplace, external agencies, or from family support), although available resources are currently limited.
- I feel there is insufficient understanding of the needs and capabilities of this population, ranging from the general public, employment agencies and some health professionals.
- I value research in the area of sensory processing given the shortage of studies.
- I value both quantitative and qualitative methodologies and embrace mixed methods as an alternative to answering certain questions. The opportunity for individuals with autism to express themselves in qualitative research is likely low.
- I believe that incorporating the voices of persons with autism will add a level of richness to the body of research already present and provide insight to the services required.
- I would like to encourage occupational therapists who work with this population to get involved in research as we can provide a unique view of the issues.
- I would like to encourage the autism community to focus on adult issues and researchers to incorporate various types of instruments and methods creatively in order to provide tangible resources to this population.
- With a personal connection to this topic, I sympathize with the frustration of the adults within this population that may be struggling and felt the urgency to pursue this issue.
Appendix P: Ethics Approval for Recruitment Strategy Amendment

October 10, 2008

Ms. Tiziana Bontempo
School of Rehabilitation Therapy
Louise D. Acton Building
Queen's University

Re: "Sensory Processing Patterns in the Workplace in Adults with Autism Spectrum Disorders" REH-438-08

Dear Ms. Bontempo,

I am writing to acknowledge receipt of your letter dated October 9th, 2008 which requested approval for the following:

- Announce the study through Autism Connects - www.AutismConnects.com
- Obtain additional consent from the participants recruited through the Autism Research project to agree to have the results from the Adolescent/Adult Sensory Profile questionnaire and the demographics form added to the ASD-CARC research registry data set
- Provision of the consent form

I have reviewed your proposed additions to the study recruitment process and hereby give my approval. Receipt of these additions will be reported to the Research Ethics Board.

Yours sincerely,

[signature]

Albert Clark, Ph.D.
Chair
Research Ethics Board

AFC/kr
March 5, 2009

Ms. Tiziana Bontempo
School of Rehabilitation Therapy
Louise D. Acton Building
Queen’s University

Re: “Sensory Processing Patterns in the Workplace in Adults with Autism Spectrum Disorders” REH-438-08

Dear Ms. Bontempo,

I am writing to acknowledge receipt of your memorandum dated March 3, 2009 which requested approval for the following:

- Inclusion of a control group
  - Adults aged 18-64 years of age who are fluent in English with no diagnosis of ASD themselves or in a family member
  - No intellectual disability or learning disability
  - No significant hearing or visual impairment
- Information/consent form
- Demographic form
- Adult Sensory Profile Questionnaire

I have reviewed these amendments and the forms and hereby give my approval. Receipt of these documents will be reported to the Research Ethics Board.

Yours sincerely,

[Signature]

Albert Clark, Ph.D.
Chair
Research Ethics Board

AFC/kr