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The impact of sensory stimuli on the stress response of children with autism spectrum disorders

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THE IMPACT OF SENSORY STIMULI ON THE STRESS RESPONSE OF CHILDREN WITH AUTISM SPECTRUM DISORDERS

BY

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B.S., Quinnipiac University, 1996

THESIS

Submitted to the University of New Hampshire
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Master of Science

in

Occupational Therapy

December, 2010
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ABSTRACT

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by

Noelle Schreiber

University of New Hampshire, December, 2010

Advisor: Barbara Prudhomme White, Ph.D, OTR/L

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INTRODUCTION

THE IMPACT OF SENSORY STIMULI ON THE STRESS RESPONSE OF CHILDREN WITH AUTISM SPECTRUM DISORDERS

This thesis is a research project conducted as a pilot study involving children with autism spectrum disorders (ASD) and neuro-typical children. The purpose of this study was to look at the stress response of children with autism when exposed to a sensory stimulus to see if it differs from their neuro-typical peers. Research suggests that children with autism process sensory information differently. There are both clinical reports and parental reports of increased attention or avoidance of sensory stimuli across all the senses (Iarocci & McDonald 2006). These observations led us to take a closer look at the behavioral response and the stress response of children with ASD when exposed to certain types of sensory stimuli. We developed a “sensory probe” of eight items to use in our study in an attempt to elicit a response from the participants. We chose to pair a behavioral observation with a stress response biomarker to help identify changes that may occur in response to a sensory stimulus. A biomarker is a way of measuring or evaluating internal response to external events (White & Mulligan, 2009). We used cortisol in this study to measure each participants stress response after being exposed to a sensory stimulus. There is little documentation on the stress response of children with autism at this point. The purpose of this research was to provide some insight into whether the behavioral presentation of distress to a sensory stimulus was aligned with a physiological
stress response, as well as to investigate whether children with autism spectrum disorder and sensory sensitivity had indications of higher daily physiologic stress.
CHAPTER I

LITERATURE REVIEW

Autism Spectrum Disorders

According to the ASA autism is a “neurological disorder that disrupts a child’s learning and socialization” (http://www.autism-society.org/site/PageServer, 2008). It is derived from the Greek word meaning self, or self-absorbed and it is the lack of ability or desire to socialize with others that we associate many children with autism. Because autism is a spectrum disorder, meaning the presence of a wide array of symptoms, different children with autism may present very differently from one another. Children can range from high functioning, with minimal functional impairment to profoundly impaired with limited independence. Symptoms may occur in any combination and with varying degrees. Characteristics of autism may or may not be apparent in infancy, but often become more visible during early childhood.

According to the Individuals with Disabilities Act (http://www.autism-society.org/site/PageServer, 2008), autism spectrum disorder (ASD) is defined as a “developmental disability that significantly affects a person’s ability to communicate and use nonverbal cues”. The Center for Disease and Prevention reports that about 1.5 million Americans have autism. It is the third most common developmental disability after mental retardation and cerebral palsy according to Autism Society of America (The ASA). The U.S. Department of Education reports that ASD incidence is increasing at a rate of 10-17% each year. Currently autism is diagnosed at about 1 in every 110 children.
Autism continues to be more prevalent in boys at approximately 4:1 over girls. However, population estimates are the topic of some controversy (Becker, 2009).

In 1987, the Diagnostic and Statistic Manual of Mental Disorders (DSM) began broadening the definition of autism to children for whom socialization is difficult as well as those with varying levels of ability to interact and participate independently across several domains of their daily life including school, play and community activities. What was once a devastating diagnosis known to most as “autism” evolved over time into a “spectrum” of disorders, encompassing the range of profound impairment to mild challenges. Accurately diagnosing is difficult for professionals due to the subjective nature of the diagnostic criteria. According to Jody Becker many children are given the diagnosis while demonstrating only mild symptoms to receive state funding. Becker advocated for a more expansive definition of autism and inaccurate diagnosing may help explain the explosive increase in diagnoses in recent years (Becker, 2009). What is still not available is a reliable biomarker that can be paired with social and behavioral symptoms for a more specific diagnosis of autism. Biomarkers are a way of evaluating internal body responses to external internal appraisals of events or emotions (White & Mulligan, 2009).

Autism falls under Pervasive Developmental Disorder’s according to the DSMIV-r. Autism includes:

- Autistic Disorder
- Rett’s Disorder
- Childhood Disintegrative Disorder
- Asperger’s Disorder
• Pervasive Developmental Disorder-Not Otherwise Specified.

*Autistic Disorder* is marked by the presence of impaired social and communication skills and a restricted interest in play (DSM-IV, 2000). Children with this disorder often display limited affect as well as a delay or lack of verbal skills. While often displaying a lack of interest in social interactions, they are often preoccupied with one narrow, nonsocial interest such as numbers, trains, wheels etc. Infants will often be averse to cuddling, lack eye contact and fail to respond to parents voices in the first few month of life often resulting in parents initially thinking their child may be deaf (http://www.autism-society.org/site/PageServer, 2008). The onset of autism is prior to age 3 years with some parents reporting concerns from birth. Most children diagnosed with autism will go on to have difficulty with social interaction and communication throughout adulthood (DSM-IV, 2000).

*Rett's Disorder* is diagnosed only in females and features a pattern of normal development followed by specific deficits including decelerated head growth from 5-48 months, decreased hand skills from 5 to 30 months with hand wringing, poor gait, impaired receptive and expressive language and motor retardation (DSM-IV, 2000).

*Childhood Disintegrative Disorder* requires the presence of marked regression following at least two years of normal development but onset prior to age 10. The child loses almost all previously attained skills such as bowel and bladder control, play skills, motor skills and language skills (DSM-IV, 2000).

*Asperger's Disorder* is most notably featured by impairment in social skills and restricted or limited interests and the child must have no clinically significant cognitive delays. Children often exhibit non-verbal delays such as poor eye-gaze and awkward
facial expressions as well as failure to develop peer relationships. They are also often eccentric and one-sided in their interests impacting social relationships. This disturbance must cause significant impairment in social functioning (DSM-IV, 2000).

*Pervasive Developmental Disorder Not Otherwise Specified* is used when a child does not meet the criteria for any of the other ASD diagnoses but displays severe deficits in social interactions and stereotypical behaviors. This can also be used for a diagnosis of atypical autism of late onset or not meeting all criteria (DSM-IV, 2000).

There are proposed changes to the current DSM-IV that will include changes to the diagnostic criteria for autism. The name is being changed to autism spectrum disorders to include autistic disorder, childhood disintegrative disorder, asperger’s disorder and pervasive developmental disorder not otherwise specified.

Autism is diagnosed by observations and testing of the child by a team of specialists and interviewing the parent/guardian, however across the nation there is not a standard tool being used consistently which leads to subjectivity among the diagnostician. While the Autism Diagnostic Observation Schedule (ADOS) and the Autism Diagnostic Interview-Revised (ADI-R) are common diagnostic tools and the most reliable they are not used consistently. The ADOS is a structured assessment that looks at communication, social interaction and play and is divided into four modules. Each module is based on the level of functioning the individual is currently at. Each module contains a variety of tasks that observe social behavior and communication skills (Lord, Rutter, DiLavore & Risi, 1989). The ADI-R is an assessment to assess autism in both children and adults. It uses and algorithm using the criteria described in the DSM-V. The assessment focuses on behavior in social interaction, communication and language, and stereotyped interests and
behaviors. It is a care taker interview of 93 items and requires training in administration and scoring (LeCouteur, Lord & Rutter, 2003). The child must exhibit some symptoms in all three categories in the DSM-IV. They are qualitative impairment in social interaction, qualitative impairment in communication and restrictive, repetitive and stereotyped patterns of behavior, interests, and activities (http://www.autism-society.org/site/PageServer, 2008). The most common features of ASD are lack of eye contact, lack of joint attention, lack of reciprocal conversation and atypical sensory motor processing (Thiers, 2007). According to the National Education Association (www.nea.org, 2009) children with ASD typically have difficulty in five areas including communication, socialization, breadth of interests, sensory integration and behavior. They included sensory and behavior categories which are not included in the DSM-IV clinical categories.

While there is no known cause for ASD, some studies are investigating possible irregular genetic coding that is passed down within families (Thiers, 2007). Newer studies on genetic coding have linked autism to chromosome 11, a gene called neurexin 1 that is responsible for transmitting glutamate in the brain (http://www.autism-society.org/site/PageServer, 2008). Irregular brain scans in children with ASD have shown differences in shape and structure such as the amygdale which may also provide new information on the cause of autism. The ASA (http://www.autism-society.org/site/PageServer, 2008) reported that researchers believe several genes possibly in combination with environmental factors may contribute to autism and that while some studies have shown abnormalities in several regions in the brain such as the cerebellum, amygdala and hippocampus; they still require further testing. A recent study
out of the University of North Carolina (http://www.autism-society.org/site/PageServer, 2010) found consistently large amygdala in children with autism by the age of two. They associated the amygdala with the ability to recognize faces and emotion which is associated with joint attention. Because of no clear etiology, diagnosis is dependent on symptoms, but there are promising interventions that have been shown to be effective for reducing symptoms and for promoting the development and level of functioning in those with ASD.

Some interventions that have been documented and are widely used by the autism community include but are not limited to applied behavioral analysis (ABA), floor time, sensory integration, social stories, auditory integration training (AIT) and picture exchange communication systems (PECS) (Heflin & Simpson, 1999).

The ASA (http://www.autism-society.org/site/PageServer, 2008) notes that children with ASD are not the result of poor parenting; they are not unruly or spoiled children and are typically not without feelings or emotions. They do however struggle with the ability to communicate effectively and understand conventional language which ultimately becomes a barrier in the community.

Theories, both current and dated on autism are based on the premise that children with autism process sensory information differently. There are both clinical reports and parental reports of increased attention to or avoidance of sensory stimuli across all the senses (Iarocci & McDonald, 2006). Iarocci et al. (2006) placed sensory abnormalities as a main symptom which in turn impacts the ongoing development of the perceptual system of those with autism (Iarocci & McDonald, 2006). However, Iarocci et al. (2006) believed that those with autism display atypical sensory behaviors in an effort to help
manage their environment both internally and externally. The incidence and intensity of these sensory differences vary from person to person. There are several current psychological theories on how sensory processing and autism are related. The “weak central coherence” theory suggests that the ability to integrate multiple information (via multiple senses) is impaired (Iarocci & McDonald, 2006). Another theory, temporal binding, suggests that children with sensory processing deficits having the primary deficit in the ability in the area or perceptual and high level order tasks (Iarocci & McDonald, 2006). Those studying neurological aspects of autism find abnormalities in the cerebellum causing deficits in attention and difficulty shifting attention from visual to auditory information (Iarocci & McDonald, 2006). Others find a larger neurological problem in executive functioning deficits and coordinating information from different modalities. While each theory differs in root causes, they all allude to atypical sensory processing in some way as a main feature in autism (Iarocci & McDonald 2006).

**Sensory Processing in Children with ASD**

Defined by Jean Ayres in 1972, sensory integration is “the neurological process that organizes sensations from one’s own body and from the environment and makes it possible to use the body effectively with in the environment” (p.11). Ayres explained sensory integration theory as the relationship between the difficulty that was observed in children being able to interpret sensation from the body and their environment which then ultimately caused learning and motor problems (Bundy, Lane & Murray 2002). It is a hierarchal process that requires each step to be successful to build on the next. Essentially Ayres explained that the central nervous system is arranged vertically systems are both hierarchal and interdependent. The more primitive systems such as tactile, proprioceptive
and vestibular systems provide the foundation for which the higher level functions is able to build off. Without out the foundational skills, the higher level functions will be less skilled (Bundy et al., 2002). Therefore sensory integration is based on the belief that successfully integrating our sensory systems is the foundation for developing higher order skills such as social skills, fine motor skills, gross motor skills, cognitive organization and language (Mauer, 1999). While Ayres originally defined SI as “the ability to organize sensory information for use” (Ayres, 1979, p.11) it has been elaborated on and contributed to by many professionals over the past forty years. Fisher and Murray (1991) expanded on SI theory adding three postulates. They suggested that the sensory information we take in from the environment and movement from our bodies is processed through the central nervous system and we use this to plan and execute behaviors; the second is that deficits in integrating sensory information will cause difficulties with motor learning; and the third is providing sensory experiences (SI therapy) with in the context of meaningful experiences will improve sensory integration. It is important to note that SI is a continuous process as documented by Ayres back in 1979 and that each level of integration is dependent on the next. By having solid tactile, vestibular and proprioceptive functioning one is able to develop eye-hand coordination, fine motor and gross motor skills. These systems also interact with the visual and auditory system and then children develop solid communication skills (Mauer, 1999). In most children, sensory integration develops during the course of normal development as children explore their environments and play without any visible signs of effort (Schaaf & Miller, 2005). Sensory integration dysfunction emphasizes the importance of vestibular, proprioceptive and tactile functioning for learning and behavior. Schaaf and Miller
(2005) first articulated, when sensory systems do not respond to information effectively and accurately, motor responses and emotional responses are impaired. The ability to interact with others as well as adapt to the environmental demands becomes increasingly difficult.

Sensory integration dysfunction can be divided into two main subtypes, sensory modulation disorder and dyspraxia; those with poor modulation and those with poor praxis. These two subtypes can also co-exist (Schaaf et al., 2005). Poor modulation (sensory modulation disorder) is associated with disorders such as gravitational insecurity or tactile defensiveness (Schaaf et al., 2005). Sensory Modulation Disorder is defined as a problem in the capacity to regulate or respond to sensory input in a graded manner which causes difficulty in the ability to perform and adapt to challenges in daily life situations (Schaaf et al., 2005). These children will often over or under respond to subtle environmental changes such as seasonal changes, time changes, routine changes and holidays making anything unpredictable a major challenge to overcome. Children with deficits in sensory modulation that are thought to be due to the CNS not modulating input coming in from the vestibular system will demonstrate gravitational insecurity and have difficulty climbing on playground equipment, riding in cars, going on swings and exploring other movement activities (Schaaf et al., 2005). Vestibular disorders can impact many areas of a person’s life as they have difficulty judging personal space, riding in elevators or going on a boat/ferry ride (Schaaf et al. 2005). Tactile defensiveness is also commonly seen in children with sensory modulation disorder. These children may withdraw and significantly overreact from light touch, have a limited food repertoire, avoid personal hygiene routines and only wear certain kinds of clothing (Schaaf et al.,
It is important to note that these types of behaviors typically cause a disruption in the function of daily life for these persons.

Poor praxis or dyspraxia is associated with clumsiness, poor pressure modulation or poor bilateral integration and coordination (Bundy et al., 2002). Poor praxis or sensory-based motor disorders may result in clumsiness that may impact the ability to learn to ride a bike, learn to catch and throw because of poor midline integration, learn to tie their shoes, and learn to negotiate through a busy classroom without bumping into every object.

Children with autism appear to present with issues in sensory modulation overwhelmingly. They often present with the difficulty in their ability to interpret sensory information according to research and parent report. Although it can vary greatly amongst children with ASD from those who are hypersensitive to sounds and touch to those that have an extremely high threshold for pain and others who crave heavy input, most will display some type of unusual sensory behaviors (O’Riordan & Passetti, 2006). Further, it appears that they frequently are more easily stressed by sensory sensations and that a simple tactile or auditory trigger can cause what looks like a stressful response in a child with autism. O’Riordan & Passetti (2006) discussed sensory disturbance in children with ASD, and reported that difficulties extending across all sensory modalities and that disturbed processing of incoming stimuli has long been associated with ASD. These authors focused on the auditory system as being the most affected system and that it may be linked to the development and use of language and communication or lack there of. They suggested that children with ASD are hypersensitive to many noises that are not intrinsically threatening or uncomfortably loud to the typical individual. O’Riordan et al.
(2006) reported via parental report that their children have excessive fascination with certain textures or the avoidance of other textures along with refusing human contact or being held. As far back as 1943, Kanner described sensory fascinations in some children with ASD. He observed behaviors that provided “endless joy” such as staring at light reflecting from mirrors, or observing heightened sensitivities that caused distress; such as covering of the ears to certain sounds (Kanner, 1943). Many children with ASD struggle with busy shopping markets, or cringe at the thought of an upcoming fire drill. From parental report and clinical observation the sound of a background fan can make it impossible for a child with ASD to focus on his spelling test while the other children in the room would not even notice. Baranek et al. 2006 through exploring the literature found common thread in that children with ASD respond differently to their environment; most commonly the sensory stimuli within it via a hyper or hypo response. They suggested that the two most common sensory patterns found in children with autism appear to be hypo-responsiveness and hyper-responsiveness. Hypo-responsiveness refers to the lack of response or insufficient intensity of response to sensory stimuli. Hyper-responsiveness refers to the exaggerated behavioral response to sensory stimuli. These two over-reaction tendencies may also co-exist in the same individual (Baranek et al. 2006).

Leekam, O’Riordan and Passetti (2006; 2007) noted that children with ASD have difficulty processing incoming stimuli and are disturbed by sensory stimuli and that this is a common feature within the diagnosis. They also recounted first person accounts including Temple Grandin’s suggesting that those with ASD often have unusual sensory experiences (Leekam, Nieto, Libby, Wing & Gould, 2007). Temple Grandin is a woman
diagnosed with autism that reflected in her 1992 autobiography of her own unusual sensory sensitivities and has since become a public speaker on Autism and Sensory Integration. Despite some research evidence and clinical observations, there is no clinical category for sensory modulation dysregulation in the diagnostic criteria for ASD. According to Wood and Talay-Ongan (2000), the DSM-III diagnosis for ASD did not include criteria for under or oversensitivity for autism however, it was included in the DSM-III for childhood onset for pervasive developmental disorder (American Psychiatric Association, 1980). The current DSM-IV-r does not include sensory or perceptual disturbances in its diagnostic criteria for autism (American Psychiatric Association 1994). As noted earlier there are proposed changes to the current DSM-IV-r as it changes to the DSM-V, which will not include sensory disturbances.

In 1997 studies were done using questionnaires (a pilot version of the Sensory Profile) that compared children w/ ASD to their same aged peers (ages 3-10 years) who were typically developing. The Sensory Profile created by Winnie Dunn is a caregiver questionnaire which measures children’s responses to sensory events in everyday life. There are 125 items in the profile and it is completed by the child’s care taker by reporting how frequently their children respond to the item. They use a 5 point Likert scale (nearly never, seldom, occasionally, frequently, and almost always). Results indicated that the children with ASD performed differently than their same aged peers on 84 of 99 items (Keintz & Dunn, 1997). In 2000, Talay-Ongan and Wood took a closer look at the “unusual” sensory behaviors that occur in children with ASD. They studied these unusual behaviors in 30 children with ASD. One of their goals was to interpret associations between the presence of unusual sensory behaviors or sensitivities as they
were referred to at that time and the areas of impairment in ASD. The authors expected that the results would show a greater number of positive responses as well as a decline in positive responses as age increased. The first hypothesis was true; however the second was not. Their data suggested that sensory sensitivities increased over age. This could have been due to the older children being better able to communicate their discomfort and better able to report. This is one of the few studies where the children themselves were the reporters. Notably is that several of the children in the study were found to respond with tears and distress to relatively inoffensive experiences such as getting wet, wearing wet clothes, brushing their teeth or touching a sticky substance. Several which would occur during a typical day and should not cause stress to a typical child. The children with ASD were also often oblivious to pain and temperature. Overall the study suggested that children with ASD “frequently perceive sensory information in ways significantly different from other children” (Talay-Ongan & Wood, 2000). Their responses to these events appeared to be perceived as stressful. For example if a child is brought to tears by brushing his teeth or getting wet and is inconsolable this is not a typical response but a stressful one.

A slightly different approach was taken by Reese and colleagues in 2003 while looking at functional assessment interviews and disruptive behaviors. Forty percent of care takers reported sensory disturbances in 100 children ages 2-5. Of all the care takers in the study 12% reported their child displayed disruptive behavior to avoid an uncomfortable sensory situation. Others observed disruptive behavior due to the inability to attain a sensory seeking behavior (Reese, Richman, Zarcone & Zarcone, 2003). In 2003 another study analyzed parent reports of sensory symptoms in toddlers with ASD.
Results suggested that there were significantly elevated levels of sensory symptoms in children with autism compared to typical children and those with developmental delay (Rogers, Hepburn & Wehner, 2003). In 2006, Baranek et al. found that unusual sensory symptoms could not be attributed to deficits in visual or hearing acuity. Using the Sensory Experience Questionnaire they also found that it was possible that social cognitive deficits that were prevalent in ASD could impact on a child’s ability to understand other’s intentions and therefore create increased variability when trying to respond to particular types of sensory experiences. Results from this particular study found that 69% of children with ASD performed at least 1 standard deviation above the control group while 39% present with severe levels of overall sensory symptoms. IQ was insignificant and children with autism scored higher than children with PDD (Baranek et al., 2006). Another study in 2006 by Bryson and colleagues attempted to look at high risk infants who may develop ASD. Their profiles were marked by irritability, distress and a dysregulated state. As high as 50% of the parents of the children in this study can recall abnormalities that date back to the first year of life in sensory behaviors or sensory-motor development as noted in the study. The atypical sensory behaviors were noted as symptoms such as visual interest in the carpet and feeling with the index finger. Other observations noted were poor self regulation and striking sensory interests such as playing with strings and round things. There were also noted instances of repetitive behavior during the first year of life. Bryson and colleagues noted that together with the increase in irritability and executive dysfunction these children became more and more sensitized to various forms of stimulation. It appears in these studies the authors found that children with ASD found pleasure in certain sensory seeking behaviors that can be
repetitive in nature. When denied this behavior and if not replaced with something considered more “socially appropriate” a negative behavior may have developed. Leekam and colleagues (2007) used the DISCO; a questionnaire of 21 items related to sensory abnormality and found results similar to the Baranek study, only 2 of the 33 children with ASD were not affected by a sensory symptom compared to 12 of the 34 children in the control group. In the ASD group the children were more likely to have abnormalities in multiple areas where in the control group they were more likely to have difficulty in only one. Also in 2007, Tomcheck and Dunn matched 281 children ages 3-6 with ASD to those who were typically developing. They used the Short Sensory Profile. Results found that 95% of the children with ASD demonstrated some degree of sensory processing dysfunction. On 92% of the items, 92% of the children with ASD performed significantly different. Several studies, according to Ventola et al. (2007) have investigated sensory processing in children with ASD. This group in particular wanted to compare characteristics of children with ASD, DD and LD and the incidence of overlap between them. It occurs often that children with DD will display similar characteristics or symptomatology of ASD however he or she does not fit the criteria for ASD and there are many cross over symptoms of children with language disorders, or Down Syndrome or MR that do not meet the criteria for ASD. According to Ventola et al. (2007) there is a lack of research that looks at the behavioral differences between these populations. Some studies as noted here have found significant differences in sensory processing within the ASD population while those with the milder forms of PDD-NOS may not display that. The results suggested that on the Childhood Autism Rating Scale (CARS) the atypical sensory-related items differentiated the ASD group from the group with the other delays.
The ASD group scored higher or with more significant delays in sensory deficits. Overall the ASD group was more impaired in their sensory responses (Ventola et al., 2007). Taking another look at the Sensory Profile Brown and colleagues (2008) compiled a study of 26 children with ASD and 26 typically developing children. They found that the children with ASD scored significantly lower in all 14 categories on 8 of 9 factors and in all 4 quadrants. The authors also suggested that sensory and perceptual problems were common in children diagnosed with ASD and it was estimated that between 30-100% of children with ASD had some form of sensory abnormality. Some authors suggested that there was a link between sensory processing difficulties experienced by children with ASD and the problems they experienced managing daily life routines and environments (Brown et al., 2008).

Lytle and Todd (2009) suggested that impairments in sensory systems (auditory, visual and tactile) can cause increased stress. A response to a visual stimulus such as light or a reflection can cause an arousal to the nervous system in a child with autism. Those with autism reported feeling overstimulated in typical situations caused by a variety of stimuli in textures of clothing and food. These types of situations cause stress in these individuals and in turn cause stress in their caregivers. Much of the behavior ultimately seems to be rooted with underlying stress in either the person with autism or the caregiver, regardless of the initial trigger. Current research suggests that 84% of children with autism also have a comorbid diagnosis of anxiety and indicates that they have a heightened stress response and took longer to recover from stress (Lytle & Todd, 2009). According to Lytle and Todd (2009) who explored atypical responses of children and adults with autism, research suggested that children and adults with autism displayed
a heightened response and took longer to recover from a stressful experience. A stress response is the physiological reaction of the body to life’s situations that can either be happy events or unhappy events (Selye, 1974).

Further research is needed to understand what is triggering possible stress responses in children with ASD and to determine possible long term impact of the stress. Kern et al. (2006) suggested that “A better understanding of sensory processing in autism, including threshold differences, will improve our understanding of what persons with autism experience everyday and how their sensory experience may shape their behavior and their responses to their world” (p2.).

**Stress**

A stressor can be either physical or psychological and it is defined as a threat to homeostasis. Homeostasis is defined as life sustaining processes that are in balance and functioning optimally, including blood flow, heart rate, immune system integrity, repair and replenish activities etc. According to Sapolsky (2004), stress is the state of homeostatic imbalance. Stress is an adaptive state designed to generate action for meaningful purposes, and is available to help us respond to everyday challenges. Without an adaptive stress response system, we would be unable to function. Intended for short term engagement to rise to life challenges, stress is the opposite of homeostasis and also termed allostasis (McEwen, 2002). The human stress response system has two arms; one is fast acting and the other is slow responding. Both work in synchrony to support adaptive behavior (McEwen, 2002).

The fast acting arm is initiated upon perception of threat within the sympathetic-adrenomedulary system (SAM). The SAM provides an immediate response to stress and
is part of the autonomic nervous system. It releases epinephrine or adrenaline via the adrenal gland (McEwen, 2002). This response is also better known as the fight or flight response. Norepinephrine is also released during this process which binds to adrenoceptors setting into motion such reactions as increased heart rate, increased stroke volume, constriction of blood vessels and increased blood supply to the brain and muscles. Increased levels of glucose are supplied for increased energy levels for defensive responses. This reaction all supports narrowed attention, vigilance and arousal as well as activating the second response; the hypothalamic-pituitary-adrenocortical system (HPA) (McEwen, 2002).

The HPA system or slower acting arm or the stress response system produces hormones called glucocorticoids of which cortisol is the most primary one. Cortisol is a corticosteroid and is a major hormone in our body that helps to regulate alert levels in both physical and emotional states (Gunnar & Quevedo, 2007). It helps individuals respond to environmental challenges by increasing metabolic activity, blood pressure and heart rate. This system is designed to sustain action for longer lasting challenges. Cortisol crosses the blood/brain barrier unlike epinephrine and it takes twenty-five minutes to reach peak levels (Gunnar et.al, 2007). The HPA is activated upon the perception of longer lasting threats. The hypothalamus produces cortico-releasing hormone (CRH) to the pituitary which then responds with increased production of adreno-corticotropin hormone (ACTH). ACTH stimulates the adrenal cortices to produce cortisol. The HPA works by a negative feedback loop; increased amounts of CRH in the blood and cortisol cause the system to produce less of both hormones. However, humans are unable to sustain chronic production by psychological manipulation and heightened perception of
stress in the environment (McEwen, 2002). The negative feedback loop can be modified through constant engagement such that the system can be shaped to be less sensitive to CRH, ACTH and cortisol which then produces abnormally high cortisol levels (Cohen, Perel, Debellis Freidman & Putnam, 1991). Gunner and Quevedo (2007) suggested that we all differ in our vulnerability to stress but also noted the high threshold of infants and young toddlers reporting no increase in cortisol to stressors that would typically provoke behaviors. During the first year of life studies have shown how difficult it is to provoke cortisol level increases to mild stressors such as stranger approach or inoculations. It is thought that a combination of physiological changes in the system and decreased sensitivity of the adrenal cortex to ACTH may play a role in the HPA stress response. There is also account for the child’s ability to access parent/care taker support which seems to buffer the HPA system (Gunner et al., 2007).

Cortisol is a major stress hormone and often used in studies because it can be collected noninvasively in saliva. Cortisol is released by the adrenal gland as part of the HPA hypothalamic-pituitary-adrenal axis. The HPA is also responsible for maintaining levels of cortisol as the right amount is important for adaptive responses. Typically, cortisol levels will peak in the morning and be lower in the afternoon (circadian cycle). They will also increase in a challenging situation and return to baseline when the challenge settles. The HPA appears to be highly influenced by experiences environmentally starting in utero both positively and negatively (White, 2009).

Case-Smith (2009) reported on the potential of using biophysical measures to help with our understanding of how stress affects behavior. Biomarkers are a way of measuring or evaluating internal response to external events (White & Mulligan, 2009).
Cortisol is found in blood, urine and saliva. It can most easily and least invasively be sampled by saliva via swabbing ("salivette") or free drool in field studies. The saliva is then analyzed by substances that bind to the cortisol to get a value for the amount of cortisol present. It is easier to use a control group for comparative data as there is no current normative data on cortisol levels (White & Mulligan, 2009).

It is important to look at the stress response in children with ASD since it is plausible based on observations of behavior presented earlier in the paper, that sensory experiences may produce anxiety, atypical responses and increased stress. We know from authors such as Leekam et al. and Brown et al. (2006, 2008) that children with ASD are bothered by sensory stimuli and it impacts their daily routines as well as causes changes in their behavior. What we don’t know is how it impacts their stress response. The stress response plays an important role in alerting and arousing the body for survival therefore stress is not always an unhealthy response especially when functioning appropriately. Gunner et al. (2007) reported that even though the stress response process is essential for survival, when occurring too frequently can lead to an increase risk in physical and mental health problems possibly even more so when occurring during times of rapid brain development. Noticing that children with autism seemed to be stressed more often and by events that are not typically stressful suggests that their stress response systems are not functioning in a typical fashion. We need to take a closer look at the behaviors described by parents, teachers and therapist such as withdrawing from light touch, hands held over ears during music, screaming during haircuts or hygiene routines, crying in a busy shopping mall or screaming at the site of a new food to better understand the role of the stress response system such behaviors. Using biomarkers and behavioral
observations is one way to look at both behavior and internal arousal systems. Lytle and Todd (2009) found that levels of endorphins and ACTH were significantly higher in individuals with autism suggesting a heightened response to stress as well as variations in amygdale volume correlating with non-verbal social impairments and anxiety. Baron et al. (2006) found that children with ASD had a high mean blood flow with a low peripheral vascular resistance which did not change with sensory intake as they were making a defensive response rejecting information from the environment in response to stress suggesting an atypical response to stress. Parents with children with autism also reported concern regarding their children’s stress and their ability to cope (Lytle & Todd, 2009). In a study by Corbett, Mendoza and Abdullah (2005), children with autism were found to have more variability in their circadian cortisol which may have been due to increased sensitivity to daily changes. Results also showed that the majority of the children with ASD (8 out of 10) had an increase in cortisol following an exposure to a non-social stressful event suggesting an exaggerated stress response while the majority of the typical children showed either no response or a reduction in cortisol. The study also reported that a majority of the children demonstrated no observable behavioral responses despite the change in cortisol response thus supporting the importance for biomarker indicators. According to Groden and colleagues (2001) most studies regarding stress and children with disabilities were done on the stress levels of those who work with the disabled populations. There have been limited studies on stress for persons with autism and other developmental disabilities. Groden et al. (2001) suggested how important a measuring tool is in order to help create coping mechanisms for this population due to their specific vulnerability.
Summary of Literature and Rationale for Study

In summary, the majority of the literature indicates that children with autism responded differently to sensory stimuli and that their bodies demonstrated visible signs of stress. Multiple studies have show that children with ASD responded differently to sensory stimuli in their environment than do their typical peers and that they responded differently than children with other developmental delays. It also seems that these sensory abnormalities may lead to behavioral signs of stress, especially hyper responsivity. Whether children with ASD and sensory modulation problems also show signs of physiological stress in addition to behavioral signs is unknown. This pilot study, using small samples will determine whether this topic should be explored in a larger sample; the study will also assess the utility of sensory probe as a stress response inducer in children. The purpose of this study is to examine differences in sensory processing in children with and without ASD and to examine differences in stress responses to a sensory probe between children with and without ASD.
CHAPTER II

METHODS

Research Design

This thesis describes a pilot study using a quasi-experimental two group design to investigate the potential differences in stress responding to a sensory stimulus, between children with and without autism spectrum disorders. This thesis describes one part of a larger study (N=41): an analysis of those children (N=14) who experienced a sensory stimulus as well as their diurnal cortisol patterns were completed for the purpose of the pilot. Physiological responses were assessed through pre-post assessment of cortisol before and after the sensory stimulus. In addition, diurnal patterns were assessed by two days of saliva collection at 4 time points throughout the day. The study hypothesis stated that children with ASD will respond different than their neuro-typical peers when exposed to a sensory stimulus as measured by results of salivary cortisol samples and behavioral response to stress. Further, we suspected that the diurnal patterns would suggest higher levels in children diagnosed with ASD in comparison to their neuro-typical peers.

Participants

The study was conducted using both neuro-typical children and those with ASD. Children with ASD were included in the study by a confirmed diagnosis of autism, PDD, PDD-NOS or Asperger’s from a medical doctor. If the child had a confirmed diagnosis
based on parent confirmation and clinic notes they were accepted. Children in the neurotypical group were included study by confirmation by the thesis author and/or thesis advisor of no existence of a developmental delay or neurological condition. Participants were recruited by convenience sampling, through participating clinics and a summer camp in the New England area at which the principal investigator worked, and through advertisements posted on the UNH and Autism Society of NH websites. Initial letters (appendix A) or emails were sent after first contact to explain the study. With verbal consent, packets of materials to collect diurnal samples with directions and pictures (Appendix B) were sent to the families for saliva collection. When possible, families were shown how to collect saliva from their child. Written consent (Appendix F) was obtained from the parents of the participants because all participants were under 18 years of age. Child assent was obtained verbally. After confirmation that diurnal collection packets were received, sensory probes were completed by the author of this thesis who is also an occupational therapist at the treating clinic and summer camp as well as two graduate students at UNH and the research advisor. The cortisol samples were then sent to the University of New Hampshire via US mail or hand delivery. There were a total of 41 (N=41) participants in the larger study. This thesis presents data on a total of 14 participants (N=14) who were able to complete both the probe and the diurnal saliva samples. Of those 14 children 8 were on the autism spectrum and 6 were in the control group. All participants were White. Of the 8 children in ASD group there were 7 males and one female. Their ages ranged from 5 years to 8 years. They all came from homes of married couples. Of the 6 children in the control group there were 4 boys and 2 girls.
Their ages ranged from 4 to 12 years. Four of the children resided in 2 parent homes while 2 of the children lived with a single parent.

**Dependent Variables**

**Cortisol Samples**

Salivary cortisol was used for this study because it is found a non-invasive means of collecting and measuring for changes in the body due to stressful experiences. Cortisol is a glucocorticoid hormone (i.e. steroid) released by the adrenal glands as part of a complex system, the hypothalamic-pituitary-adrenal axis HPA or LHPA when referring to the Limbic system and emotional component of the system (Kandel et al., 2000). Cortisol may be measured through saliva samples obtained by various methods, including collecting free drool and sponges (e.g. "salivette"). For our study purposes we used both salivettes and free drool. The parents and children were asked to collect four saliva samples on two consecutive days. These samples were collected at wake time, 30-45 minutes post wake, around 4 p.m. and just before bed time. Once they had collected all of the daily samples, they were asked to mail them into the university or pass them over to the researcher. All diurnal salivary samples were stored in participants’ home refrigerators until brought or sent to the university. Samples were stored at the University in a -80° freezer until they were batched for analysis without thawing, and replaced in the freezer until assayed. Samples were thawed, centrifuged and then assayed for cortisol using an Expanded Range High-Sensitivity Salivary Cortisol Enzyme Immunoassay (Salimetrics, State College, PA), following a standardized lab protocol (http://www.salimetrics.com/products_and_services/salivary_assays/). Salivary assays have been validated to accurately reflect the biologically active fraction of cortisol in
Cortisol assay intra-assay duplicates within 15% variation are accepted to be within sufficient reliability in studies using salivary cortisol as a biomarker (White, 2009). The intra-assay co-efficient of variation (CV) was less than 15% on all duplicates; cortisol values with higher CV’s were accepted if the variation between duplicate samples fell below 0.003 µg/dL. Inter-assay coefficients of variation between batches were within 10%, based on values obtained from control samples placed within batches. All cortisol data that were analyzed for diurnal patterns were log-transformed as is common when using physiologic data. Log-transformation is done in order to normalize the data for parametric statistical analyses (Gunnar & White, 2001).

**Behavioral Responses**

A sensory probe (appendix C) was designed based on current knowledge and experience working with children with autism. As noted by Corbett et al. (2005) children with ASD who were exposed to a potential stressor by using a mock MRI demonstrated a change in cortisol. We were looking for a more common sensory experience, or something to trigger a stress response that would occur on a daily basis but that would not seem noxious to the average person. Based on information from both clinical and parent observation as to what appears to elicit stress in children with autism we developed an experience that contained a number of items that we expected would challenge sensory systems in children with sensory processing disorder. Items used were a feather, a toothbrush, a fuzzy ball, silly string, “goop”, toe socks, a whistle and finger nail clippers. The children were asked to participate or help the researcher with some activities for a project. The child was seated across from the examiner and shown the stimulus (feather, toothbrush, and fuzzy ball) which was swiped three times across the cheek (right or left
The silly string was shown to the child and squirted into the palm three times. The goop was presented to the child and the child was asked to put one finger in, then two fingers and then three fingers in the container. The socks were presented to the child and he was asked to put one on, then two on and then he was asked to pull them up. The whistle was blown without warning on three occasions. The child was shown the nail clippers and asked if the research could clip a nail. Three nails were attempted. On each attempt a behavioral code was scored. The items were placed in order from potentially least stimulating to most stimulating to the nervous system. Children’s behavioral responses were coded on a scale of +4 to -5 based on verbal and physical behavior responses of the child. The child scored a 0 for a neutral response up to a +4 for an extremely positive response and as low as -5 if the child refused to attempt the task. The coding system was adapted from a similar one used by J. Wilbarger and M. Schneider at the University of Wisconsin, Madison. Each task was administered three times to attempt to trigger a response. All three scores were averaged together to obtain a single item score. All items remained independent scores vs. averaging all scores together for a total behavior score to observe patterns across items. Averaging all scores together tended to negate high and low scores. Four researchers collected data and were trained in applying the sensory probe and coded at least one child with one another. These individuals were the faculty advisor who designed the coding scheme using M. Schneider’s organizational template, the master’s student researcher in this study (thesis author), and two graduate occupational therapy students. The faculty advisor coded two cases, each master’s student coded one case and the remaining ten cases were coded the thesis author. In each instance for training there were no discrepancies for coding
however, inter-rater reliability was not calculated. A saliva sample was taken prior to the sensory probe and at 10 and 20 minutes following completion of the stimulus.

**Short Sensory Profile**

The Short Sensory Profile (SSP) by Dunn (appendix E) is a 38-item parent questionnaire that measures behaviors related to abnormal sensory responses. The parent or care taker rates the child’s response to visual, tactile, vestibular and auditory stimuli on a Likert scale ranging from always to never responses. These responses are given a number value of 0-4. The higher number is a more typical response and the lower number suggests that a sensory difference is likely present. The total score is a better indicator of a sensory modulation problem rather than subgroups or area number. The SSP was derived from the longer Sensory Profile Questionnaire (Dunn, 1999). The SSP has a reliability of .90 and a discriminate validity of > .95 (McIntosh et al., 1999). An occupational therapist or professional trained in sensory processing scores the sensory profile. Scores that fall within one standard deviation of the mean for each category represent "Typical Performance;" one to two standard deviations below the mean, "Probable Difference," and scores below two standard deviations below the mean, "Definite Difference." Children scoring in the probable or definite difference range suggest that further assessment or possible therapeutic intervention may be warranted. The Short Sensory Profile was piloted among children with ASD and found to be a useful screening tool for assessing sensory modulation and processing deficits. The Short Sensory Profile can be completed by the caregiver or teacher in 10 minutes and scored by the examiner in 10 minutes. It is therefore widely used in clinics and school-based settings as well as in research protocols (McIntosh et.al, 2009). A score of 38-141 falls within the definite difference range, a score of 142-154 falls within the probable range and a score of 155-190 falls with- in the
typical range. Several studies have used the Short Sensory Profile to distinguish children with autism from other developmental disabilities as well as identify behavior trends in the autism population. In 2008 Baker and colleagues conducted a pilot study on the relationship between sensory processing patterns and behavioral responses also using the Short Sensory Profile. They recruited 22 children with ASD to participate in the study to look at sensory processing and behavior correlation by having caregivers fill out questionnaires or participate in interviews. The authors found that most participants in this study displayed some degree of sensory processing difficulty (82%). Even without a control group the data suggests this number to be a great deal higher than that of the neurotypical population. The authors also suggest that many of the participants had marked area of difficulty in several areas of the SSP while demonstrating typical responses in others showing a pattern of sensory processing dysfunction. The authors found there to be noteworthy findings between sensory processing and behavioral data (using the Developmental Behavior Checklist-Parent DBC-P) which includes moderate correlations between emotional behavior/maladaptive behavior and the following SSP sections: Under responsive/Seeks sensation, Auditory Filtering and Low Energy/Weak (Baker et al., 2008). These authors were looking to connect poor sensory processing to issues with behavioral observations noted by parents.

For the purpose of our study, the parents were asked to complete the SSP. It was returned with the diurnal cortisol samples and scored by researchers at UNH. The total scores were used for analysis in this study.
CHAPTER III

RESULTS

To first address whether there were group differences in daily cortisol patterns, we ran a repeated measures multivariate ANOVA on 4 measures of cortisol during the day, and compared these by group. All children (N=14) showed a change in cortisol over the course of the day. $F=8.51$ (1), $p=.001$; however, there were no differences seen in patterns by group $F=3.338$ (1), $p=.108$. There was more variability at time points one and two in both groups but these were not statistically significant. Across groups there was a decrease at time points three and four which is a typical diurnal pattern. The mean values for logged cortisol in both groups were: 1) First morning sample, $M=.247$ (.17); 2) Second morning sample, $M=.240$ (.11); 3) Afternoon sample, $M=.088$ (.10); and 4) Evening sample, $M=.041$ (.035).
Figure 1- ASD diurnal group patterns

Figure 2- Neurotypical group diurnal patterns
The sensory probe data were graphed for pattern analysis of the cortisol as well as comparison to the behavior response as well. Visual analysis was chosen because there were not enough data available at all three time points taken during the sensory stimulus for statistical analysis. The scores of the behavioral responses were given a quantitative measure from +4 to a -5 (see appendix E for descriptions). After the three trials were administered the appropriate scores an average score on each item was calculated for each participant. Table 1 shows the average scores on each of the items in the probe for each participant. The fourteen plot graphs were individually analyzed and then plotted on one chart for comparison. They were then plotted on individual graphs to show trends and differences between groups.

Figure 3- ASD and Neurotypical Group Sensory Probes

![Graph showing cortisol concentration changes over time for ASD and Neurotypical groups.](image-url)
Figure 4 - Neurotypical Group Sensory Probe

Salivary cortisol concentration in μg/dL

1 = Baseline (pre-sensory probe)  2 = 10 minutes post  3 = 20 minutes post

Figure 5 - ASD Group: Sensory Probe

Salivary cortisol concentration in μg/dL

1 = Baseline (pre-sensory probe)  2 = 10 minutes post  3 = 20 minutes post

35
Table 1-Behavior Observation Chart

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Table 2-Short Sensory Profile Scores

Definite Difference Range – 141-38
Probable Difference Range – 154-142
Typical Performance Range – 190-155

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All Short Sensory Profiles were scored and charted below. Seven out of eight children with ASD scored in the Definite Difference Range with the eighth meeting the minimum requirements for typical performance. All six of the neuro-typical participants scored in the Typical Performance Range. We ran a Chi Square test to determine to probability of one group scoring in the atypical range vs. the other. The results of the Pearson Chi-Square were significant, $\chi^2 = 9.479 \ (1), \ p=.002$ suggesting that the ASD group scored significantly different than did the typical group.

Sensory probe scores were categorized from negative to positive with the negative scores being behaviorally observed as challenging or unable to tolerate and the positive scores being either enjoyable or over stimulating. ASD participants 2219, 2220, 2223, 2230, 2236 and 2240 all received scores that were relatively negative with some neutral scores (0) indicating that they did not enjoy the stimulus and had a behavioral response that would indicate some stress may be caused by the stimulus as observed by their behavior. ASD participant 2205 also had several negative behaviors combined with some hyper responsive behaviors which would also indicate and usual behavior response and possible signs of stress. There seemed to be some correlation between negative behavioral responses and increased cortisol levels in some participants. These participants (2219, 2220, and 2240) demonstrated higher spikes in cortisol while also registering neutral to consistently negative responses on the behavior scale. Neuro-typical participants 3351, 3353, 3354, 3355 and 33362 all demonstrated behavioral responses in the neutral range or mildly positive range suggesting they either enjoyed the experience or had no reaction. Neuro-typical participant 3305 had an extremely positive reaction.
suggesting he had a hyper responsive reaction to the stimulus may also suggest he was very excited by the stimulus.

Cross tabulations were done to look at whether the children with ASD differed in behavioral response from the control group. We analyzed behavioral responses using Chi Square analysis. We found that five of the probe items showed a significant difference between the groups. The items that showed difference in behavioral response were the fuzzy ball, $\chi^2 = 11.48\ (5), p=.043$; the silly string, $\chi^2 = 13.576\ (6)\ p=.035$; the goop $\chi^2 = 16.349\ (7),\ p=.022$; the fuzzy socks $\chi^2 = 11.483\ (5),\ p=.043$ and the whistle $\chi^2 = 11.483\ (4),\ p=.022$. Of significance was that only one child in the control group registered one negative response in one item while there were 28 negative responses recorded in the ASD group.
CHAPTER IV

DISCUSSION

The purpose of this study was to take a closer look at how sensory stimuli may impact the stress response of children with ASD. By using cortisol levels to measure a change in stress response we were able to look at the response and compare that to a behavioral response from the subjects. It was interesting to see that four of the eight participants on the spectrum responded with an increase in cortisol level at 20 minutes. One had no change and two had a decline or typical response. Of the typical participants, three out of four had a decline (expected response) and one had a mild increase. Behaviorally it is interesting to look at the data and note that of all the neuro typical children’s responses only one of the children on one response item indicated a negative response suggesting he/she did not enjoy or accept that item in a positive manner. Also, seven out of the eight children with ASD scored in the atypical range on their Short Sensory Profile while respectively all the children in the control group scored in the typical range on their Short Sensory Profile. This suggests that the children with ASD were more likely to be provoked by the stimulus than the children without ASD diagnoses. When looking at all the data combined it is easier to see the whole picture. While the cortisol levels may not be definitive in themselves the behavior observations allow a helpful look into the stress level and manifestation of the child at the time of the stimulus probe. It allows the observer to determine if the child was becoming stressed as
noted by their external behavioral signs and to begin to determine and make some estimation regarding how they responded.

It appears that in some children with autism (57%) a sensory stimulus may elicit a stressful response behaviorally and by also a change in cortisol levels. It also appears that the sensory stimulus presented in this study did not induce a stressful response in most neuro-typical children (75%). The diurnal cortisol baseline levels did not demonstrate differences across groups in this study. Only one participant in the ASD group (2230) showed an afternoon spike in cortisol suggesting the possibility of an atypical diurnal pattern. However, as discussed below, the participants in the ASD group were heterogeneous in diagnosis in that we did not have diagnostic information regarding the type of spectrum disorder or degree of disability.

**Limitations and Implications for Future Research:**

This study had several limitations which should be considered when considering the results. Our study did not have specific diagnostic criteria for the ASD group such as the ADOS or other diagnostic testing criteria. We used only a confirmed diagnosis as a criterion. Another limitation was the familiarity existing between subjects and the treating therapist. This tended to decrease the stress level with the participants that may have been present typically and may have made the client comfortable with the sensory experience. Although numbers were used to identify participants this was not a true blind study due to the researcher knowing the majority of the participants and their typical behaviors. This study also had a small number of participants and should be considered as a pilot only. There was also some difficulty in saliva collection which required some samples to be removed from the study. Better description and saliva collection
procedures will help with minimizing the loss of data due to insufficient sample for analyses.

In going forth, all participants should have a confirmation of the form of autism spectrum disorder. A true blind study would be ideal as well using only numbers to identify the participants and removing all names with in both groups. It would also be ideal for researchers to be scored on inter-rater reliability for the sensory probe scoring. It was not done in this study because almost all of the participants were tested by the thesis author. The implications for research and possibility for identifying a biomarker for autism are certainly noteworthy in this study as well as further looking at biomarkers and stress response in children with sensory processing disorder. There are implications for the field of occupational therapy and treatment protocols and the ability to identify a response to a sensory stimulus as well as a change in response based on effective treatment using cortisol measures. There is also potential for assisting those with ASD in identifying triggers of stress as well as behavioral signs of stress to help them manage their own stress levels. Developing a behavioral coding system similar to the one used in this study for identifying signs of stress is one option for those working with children with ASD.
REFERENCES


APPENDIX A-INITIAL LETTER

UNIVERSITY of NEW HAMPSHIRE

February 12, 2008

Dear parents:

I am conducting a study at the University of New Hampshire to look at whether children who are diagnosed with an autism spectrum disorder have measurable differences in how they react to their environment. A number of other therapists and students are helping with this project. The markers that I am studying are a stress hormone, cortisol, and a digestive enzyme, alpha-amylase. Both markers are detected in saliva. I am asking if you would consider helping me with this project: there are no financial incentives for participating but you would be helping to contribute to a better understanding of why children with autism and Asperger's react to things in their environment in sometimes unusual ways. We are looking for children ages 3-12 years with a diagnosis of ASD from two sources, a physician and other clinical specialist trained in diagnosing autism (e.g. psychologist, or other specialist using the Autism Diagnostic Observation System (ADOS), as well as children aged 3-12 years who do not have known behavioral or social disabilities. The tasks asked of you include filling out a few short surveys and collecting 8 saliva samples from your child over a two-day period (4 times each day at specified times). All materials are mailed or given to you and you mail samples back to me so that no travel is involved.

I would very much appreciate your participation, and thank you in advance for considering the study. I have attached a consent form for you to review. If you would like to know more or have materials sent to you, please call me at 603-862-2461 or email bpwhite@unh.edu.

Thanks!!!
Barb Prudhomme White
Dear parents:

Thanks for helping us with this study! We will keep you posted regarding any information that we learn, so please make sure that we have your updated contact information.

In this envelope you will find:
1. A consent form: please sign one copy and return. An extra is included for your files.
2. A family information sheet
3. A health information sheet
4. A Short Sensory profile
5. Directions on how to collect saliva
6. A bag of labels and vials.

Please read directions carefully. Essentially, we are asking that you collect saliva samples from your child 4 times per day at specified times, for two consecutive days.

Things that are most helpful:
1. Apply your participant number to EVERYTHING, especially the labels.
2. Collect TWO really soaked sponges from your child each time.
3. Put time of sample on the labels, and
4. Make sure that you tighten the vials.

Once you are done, please mail the envelope back to us.

Thanks!
If you have any questions please call Barb at 603-862-2461 or email at bpwhite@unh.edu.

© Barb
Family Information

Date: __/__/____

I. Identification
Home/Message Phone: __________________________
Name of Mother: __________________________ OR Name of Father: __________________________
Age: __________ OR Age: __________
Mother’s Address: __________________________
Father’s Address: __________________________

Current Relationship Status of Parents (Check One)
☐ Married ☐ Divorced ☐ Separated ☐ Single ☐ Living Together ☐ Widowed

Total Number of People living in home: ______
Ages of Males: ______ ______ ______ Ages of Females: ______ ______ ______

II. Education
Highest grade completed: Mother: (Check one)
☐ Less than 12th grade ☐ High school graduate ☐ Higher than 12th
currently enrolled in school? ☐ Yes ☐ No

Highest grade completed: Father: (Check one)
☐ Less than 12th grade ☐ High school graduate ☐ Higher than 12th
currently enrolled in school? ☐ Yes ☐ No

III. Family Income
What is the yearly combined family income of your household? (Check one)
☐ $0-$15,000 ☐ $15,001-$30,000 ☐ $30,001-$60,000
☐ $60,001-$100,000 ☐ $100,001 and above

IV. Demographic Information (child info)
Date of Birth: ______/_____/______
Gender: ☐ Male ☐ Female

Month Day Year

Relevant health and developmental history: (e.g. developmental or health diagnosis or well child)

Ethnic Background: (Check any that apply)
☐ White/Caucasian ☐ Native American
☐ Asian ☐ Other (Please Specify)
☐ Black/African American ☐ Latino/Latina

Saliva collection to coincide with sensory stimulation probe and behavioral scoring
1. Make sure that the child and parent are settled in the clinic or waiting room.
2. Collect baseline sample by asking the child to suck on the saliva sponges. This is a great time to show them the item and to demonstrate to the parent how to collect saliva. Make this as fun and non-intrusive as possible... sing a song or ask the child to try and figure out the “flavor”. We need 45 seconds of sampling in order to get enough saliva.
3. Once baseline is collected make sure that you label the sample with date and TIME. This is critical. The sample can be placed in the clinic area until you are finished collecting all samples.
4. Begin the sensory stim probe prior to your intervention session.
5. Once you have completed the protocol for all 8 items, start timing for the next sample.
6. The SECOND sample is taken 10 minutes from the end of the last item, finger nail clippers. Make sure that you note the time of the sample!
7. The THIRD sample is taken 20 minutes from the end of the last item (10 minutes after the 2nd sample). Make sure that you note the time of the sample!
8. Once all 3 samples are collected, place them in the refrigerator. Do not freeze them. Mail them back to UNH or deliver by hand,

**Saliva sample collection set up:**

Home: 16 swabs, 8 vials, 8 labels, Short Sensory Profile, health data form, demographic form, 2 consent forms (1 for parent, 1 for us), saliva collection schedule & instruction

Sensory Probe: 3 vials, 6 swabs, 3 labels, behavioral code sheet, test protocol
My child's two saliva days are ___________ &

We know morning routines can be hectic, but we truly appreciate you and your family's cooperation and help! Please try to stick to a few simple rules while collecting saliva samples for these two days.

ABSOLUTELY NO
* Food
* Drink
30 MINUTES PRIOR TO TAKING EACH SALIVA SAMPLE

** Your child can drink water anytime.
** If by accident, your child eats a bite of food or drinks a beverage such as milk, please have him/her wash the mouth out with water 15 minutes prior to the sample time.

** Please remember to record the date of the sample, time of sample, and what sample day (Day 1 and Day 2). Here is a list of the times for each sample. There are 4 samples times each day, and we ask that you sample on two consecutive days: Day 1 and Day 2.

** First Sample: Upon waking IMMEDIATELY (before brushing teeth)

** Second Sample: 45 minutes after waking up: Before brushing teeth and before eating any food or drinking. If your child takes a quick sip of something, please rinse his/her mouth out with water before sampling.

** Third Sample: 4:00 PM: No food or drink 30 minutes prior Wait 30 minutes after waking from a nap

** Fourth Sample: Right before bed: No food or drink or brushed teeth 30 minutes prior.

SEE BACK

52
Saliva sample directions

1. Remove 2 swabs from the packet tongue.

2. Place the swabs under your child’s

3. Hold the swab in the mouth for 45 point-
   seconds. Ask the child to try and figure
   out the “flavor” or sing a song to pass the time.

4. Remove swabs and place down in the tube.

5. Cut the swab stick with scissors so that it
   just fits in the tube, leaving about ½ in of
   pink handle.

5.Alternate Method without Using Swab: Passive Drool - Have child spit about
   ¼ tsp. of saliva into the tube.

6. Replace cap. Write down the date and time of sample on the label, and attach to
   the tube. Time of sample is critical.
7. Tighten tube cap and place in plastic bag.

Place plastic bag in the refrigerator until 2 days of samples are collected. Then send in the prepaid mailer back to UNH. Thank you!!! 😊
APPENDIX C-SENSORY PROBE

Sensory Stimulation Probe

(Prior to starting, make sure a baseline saliva sample has been collected)

Materials: Feather, Fuzzy Ball, Goop, soft toothbrush, fingernail clippers, silly string, fuzzy socks, whistle. Behavior Scale of Sensory Processing-Child (BSSP-C)

Directions:
Sensory Probe Protocol:
On all items, watch for reaction and score using BSSP-C. Tell/show the child that you have a bag of activities. Let him/her know that he/she is going to be feeling, touching and hearing different things. All items need to be administered 3 times each, in this order. There should be a 2-3 second delay between the items. Sit next to the child or in front of the child. Test one side of the face and then the other if possible. If not able to alternate R and L, then note that all testing was done on one side. *For goop, use one hand only for all 3 trials.

1. Feather: stroke the feather lightly on the face from base of ear to corner of mouth in an approximate 3-second count. R-L-R
2. Fuzzy ball- repeat stroke pattern listed above. R-L-R
3. Soft Tooth Brush: Repeat strokes used for Feather and Fuzzy Ball. R-L-R
4. Silly String: Take out silly string and show it to the child. Say “we are going to play with some of my silly string today”. Have child put hands face up on desk. Squirt a quarter size amount in their hand 3 times and once in yours. Demo playing with the silly string.
5. Goop*: While seated at table open container and ask child to put one finger in watching for response; ask child to put TWO fingers in, watch for response; ask child to put THREE fingers in and watch for final response.
6. Fuzzy Socks: If child is able to put socks on, say to child “here are some fun socks, I want you to put one on”. Repeat with the second sock. Once the socks are on, ask the child to pull the socks up.
7. Whistle: Briefly turn your head down and away from the child while you take the whistle out of the bag. As you take it out put it in your mouth blowing three times before the child sees the whistle in your mouth.
8. Finger Nail Clippers: Say to child “your finger nails look a little long, I have some clippers here and I am going to help you with them”. Approach the child’s fingers with the clippers and watch for reaction. If child allows you close enough attempt three times to clip nails.
9. At completion of all 8 items, begin a stopwatch. Second saliva sample is collected at 10 minutes; 3rd sample is taken at 20 minutes post completion of all 8 items.
**Scoring:** (see other side)

**Coding:**
Record the code that best captures the child’s behavior from the BSSP-C in the spaces below.

<table>
<thead>
<tr>
<th></th>
<th>Trial 1</th>
<th>Trial 2</th>
<th>Trial 3</th>
<th>Unable to continue</th>
<th>Comments: (note behavior)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feather</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fuzzy Ball</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Soft Tooth Brush</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Silly String</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Goop</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fuzzy Socks</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Whistle</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nail clippers</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
APPENDIX D- IRB APPROVAL LETTERS

University of New Hampshire
Research Conduct and Compliance Services, Office of Sponsored Research
Service Building, 51 College Road, Durham, NH 03824-3585
Fax: 603-862-3564

08-May-2008

White, Barbara
Occupational Therapy
Hewitt Hall
Durham, NH 03824

IRB #: 4012


Review Level: Full
Approval Expiration Date: 05-Jun-2009

The Institutional Review Board for the Protection of Human Subjects in Research (IRB) has reviewed and approved your request for time extension for this study. Approval for this study expires on the date indicated above. At the end of the approval period you will be asked to submit a report with regard to the involvement of human subjects. If your study is still active, you may apply for extension of IRB approval through this office.

Researchers who conduct studies involving human subjects have responsibilities as outlined in the document, Responsibilities of Directors of Research Studies Involving Human Subjects. This document is available at http://www.unh.edu/osr/compliance/irb.html or from me.

If you have questions or concerns about your study or this approval, please feel free to contact me at 603-862-2003 or Julie.simpson@unh.edu. Please refer to the IRB # above in all correspondence related to this study. The IRB wishes you success with your research.

For the IRB,

Julie F. Simpson
Manager
cc: File
University of New Hampshire
Research Integrity Services, Office of Sponsored Research
Service Building, 51 College Road, Durham, NH 03824-3585
Fax: 603-862-3564

21-May-2009

White, Barbara Prudhomme
Occupational Therapy, Hewitt Hall
Durham, NH 03824

IRB #: 4012
Review Level: Full
Approval Expiration Date: 05-Jun-2010

The Institutional Review Board for the Protection of Human Subjects in Research (IRB) has reviewed and approved your request for time extension for this study. Approval for this study expires on the date indicated above. At the end of the approval period you will be asked to submit a report with regard to the involvement of human subjects. If your study is still active, you may apply for extension of IRB approval through this office.

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For the IRB,

Julie F. Simpson
Manager

cc: File
21-May-2010

White, Barbara Prudhomme
Occupational Therapy, Hewitt Hall
Durham, NH 03824

IRB #: 4012

Review Level: Full
Approval Expiration Date: 05-Jun-2011

The Institutional Review Board for the Protection of Human Subjects in Research (IRB) has reviewed and approved your request for time extension for this study. Approval for this study expires on the date indicated above. At the end of the approval period you will be asked to submit a report with regard to the involvement of human subjects. If your study is still active, you may apply for extension of IRB approval through this office.

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For the IRB,

Julie F. Simpson
Manager

cc: File
**APPENDIX E- SHORT SENSORY PROFILE**

**Short Sensory Profile**

<table>
<thead>
<tr>
<th>Sensory Profile</th>
<th>Completed by: ___________________________</th>
<th>Relationship to Child: ___________________________</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sensory Profile</td>
<td>Seniors Provider’s Name: ___________________</td>
<td>Discipline: ___________________________</td>
</tr>
</tbody>
</table>

**INSTRUCTIONS**

Please check the box that best describes the frequency with which your child shows the following behaviors. Please indicate all of the statements. If your child simply by observation because you have not observed the behavior or believe that it does not apply to your child, please draw an X through the box for that item. Please do not write in the box below.

**Use the following key to mark your responses:**

- **ALWAYS**
- **FREQUENTLY**
- **OCCASIONALLY**
- **SEUM**
- **NEVER**

When presented with the opportunity, your child always responds in this manner, 100% of the time.

When presented with the opportunity, your child responds in this manner, about 75% of the time.

When presented with the opportunity, your child responds in this manner, about 50% of the time.

When presented with the opportunity, your child responds in this manner, about 25% of the time.

When presented with the opportunity, your child never responds in this manner, 0% of the time.

---

**Tactile Sensitivity**

- Item 1 | Expresses discomfort during grooming (for example, by crying or resisting) during bathing, hair cutting, face washing, fingernail cutting |
- Item 2 | Prefers long-sleeved clothing when it is warm or short sleeves when it is cold |
- Item 3 | Avoids going outside, especially in sand or grass |
- Item 4 | Requires emotional or physical proximity to touch |
- Item 5 | Wilts away from splashing water |
- Item 6 | Has difficulty standing, lying, or sitting close to other people |
- Item 7 | Rubs or touches out a spot that has been touched |

**Section Raw Score Total**

**Text/Smell Sensitivity**

- Item 8 | Avoids certain tastes or food smells that are typically part of children's diets |
- Item 9 | Will only eat certain tastes first |
- Item 10 | Limits self to particular food textures/consistencies first |
- Item 11 | Eats only specific foods that have been washed (for example, tomatoes, raw potatoes) |

**Section Raw Score Total**

**Movement Sensitivity**

- Item 12 | Becomes irritable or distressed when feet leave the ground |
- Item 13 | Fears height or heights |
- Item 14 | Difficulties getting up, getting out of bed, for example, proportionately, reaching, bending |

**Session Raw Score Total**

**Sound/Sensory Sensitivity**

- Item 15 | Enjoys simple noises/whistles to make faces or noises while sitting |
- Item 16 | Displays all kinds of movement and this interferes with daily routines, cannot sit still, fidgets |
- Item 17 | Becomes very irritable during movement activity |
- Item 18 | Touches people and objects |
- Item 19 | Doesn't want to wash when face or hands are messy |
- Item 20 | Likes to be able to practice on that activity with play |
- Item 21 | Wavers, calling voices, hearing |

**Section Raw Score Total**

---

0371150160

60
<table>
<thead>
<tr>
<th>Item</th>
<th>Auditory Filtering</th>
<th>Always</th>
<th>Frequently</th>
<th>Occasionally</th>
<th>Occasionally</th>
<th>Never</th>
<th>Section Raw Score Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>22.</td>
<td>Is distracted or has trouble focusing if there is a lot of noise around</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>23.</td>
<td>Appears to not hear what you say (for example, does not &quot;turn on&quot; to what you say, appears to ignore you)</td>
<td></td>
<td></td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>24.</td>
<td>Can't work with background noise (for example, fan, refrigerator)</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>25.</td>
<td>Has trouble completing tasks when the music is on</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>26.</td>
<td>Doesn't respond when name is called but you know the child hearing is OK</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>27.</td>
<td>Has difficulty paying attention</td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Section Raw Score Total</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Item</td>
<td>Low Energy/Weakness</td>
<td>Always</td>
<td>Frequently</td>
<td>Occasionally</td>
<td>Occasionally</td>
<td>Never</td>
<td>Section Raw Score Total</td>
</tr>
<tr>
<td>------</td>
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</tr>
<tr>
<td>28.</td>
<td>Seems to have weak muscles</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>29.</td>
<td>Tired easily, especially when standing or holding particular body position</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>30.</td>
<td>Has a weak grip</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>31.</td>
<td>Can't lift heavy objects (for example, week in comparison to same age children)</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>32.</td>
<td>Pers to support self (e.g., doing activity)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>33.</td>
<td>Poor endurance (tired easily)</td>
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</tr>
<tr>
<td>Section Raw Score Total</td>
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<td></td>
<td></td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>Item</td>
<td>Visual/Auditory Sensitivity</td>
<td>Always</td>
<td>Frequently</td>
<td>Occasionally</td>
<td>Occasionally</td>
<td>Never</td>
<td>Section Raw Score Total</td>
</tr>
<tr>
<td>------</td>
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<td>------------------------</td>
</tr>
<tr>
<td>34.</td>
<td>Responds negatively to unexpected or loud noises (for example, ears or head at noise from motor drill, dog barking, hair dryer)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>35.</td>
<td>Holds his own hands to protect ears from sound</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>36.</td>
<td>Is bothered by lights, glare, or other visual input in the light</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>37.</td>
<td>Wakes up crying when they move around the room</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>38.</td>
<td>Covers eyes or avoids to protect eyes from light</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Section Raw Score Total</td>
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<td></td>
</tr>
</tbody>
</table>

**Summary**

Instructions: Transfer the scores for each section to the Section Raw Score Total column. Place these scores by entering an X in the appropriate classification column (Typical Performance, Probable Difference, Definite Difference).

<table>
<thead>
<tr>
<th>Section</th>
<th>Section Raw Score Total</th>
<th>Typical Performance</th>
<th>Probable Difference</th>
<th>Definite Difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Movement Sensitivity</td>
<td>15</td>
<td>15-20</td>
<td>21-25</td>
<td>26-39</td>
</tr>
<tr>
<td>Understanding/Social Sensitivity</td>
<td>22</td>
<td>20-25</td>
<td>30-39</td>
<td>40-59</td>
</tr>
<tr>
<td>Auditory Filtering</td>
<td>23</td>
<td>20-25</td>
<td>30-39</td>
<td>40-59</td>
</tr>
<tr>
<td>Total</td>
<td>156</td>
<td>120-130</td>
<td>140-150</td>
<td>160-180</td>
</tr>
</tbody>
</table>

*Classifications are based on the performance of children without disabilities (p = 1.050).*
APPENDIX F- PARENTAL CONSENT

University of New Hampshire

Institutional Review Board for the Protection of Human Subjects in Research

Parental Consent for the Autism and Stress Biomarkers Project

Purpose:
The purpose of this study is to document any potential differences in stress hormone patterns between children who have autism spectrum disorder (ASD) and those who do not. Stress hormones, including cortisol, are a natural substance in our bodies and support adaptive behavior or the ability to respond to environmental and unpredictable situations. When studied, we sometimes refer to this and other body hormones and processes as a “biomarker”. High levels of stress hormones may be linked with discomfort to loud noises or different textures; there may also be a link to increased anxiety. Anxious behaviors are commonly observed in children with ASD, especially in relation to touch, movement, sound, smell, taste, and visual sensations. Very little is known regarding the baseline levels of stress hormones in children with ASD. Only one other study has documented that there may be some differences in stress biomarkers between children with and without ASD, and that the differences appear linked with very sensitive responses to the environment. We are asking children with ASD as well as children without ASD, and their parents, to participate in this study. This study is being conducted by Barbara Prudhomme White at the University of New Hampshire.

Description:
If you elect to participate in this study with your child, we would ask you to do the following:

1. Answer questions that describe you and your family, including your education level, ethnic background, and general health history. Provide information about your child’s birth-date, health status, and developmental and IQ level, if known. The time needed to fill out the forms is approximately 15 minutes.

2. We will show you how to collect saliva samples over two consecutive days at home. Samples are collected at morning wakeup, 45 minutes later, at 4 pm in the afternoon, and at bedtime before brushing teeth. Samples take about 45 seconds. The collection swab is stored in a vial, kept in the refrigerator, and then mailed to the university. We provide you with a pre-paid envelope as well as a visual
instruction sheet that guides you in collection methods as well as asks you to be careful to not let a child handle the swab without a parent holding it at all times. The estimated time to collect samples and mail them is approximately 20-30 minutes spread over two days.

3. Some children will be asked to participate in a sensory experience, using feathers, fuzzy socks, slimy silly putty, a whistle, silly string, and a fuzzy magic wand. This experience would happen at a regular clinic visit during therapy, if relevant, or in your home. We anticipate that some children will not like the sensory touch and sounds of these items. If your child has a strong negative response to them, we will discontinue the experience immediately. At this visit, your therapist (or you if preferred) will be asked to collect a saliva sample from your child prior to the sensory experience, and then 10 minutes and 20 minutes after the experience. These samples will also be mailed or delivered by your therapist or research assistant to the BPW at UNH.

4. We will ask your child for his/her participation in this study. Your child may discontinue at any time if he/she protests by saying “no” or other gesture.

- There are no direct benefits to you and your child for participating in this study. Your efforts may contribute to a better understanding of how stress response systems may be involved in over-sensitive reactions to generally non-threatening sensory experiences.
- Risk associated with this study include a potential choking hazard if the swabs used to collect saliva are left unattended in the hands of small children or older children with ASD. We will reduce this risk by careful instruction to you regarding how to handle the swabs. We also would like to ensure that you know the Heimlich maneuver for choking if this becomes necessary. We will review this procedure with you. The other potential risk is confidentiality. We will reduce this risk by ensuring that all information that you provide us is kept confidential. You and your child’s information will be coded and only the Principle investigator (Barbara Prudhomme White), your child’s clinical therapist (if relevant), or student research assistant will have access to your identifying information. All information will be kept in a locked file in the principal investigators office at UNH.

Therapists/students participating in this study:
Barbara Prudhomme White, Ph.D., OTR/L UNH
Noelle Schreiber, OTR/L
Students in the Master's program in Occupational Therapy, UNH

1. You understand that the use of human subjects in this project has been approved by the UNH Institutional Review Board for the Protection of Human Subjects in Research.

2. You understand the purposes of this research project and the procedures to be followed and how much time the tasks are anticipated to take.

3. You have received a description of any reasonable foreseeable risks or discomforts associated with your child’s participation in this research, have had them explained to you, and understand them.
4. The investigator seeks to maintain the confidentiality of all data and records associated with your participation in this research. You should understand, however, there are rare instances when the investigator is required to share personally identifiable information (e.g., according to policy, contract, and regulation). For example, in response to a complaint about the research, officials at the University of New Hampshire, designees of the sponsor(s), and/or regulatory and oversight government agencies may access research data. You also should understand that the investigator is required by law to report certain information to government and/or law enforcement officials (e.g., child abuse, threatened violence against self or others, communicable diseases).

5. You understand that your consent to have your child participate in this research is voluntary, and that your refusal to participate will involve no prejudice, penalty or loss of benefits to which you would otherwise be entitled. If you choose to not participate, there will be no changes or affect to your regular therapy or in your relationship or potential relationship to the occupational therapy department at UNH.

6. You further understand that if you consent to participate, you and your child may discontinue your participation at any time without prejudice, penalty, or loss of benefits to which you would otherwise be entitled.

7. You confirm that no coercion of any kind was used in seeking your participation in this research project.

8. You understand that if you are injured or require medical treatment, you may seek treatment from your primary care provider.

9. You understand that if you have any questions pertaining to the research (or any research related injury) you can call Barbara Prudhomme White at UNH, 603-862-2461 be given the opportunity to discuss them. If you have questions, pertaining to your rights as a research subject you can call Julie Simpson in the UNH Office of Sponsored Research, 603-862-2003, to discuss them.

10. You understand that you will (or will not) be provided financial incentive for your participation by the University of New Hampshire.

11. You certify that you have read and fully understand the purpose of this research project and the risks and benefits it presents to you as stated above.

I consent to participating and having my child participate in this study. I understand that my child will be asked to participate as well, and may refuse by saying “no” or other refusal gesture.

__________________________________________________________
Date ____________________________________________________________________