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## Life as a sensory over-responsive adult : social/emotional challenges, coping mechanisms and treatments

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Sarah Kyungwha Ahn  
Life as a Sensory Over-Responsive  
Adult: Social/Emotional Challenges,  
Coping Mechanisms and Treatments

### **ABSTRACT**

The purpose of this exploratory, qualitative research study was to explicate the lives of 14 Sensory Over-Responsive adults with a particular focus on social/emotional challenges as well as coping mechanisms and treatments.

The findings suggest that Sensory Over-Responsivity has had a far-reaching influence on every aspect of a respondent's life: from family to school to relationships to work and to play. Respondents believed that there was a link between their Sensory Over-Responsivity and accompanying social and emotional issues such as anxiety, depression, isolation, withdrawal, and lowered self-esteem, and they displayed a wide range of adaptive coping behaviors including avoidance, control, self-awareness, relaxation, use of humor, and downtime. In addition, study participants sought out many types of treatment for their Sensory Over-Responsivity most notably, mental health counseling, occupational therapy, exercise, listening therapy, meditation, chiropractic/massage, journaling, and nutritional intervention. The severity of impairment varied by participant, but overall I was struck by the persistence, depth, and breadth of Sensory Over-Responsivity within this small sample. The implication for future work is clear; while this study highlighted some interesting themes, further research is needed.

**LIFE AS A SENSORY OVER-RESPONSIVE ADULT:  
SOCIAL/EMOTIONAL CHALLENGES, COPING MECHANISMS  
AND TREATMENTS**

A project based upon an independent investigation,  
submitted in partial fulfillment of the requirements  
for the degree of Master of Social Work.

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2013

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I feel blessed to have three amazing children, supportive in-laws, steadfast friends, and a wonderful partner in life. I could not have survived these last two years without your smiles, hugs, and kisses.

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## **CHAPTER I**

### **Introduction**

“Is being a Mom supposed to be this hard?” I thought to myself as I readied for mealtime with my 14 month old firstborn, Jackson. Laden down with squeaky toys and waterproof books, I approached his highchair wearily. “Okay, sweet pea, it’s dinner time – what should we do first?” This had become our daily routine. The only way I could get my baby to eat was to distract him with books or toys as I quickly shoveled in as much food as he would tolerate. Sometimes it was a few spoonfuls and if I was lucky a bowlful of his preferred texture. Jackson would cry if any food would drop on his hands or face and he would not settle until the offending stimulus was quickly removed. He never showed signs of hunger and he would rarely feed himself. As a baby he never went through the mouthing stage and at first, I was thrilled. I didn’t have to worry about him sucking on random, germy toys but then I soon realized that he didn’t like to put anything in his mouth, including food. He was my very sensitive baby. He would cry uncontrollably when I’d blow-dry my hair or if the doorbell rang or a toilet would flush. He was slow to sit up, reluctant to crawl, and did not walk until 19 months. But, it was his eating, or lack thereof, that finally made me realize that something was not quite right. Our pediatrician dismissed my concerns saying, “He’ll eat when he’s hungry,” despite my protestations that this, in fact, was not the case. Help came from someone whom I never met. In desperation I described my situation and emailed it to a listserv of local Moms. The reply was direct and to

the point. “Have you heard of Sensory Processing Disorder? You should have your baby evaluated by an occupational therapist.” And thus our journey began eight years ago.

Sensory Processing Disorder (SPD), formerly called Sensory Integrative Dysfunction, is an umbrella term for a number of sensory-based disorders. Sensory processing refers to the way the nervous system receives messages from eight senses: auditory, tactile, visual, olfactory, gustatory, vestibular, proprioceptive and interoceptive; interprets the sensory messages; and then organizes motor and behavioral responses to the sensory inputs (Ahn, 2012). Researchers characterize sensory processing as the way we make sense of the world by understanding what our senses are telling us (Sicile-Kira, 2008). Sensory Processing *Disorder* is a condition that exists when the nervous system is *unable* to respond to sensory messages with appropriate responses (Ahn, 2012). With SPD, sensory difficulties are chronic and they disrupt everyday life (Miller, 2006). It is estimated that the incidence of SPD among children ranges from 5% to 17%, depending on the severity criteria used (Ahn, Miller, Milberger, & McIntosh, 2004; Ben-Sasson, Carter, & Briggs-Gowan, 2009).

In this research study, I focused on a subset of a subset of SPD. Sensory Modulation Disorder (SMD) refers to a smaller group within the larger umbrella term of SPD (see Appendix A for a diagram of SPD and its subtypes). People with SMD consistently over-respond, under-respond, or have fluctuating responses to environmental stimuli to a level that results in disruptions in daily functioning (Lane, Miller, & Hanft, 2000). Another subset of SPD is called Sensory-Based Motor Disorder (SBMD). People with SBMD have difficulty stabilizing, moving, or sequencing movements in response to sensory input (Miller, 2006). The last subtype is called Sensory Discrimination Disorder (SDD). Individuals with SDD have difficulty sensing similarities and differences between sensations (Miller, 2006). For example, if one has difficulty



with SDD in the tactile sense, he/she may have trouble delineating a fork from a spoon in a dark drawer. Likewise, some with SDD in their auditory sense may not hear the difference between a “g” and a “k” sound (Miller, 2006). My research study focused on those who consistently **over-respond** to sensory input in at least two of their eight senses. Adults with Sensory Over-Responsivity (SOR) react to sensory stimuli more quickly, more intensely and for longer periods of time than those with typical sensory sensitivity (Miller, 2006). Those with Sensory Under-Responsivity (SUR), often show little or no reaction to stimulation. SUR may lead to poor body awareness and a reduced ability to detect pain or changes in temperature (“What sensory processing disorder looks like,” 2013). SOR is a subset of Sensory Modulation Disorder (SMD) and it is also called Sensory Defensiveness. The prevalence rate of adults with SOR is unknown.

The field of Sensory Processing Disorder is characterized by both a dearth of research and an abundance of controversy. There are many who do not believe that Sensory Processing Disorder is a stand-alone disorder, but rather a symptom of other developmental disorders such as Asperger’s or Autism Spectrum Disorder (American Academy of Pediatrics, 2012). Some neurologists feel that sensory symptoms are a “non-specific indicator of neurodevelopmental immaturity, not a sign of a distinct disorder” (Heilbroner, 2005, p. 1). This viewpoint was reinforced with the December, 2012, decision to not include SPD as a stand-alone disorder in the *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; DSM-5; American Psychiatric Association, 2013). Instead sensory processing challenges are listed as potential criteria for diagnosing Autism Spectrum Disorder. There are five key diagnostic criteria for Autism Spectrum Disorder and sensory reactivity is listed under, “Criteria B: Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text): (5th ed.; DSM-5;

American Psychiatric Association, 2013, p. 50).” Listed under Criteria B are four examples.

Criteria number 4 under Criteria B reads:

Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement). (5th ed.; DSM-5; American Psychiatric Association, 2013, p. 50).

This description is woefully incomplete, as there are many more examples of sensitivity in the eight senses that would lead one to select these criteria. To expect that clinicians are well aware of the breadth of dysfunction possible in all eight senses is optimistic, leading many to worry that even within Autism Spectrum Disorder, SPD will be overlooked.

It is widely accepted within the SPD community that there is a need for additional research. While the number of research projects has quadrupled over the last 10 years, there are still significant gaps. Specifically, there has not been enough rigorous research to confirm that Sensory Processing Disorder is or is not a stand-alone condition. To date, the majority of research on SPD and SOR has been conducted by occupational therapists. There is a need for mental health clinicians to further research and understand the possible linkages between SOR and co-occurring internalizing, externalizing and dysregulating behaviors. When assessing treatments, there is a need for repeatable studies that look at the effectiveness of sensory integration occupational therapy overall and its effect on social and emotional issues (May-Benson & Koomar, 2010). There are also very few studies that have focused on SPD in adults or adolescents; rather, the bulk of research has been conducted with children, leading many to falsely believe that SPD is a childhood disorder only.

In this research study, I have sought to contextualize the lived experiences of *adults* who live with SOR in at least two of their eight senses. My in-person, qualitative interviews explored

how SOR affects every facet of a respondent's life: from family to school to work to relationships. I was particularly interested in the mental health of my respondents and if they saw any linkage between their sensory sensitivities and feelings of anxiety, depression, isolation, withdrawal, and low self-esteem. For those respondents who did seek treatment for their sensory difficulties, I was interested in their perceptions of what worked and why. For those who didn't seek treatment, I was interested in their adaptive behaviors and various coping mechanisms. I was also interested in seeking a balanced perspective on SPD and SOR; too often the focus is on sensory sensitivity as a disorder and not a benefit. What many of my respondents demonstrated was how their sensory sensitivities have been an asset in their family, their work, their relationships, and their life. I am deeply grateful to the 14 respondents who were willing to share so openly and honestly with me. My hope is that this body of work will be an important addition to the growing conversation about Sensory Over-Responsiveness (SOR) and its impact on mental health and implications for treatment.

## **CHAPTER II**

### **Literature Review**

#### **Introduction**

The purpose of this exploratory, qualitative study was to explicate the lives of Sensory Over-Responsive adults with a focus on social and emotional issues as well as coping mechanisms and treatments. In this chapter, I will summarize current research in five key areas. First, I will explore what it means to have Sensory Processing Disorder (SPD), then look at key studies that support: the validity of SPD and SOR, the relationship between SOR and anxiety, the linkage between SOR and temperament, and the effectiveness of sensory integration occupational therapy treatments.

#### **What is Sensory Processing Disorder?**

In order to fully understand the specificity of Sensory Over-Responsiveness (SOR), it may be helpful to start with a broader understanding of sensory processing, then look specifically at the role of modulation. Dr. A. Jean Ayres, an educational psychologist and occupational therapist, who is credited as the founder of Sensory Integration Dysfunction, once wrote that, “Over 80% of the nervous system is involved in processing or organizing sensory input, and thus the brain is primarily a sensory processing machine (as cited in Kranowitz, 2005).” When our brain is processing sensations accurately, our responses are appropriate as well. Sensory

processing involves a myriad of functions including: reception, detection, integration, modulation, discrimination, postural responses and motor planning (Kranowitz, 2005).

### **Modulation.**

For the purposes of this literature review, I will focus primarily on modulation as SOR is a subtype of Sensory Modulation Disorder (SMD). Modulation refers to the way the brain regulates sensory input and it is made up of excitatory as well as inhibitory responses. Incoming sensations activate sensory receptors in a process called excitation (Kranowitz, 2005).

Conversely, inhibition allows us to filter out extraneous information and focus on critical matters in the moment (Kranowitz, 2005). Kranowitz summarizes that a key issue with SOR is that, “The over-responsive child’s brain cannot inhibit sensations efficiently (Kranowitz, 2005, p. 70).”

### **Habituation and sensitization.**

Habituation refers to the process by which individuals adapt to novel stimuli. For example, a sound like a car horn beeping may initially trigger the brain to worry and wonder if danger is coming but then after hearing the sound several times, the brain adapts and no longer responds as if the noise is an alarm. For those with Sensory Modulation Disorder, the time to habituation is much longer than those with typical sensory modulation function (McIntosh, Miller, Shyu, & Hagerman, 1999). Conversely, sensitization is the process by which one notices novel stimuli. SOR reflects a failure to achieve a balance between sensitization and habituation (Ben-Sasson, Carter, & Briggs-Gowan, 2010).

### **The building blocks of Sensory Processing Disorder (SPD).**

A. Jean Ayres was the first to write about the four levels of sensory integration. Carol Kranowitz, OTR, then built upon her work and created a building block model of sensory

integration. Each new block depends upon the efficient functioning of the block or layer below. However, this process is very fluid, as many of these senses are developed together, while some functioning is dependent on others. The first block is the Primary Sensory Systems. This level is tied to the development of touch, balance and movement, and body position. The second level is Sensory-Motor Skills with specific focus on the development of body awareness, use of both sides of the body, hand preference, and motor planning. The third level is Perceptual Motor Skills, which relates to the development of auditory and visual discrimination, speech and language, and eye/hand coordination. At the fourth and final level, Academic Readiness, everything comes together and the child is ready and able to work on academic skills, complex motor skills, attention regulation, self-esteem, and self-control (Kranowitz, 2005). Importantly, A. Jean Ayres, drew a connection between SPD and self-esteem in saying, “Self-esteem, self-control, and self-confidence come from feeling the body as a competent sensorimotor being, and from good neurological integration” (Ayres, 2005, p. 70). By the start of elementary school, typically developing children have successfully negotiated each of the four levels of integration.

### **The Support for SPD as a Distinct Disorder**

There is a growing body of evidence that SPD is a distinct disorder despite the January, 2012, decision by the DSM-5 committee to not include SPD as a stand-alone disorder but rather as a cluster of symptoms under Autism Spectrum Disorder. It is interesting to note that while SPD encompasses a broader umbrella of subtypes (see Appendix A: Sensory Processing Disorder and Its Subtypes), what was submitted for consideration to DSM-5 was Sensory Modulation Disorder (SMD) which includes both Sensory Over-Responsivity and Sensory Under-Responsivity.

Several studies point to unique physiological patterns in children with SMD. One study evaluates how children with SMD have higher electrodermal responses and slower rates of habituation after exposure to stimuli in five sensory areas than those children without SMD (McIntosh et al., 1999). Electrodermal activity measures changes in the conductivity of the skin related to nervous system activity. Another study looks at how children with SMD have poorer parasympathetic regulation than those children without SMD (Schaaf et al., 2010). The belief is that parasympathetic activity is an important regulator of reactivity in children (Schaaf et al., 2010). The autonomic nervous system has two main branches: the sympathetic and the parasympathetic. The sympathetic branch modulates the fight/flight/freeze response while the parasympathetic branch modulates the visceral and neuro-endocrine systems to aid in self-regulation as well as regulate the recovery process due to a stressor (Schaaf et al., 2010).

There is also an important twin study that suggests a genetic basis to the etiology of SPD (Goldsmith, Van Hulle, Arneson, Schreiber, & Gernsbacher, 2006). Goldsmith et al. (2006) found that monozygotic (MZ) twins were more similar than dizygotic (DZ) twins in both tactile and auditory responsivity. In addition, a retrospective study looking at the occurrence of pre-natal, birth, early childhood health, and development problems in children with SPD suggested possible linkages to SPD (May-Benson, Koomar, & Teasdale, 2006). In terms of pre-natal or birth-related issues, the data were as follows: 25% pregnancy complications, 42% labor/delivery complications, 34% assisted deliveries, 13% pre-term <37 weeks, and 5% umbilical cord insults. In terms of developmental and health factors, of children later diagnosed with SPD: 46% skipped the “terrible twos,” 37% had absent/brief crawling, 32% showed sleep/feeding problems, 62% had chronic ear infections, 27% developed serious injuries or illness, 25% were jaundiced at birth, and 20% had colic as infants (May-Benson et al., 2006). Lastly, a retrospective

longitudinal study of 521 children looked at the development of Sensory Over-Responsivity from infancy through elementary school and found that early sensory sensitivities continued throughout a six and a half year period (Ben-Sasson et al., 2010).

### **SOR and Social Emotional Issues**

The important question of the linkage between SOR and social and emotional issues is one that is generally accepted within the SOR community but the research behind this is sparse. There is one large scale (n=925), retrospective, longitudinal study that documented the co-occurrence of SOR and social emotional issues, such as anxiety, depression, isolation, withdrawal, and lowered self-esteem, but the relationship between the two is unclear (Ben-Sasson et al., 2009). SOR could be a risk factor for developing social-emotional problems *or* individuals with SOR may have independently co-occurring social-emotional issues (Ben-Sasson et al., 2009). Further complicating the issue is that many symptoms of anxiety are identical to symptoms of someone who has SOR. Shared symptoms include items such as: “startle from noise, distress from movement, fear of elevator, and worry of dirt” (Ben-Sasson, Cermak, Orsmond, Carter, & Fogg, 2007, p. 540). Both studies that suggest a linkage between SOR and anxiety in adults were pilot studies with small sample sizes.

#### **SOR and anxiety in adults.**

There have only been two studies that have looked specifically at the relationship between SOR and anxiety in adults. In both studies, researchers found that SOR adults experienced varying levels of anxiety and in some cases more anxiety than those without SOR (Doyle, May-Benson, Koomar, & Teasdale, 2012; Kinnealey & Fuiiek, 1999). The most recent study was the most comprehensive in terms of the tools the authors used to define sensory over-responsiveness as well as anxiety (Doyle et al., 2012). In this study, researchers looked at three



components of anxiety including: trait, state, and perceived anxiety using the Endler Multidimensional Anxiety Scale, an 88 question self-report scale (Doyle et al., 2012). Trait anxiety was defined as one of four types including: 1) *Social evaluation* – anxiety arising from situations where individual is observed by others, 2) *Physical danger* – anxiety arising from dangerous things, objects, or events, 3) *Ambiguous threat* – anxiety arising from novel or unfamiliar experiences, and 4) *Daily routines* – anxiety arising from situations of daily living. State anxiety measured an individual’s response to a current situation. Specifically, state anxiety looked at “cognitive worry,” which included feelings of uncertainty, helplessness, self-consciousness and inadequacy as well as “autonomic-emotional,” which looked at tension, perspiration, irregular breathing and heartbeat. Lastly, perceived anxiety measured a respondent’s perception of type and intensity of threat in the immediate situation. Among a sample of 42 adults, this quantitative pilot study found that individuals with higher sensory processing scores in sensory sensitivity and sensory avoiding (both of which are classified as SOR), experience greater cognitive worry, autonomic emotional reactions, total state anxiety, social evaluation anxiety, and perceived threats in immediate situations (Doyle et al., 2012). This study also reported that individuals with higher dysfunctional scores on measures of visual, auditory, tactile and vestibular systems, experience greater anxiety in: cognitive worry, autonomic emotional reactions, total state anxiety, social evaluation, and immediate threat (Doyle et al., 2012).

Similarly, in an exploratory pilot study of 32 adults, Kinnealey and Fuiiek (1999) found that adults that had identified as SOR experienced more symptoms of anxiety and depression than those adults who did not have sensory issues. The Doyle study was a pilot study presented at a SPD conference in March of 2012, and I only had summary data to review. I would have

liked to have seen this study replicated with a sample size larger than 42. To date, this has been the only study that has linked SOR with specific anxiety subtypes. Likewise, the Kinnealey and Fuiiek (1999) study was the first and only study that has looked at the relationship between sensory defensiveness and anxiety/depression /perception of pain among adults.

### **SOR and social/emotional issues in children.**

Ben-Sasson et al., looked at 925 children aged 7-11, and found that parents of children with SOR in the tactile and auditory domains reported higher frequencies of early and co-occurring internalizing, externalizing and dysregulation problems. This study defined internalizing behaviors to include: general anxiety, depression/withdrawal, separation distress and inhibition to novelty (Ben-Sasson et al., 2009). Externalizing behaviors included: aggression/defiance, activity/impulsivity, and peer aggression (Ben-Sasson et al., 2009). Dysregulation was defined as negative emotionality, sleep problems, eating problems and sensory sensitivities (Ben-Sasson et al., 2009).

### ***Qualitative support.***

Other researchers have qualitatively described the challenges of those with sensory over-responsivity in the tactile, auditory, and visual domains (Ayres, 1964; Ayres, 2005; Cohn, Miller, & Tickle-Degnen, 2000; Heller, 2003; Kranowitz, 2005; Miller, 2006; Rass, 2003). Ayres was the first to describe tactile defensiveness in response to auditory, olfactory, and visual stimuli as well as resulting anxiety. Ayres noted that, “Anxiety surrounds all tactile experiences that the child himself does not initiate (Ayres, 1964, p. 8).” When a baby is hypersensitive to tactile stimuli, his/her perception of the world feels vague and indistinct (Rass, 2003). Think of how a baby begins to make sense of the world. S/he begins by touching and grasping then moves to mouthing and finally to hearing and seeing (Sicile-Kira, 2008). If these interactions do not feel

good, this can often stymie a child's desire for independence (Rass, 2003). Tactile-sensitive children are often cautious, skeptical, and avoidant, when it comes to physical contact. Parents report that poor social participation, difficulty self-regulating, and perceived incompetence are key difficulties experienced by children with SMD (Cohn et al., 2000).

### **Link between SOR and the Highly Sensitive Person and the Introvert**

Sensory Over-Responsivity is often cited in the temperament and personality research as part of a temperament trait or behavior. What is not clear is the amount of overlap between what Dr. Jerome Kagan terms "highly inhibited or highly reactive," Dr. Elaine Aron calls "highly sensitive," Susan Cain identifies as "introverted," and what OTs call "Sensory Over-Responsive." My initial review of this research leads me to hypothesize that there is a significant overlap between the people who exhibit these traits or conditions.

Dr. Jerome Kagan, a clinical psychologist and researcher from Harvard, has spent the last 30 years studying shyness or inhibition in children. He found that there is a distinct group of children (20%) that at two months exhibited signs of "inhibition" as defined by extreme reaction to various sensory stimuli (Kagan, 1994). Two-thirds of these children continued with these symptoms throughout childhood leading him to deduce that this "trait," which is present at birth, stays with us throughout life (Kagan, 1994). From a biophysical perspective, "highly reactive" or "highly inhibited" children demonstrated higher heart rates, quick-to-dilate pupils, and tense vocal cords while under stress (Kagan, 1994). In addition, their brains showed a higher level of cortisol and norepinephrine after stressful situations, than those children deemed non-reactive (Kagan, 1994).

Dr. Elaine Aron, a research psychologist, set out to build upon Kagan's work and investigate the issue of sensitivity in the 1990s, by starting with 39 qualitative interviews

followed by six quantitative studies that would help validate her 27-question, “Highly Sensitive Person” scale (Aron & Aron, 1997). In her book, *The Highly Sensitive Person: How to Thrive When the World Overwhelms You*, she makes no reference to Sensory Processing Disorder, but makes the case for a temperament classification called “Highly Sensitive Person (HSP).” She cites the incidence of this temperament variation at 15% to 25% of the general population (Kagan, 1994). In her findings, she noted that HSPs tend to be highly sensitive to sights, sounds, and smells, that they often arrange their lives so as to minimize surprises, and they often have difficulty when being observed. In addition, HSPs describe themselves as intuitive, empathic, and vivid dreamers, who enjoy the nuances of art, music, and physical beauty. They tend to have unusually strong consciences and avoid disturbing movies (Aron, 1998). By the time I read Dr. Aron’s book, I had already completed all of my interviews but I was struck by the vast number of similarities between my small SOR sample of 14 and what she found in her larger sample of 39 HSP individuals. Unknowingly, in my interviews, I had asked a lot of questions around sensitivity that she would characterize as attributes of a HSP; these were questions which I asked in the context of being SOR. In addition, many of the study respondents thought their HSP traits of empathy, intuition, and creativity were strengths of being SOR.

When asked about the connection between SPD and HSP, Dr. Aron posted this response on the Frequently Asked Questions section of her website, [www.hsperson.com](http://www.hsperson.com).

Note that Sensory Processing Disorder or Sensory Integration Disorder is not related to what is measured by the HSP (Highly Sensitive Person) Scale or the general construct of Sensory Processing Sensitivity, the concept described here, which is a normal temperament variation found in 20% of the population, and by itself does not cause impairment or distress (Aron, 2009).

I do not understand how she proposes measuring the last part of her statement, “and by, itself does not cause impairment or distress.” When I look at her 27-question Highly Sensitive Person

(HSP) self-test on her website, [www.hsperson.com](http://www.hsperson.com), a large number of her questions imply a level of distress. For example, “I am easily overwhelmed by strong sensory input,” or “I am made uncomfortable by loud noises,” both imply a level of distress. Is she saying that the level of uncomfortableness is the key factor that delineates what is Sensory Over-Responsivity versus a Highly Sensitive Person? Does that mean that if you are only a little bit sensitive to sound, for example, then you could be deemed highly sensitive, but if you were extremely sensitive then you are auditorily over-responsive? When reading Aron’s book I felt that she was building a case for individuals with SOR as well as HSP. For example, she describes sensitive children as those who “come with a built-in tendency to react more strongly to external stimuli”(Aron, 2008, p. 28). To me, this sounds precisely like the definition of Sensory Over-Responsivity.

Lastly, Susan Cain, a psychologist who studies introversion and wrote the *New York Times* bestseller, *Quiet: The Power of Introverts in a World that Can’t Stop Talking*, is another researcher who, in characterizing introversion, sounds as if she is describing Sensory Over-Responsivity as well. In defining introversion, she states that it is important to look at the level of external stimulation needed for the person to function well. She defines introversion by noting that a key difference between introverts and extroverts is that, “Introverts feel ‘just right’ with less stimulation” (Cain, 2012, p. 11). This calibration of “how much stimulus is needed” or “sensitivity to stimuli,” appears to be an important common definitional trait between introversion, HSP, and SOR. As David Winter, a personality psychologist, states, most introverts prefer to spend time alone as “other people are arousing...they arouse threat, fear, flight, and love” (Cain, 2012, p. 11). Aron states that 70% of highly sensitive people are introverts and my question is: If we were to create a Venn diagram of HSP and Introverts and

SOR – how large would the overlap be between the three circles (Aron, 2008)? My hunch is quite large, but this research has not yet been done.

### **Effectiveness of Various Sensory Integration (SI) therapies with SMD Population**

The last section of this literature review looks at current research in the area of treatment effectiveness. It is estimated that there have been over 80 studies that look at sensory integration occupational therapy, yet overall the research has lacked depth, validity, and power (SPD Scientific Work Group, 2008). Specifically, I looked at the six studies where researchers have assessed the effectiveness of SI therapy with children who have Sensory Modulation Disorder (Bundy, Shia, Qi, & Miller, 2007; Candler, 2003; Miller, Coll, & Schoen, 2007; Miller, Schoen, James, & Schaaf, 2007; Roberts, King-Thomas, & Boccia, 2007; Schaff & Nightlinger, 2007). Five of the six studies were lacking in one or more of the following areas: homogenous samples, fidelity to a manualized intervention, meaningful outcome measures, and rigorous, piloted methodology (Miller, Schoen et al., 2007). All of the studies suffered from small sample sizes with the largest study having a sample size of 40 (Bundy et al., 2007; Candler, 2003; Miller, Coll et al., 2007; Miller, Schoen et al., 2007; Roberts et al., 2007; Schaff & Nightlinger, 2007). It is challenging to summarize these six studies because the outcomes and sensory integration treatments in each study varied widely. Bundy et al. (2007) examined the effect of sensory integration occupational therapy (SI-OT) on a child's ability to play and found no effect of intervention. A researcher in another study utilized horseback riding as the sensory integration treatment and found that there were positive gains in sensory integration after a one-week summer camp (Candler, 2003). A single-N design case study of a four year-old boy with Sensory Over-Responsiveness also detailed notable improvements in occupational performance as measured by goal attainment scales and progress in the child's ability to participate in home,

school, and family activities after 10 months of occupational therapy using a sensory integrative approach (Schaff & Nightlinger, 2007). Perhaps the most rigorous study in terms of design and methodology was a randomized, controlled pilot study of the effectiveness of occupational therapy for children with sensory modulation disorder (Miller, Coll et al., 2007). This pilot study of 24 children demonstrated that on certain measures (e.g., goal attainment, attention, and cognitive/social), the Sensory Integration - Occupational Therapy treatment group was significantly more effective than the Activity Protocol (active placebo) and No Treatment (passive placebo) groups. While this important pilot study laid the groundwork for further research, a larger randomized control trial follow up study has yet to be done.

### **Link between OT - SI Treatment and Anxiety**

While there are few robust studies that look at the effects of occupational therapy overall, there are far fewer that look specifically at the effects that OT may have on anxiety. There has been only one study to date in which researchers looked at the relationship between occupational therapy treatment and anxiety. In this quasi-experimental pilot study, the researchers interviewed 15 sensory over-responsive adults, ages 26-46, who were given a daily sensory integration treatment regimen for one month. Sensory integration treatment consisted of: 1) education regarding sensory normalization and insight into sensory defensiveness, 2) regular and daily sensory input, and 3) physical activities of the client's choice which provided tactile, vestibular and proprioceptive input. Subjects participated in an individualized self-treatment protocol using occupational therapy activities for one month. The outcomes of this study were that the mean anxiety level of participants in the study were reduced from moderate/mild to minimal on the Beck Anxiety Inventory following occupational therapy treatment for their Sensory Over-Responsivity (Pfeiffer & Kinnealey, 2003).

## **Implications for My Research Study**

In summary, the literature on SMD and SOR is growing but sparse. There is mounting evidence that SOR is a distinct disorder that is both universal and specific (SPD Scientific Work Group, 2008). Evidence presented include four studies that look at the electrodermal activity, parasympathetic reactions, heritability, and potential risk factors for SMD. The two studies that look at SOR and anxiety in adults are critiqued and this relationship is examined within children as well. Additionally, the research on HSP and Introversions is intriguing in that it talks about some aspects of SOR without acknowledging the validity of SOR as a stand-alone disorder. Furthermore, the literature on treatment is controversial, with all but one study not meeting the rigorous criteria for a randomized controlled trial. Lastly, the SPD and SOR research is strongly tilted toward children with very few published studies on SOR in adults. Given the status of the research to date, an exploratory, qualitative study that examines the lived experiences of SOR adults, with a particular emphasis on the relationship between SOR and social/emotional behaviors, as well as coping mechanisms and treatments, will help fill some important gaps in the current body of research.



## **CHAPTER III**

### **Methodology**

#### **Introduction**

The purpose of this study was to explore the lives of 14 SOR adults with a particular focus on social and emotional challenges as well as coping mechanisms and treatments for SOR. In this chapter, I will characterize my research sample and discuss the screening and recruiting process for obtaining the sample. In addition, I will describe the methodologies employed for collecting and analyzing the data and also discuss possible limitations and biases in this study.

#### **Sample**

My sample for this study was adults, ages 18 and over, who could answer “True” to at least two of seven screener questions designed to assess Sensory Over-Responsivity (SOR) (see Appendix B: Study Qualification Screener). I created the screener based upon the Adolescent/Adult Sensory Profile, a 60-item self-report instrument commonly used by occupational therapists in assessing Sensory Processing Disorder (Brown & Dunn, 2002). In addition, I asked two exclusionary questions regarding a diagnosis of Autism Spectrum Disorder and Asperger’s.

One of my respondents stated that she had been diagnosed with Autism Spectrum Disorder but after consulting with the occupational therapist who had told her about this research study, I agreed to proceed with the interview. The occupational therapist felt that she could tolerate an interview as long as I was mindful of her sensory sensitivities throughout the

interview. She had a complex sensory profile and I learned a great deal from her. Another respondent mentioned in our interview that she had been previously diagnosed as having Asperger's but that her current psychologist did not believe in that diagnosis. I found her to be an incredibly articulate and thoughtful participant. In summary, I interviewed 14 SOR adults for this study plus the mother of one of the respondents. I did not collect demographic nor screening data for the mother but she did sign an Informed Consent to be included in this study.

### **Sample Demographics**

At the beginning of each interview, participants were asked to complete a short seven question demographic survey (see Appendix C: Demographic Survey). My hope was that I would be able to reach a large and diverse group of potential participants. In reality, I took what I could and only eliminated one respondent who expressed interest and met all of the recruiting criteria. This potential respondent had contacted me after I had already completed all 14 of my interviews and was in the middle of writing my findings. I will review the results of the demographic survey in the Findings chapter.

### **Sample Recruitment**

I utilized a nonprobability, non-random method of sampling selection known as purposive sampling. With purposive or judgmental sampling I selected the sample based on my knowledge of SOR and the intent and purpose of this study. In addition, I relied on the judgment of two occupational therapists (OTs) and one clinical psychologist to determine who, from their current or former caseload, might be appropriate for my study. It was very challenging to find qualified participants so I quickly loosened the screening criteria after seeing how difficult it was to find adults who had been diagnosed by an occupational therapist *and* received at least six months of occupational therapy treatment (my initial screening criteria). There are two

organizations that are nationally known for their treatment and advocacy work with Sensory Processing Disorder but one was unwilling to help me with this study, and the other unresponsive to my inquiry. I tried to broaden my reach as much as possible in recruiting participants, and knew that working through occupational therapists would give me the greatest chance of speaking with adults who were diagnosed as SOR; but, of the six OTs that I met with, only two were able to provide potential respondents. Of the six OTs, three worked primarily with children. So, I relied primarily on two occupational therapists and one clinical psychologist to help me find potential research subjects. I met with each of the OTs and the psychologist in December and January prior to receiving Human Subject Review (HSR) approval in order to familiarize them with my research study and goals. Once I received final HSR approval in January (see Appendix D), I notified the OTs and psychologist so that could begin reaching out to potential study participants. They then either hand delivered or emailed my letter describing the study (see Appendix E), plus screener, to clients they thought might be appropriate respondents. It was then left up to their clients to decide whether or not to contact me. Overall, my response rates from the three clinicians' clients ranged from 50% to 100%. I was able to recruit 9 of the 14 respondents with help from either an OT or a psychologist. Once prospective study participants contacted me, I would then send them a copy of the screener if they did not already have one and ask them to complete it and email or mail it back to me. If they had received the screener from their OT or psychologist, they would often attach it as a PDF in their email to me. I would then send them a copy of the Informed Consent (see Appendix F) and Preview Interview Questions (see Appendix G).

In addition to recruiting through OTs and a psychologist, I also reached out to the broader community in three different ways. First, I created a recruiting flyer (see Appendix H) that I

posted, with permission, in the offices of the six OTs and one psychologist that I had met with in December and January. I also posted the flyers, with permission, at the Boulder Institute of Psychotherapy and Research (BIPR), my internship agency that sees clients with a range of mental health issues on a sliding scale basis. BIPR also hosted a number of community lectures from January through March of 2013 and I ensured that a stack of flyers were present at all of their parent as well as clinician education lectures. The flyers were my least effective way of recruiting, likely because it took more than a flyer to detail the importance of the study. That being said, I was able to find one respondent who expressed interest and was eligible for the study from a flyer posting at BIPR. Secondly, I networked with a number of the psychotherapists who are affiliated with BIPR and asked them for their help with recruiting as well. As I spoke with other therapists, I noted an overall lack of awareness and understanding of SPD -- making recruiting through them more difficult. Lastly, I made an in-person announcement at a monthly Support Group for Caregivers of Children with SPD that I co-facilitate. This group was started in September, 2013, as a way to: support caregivers, share resources, learn new skills, and advocate for SPD. I followed up my announcement with a recruiting email that explained the study in more detail. I sent this email to over 40 caregivers who had expressed interest in attending the SPD Caregiver Support Group. This recruiting effort resulted in four adults expressing interest and meeting screening criteria for my study. All four of these respondents chose to participate in the study. All interested participants contacted me by email.

### **Data Collection**

The format for data collection for this study was in-person interviews that ranged in length from 45-90 minutes. Twelve of the 14 interviews were conducted in my private office at

the Boulder Institute of Psychotherapy and Research. One of the interviews was conducted in an occupational therapist's office upon request of the participant and one of the interviews was conducted in a respondent's private office. All interviews were recorded on my iPhone 5 and transcribed by myself, a transcriber, or Rev, an online transcription service ([www.rev.com](http://www.rev.com)). The transcriber signed a confidentiality agreement (see Appendix I) and Rev guaranteed confidentiality for all of its services. All respondents were given a \$25 gift card to the online retailer of their choice as a thank you for participating in the study.

### **Question Design**

I created an interview guide for all of the interviews and the questions were divided into two sections (see Appendix J). Part One explored participants' personal experience living with SOR. In this section, I asked participants to talk about how they realized that they had SOR, what SOR looked like for them (i.e., which senses were the most sensitive), coping mechanisms, and social and emotional challenges. In determining which specific social and emotional challenges to highlight, I referenced a study, "Sensory Over-Responsivity in Elementary School: Prevalence and Social-Emotional Correlates (Ben-Sasson et al., 2009)," that looked at the relationship between SOR and various social/emotional behaviors. In addition, I asked each of them to explicate how SOR has or has not affected their family, school, work and relationships. Part Two of the interview focused on treatments and which, if any, helped improve physical as well as social/emotional challenges. In addition, I asked participants what they wanted to communicate most to others who might read this research. For those who did not receive any SOR treatments I focused the interview on Part One. I constructed the interview questions solely as a guide. I tried to incorporate as many open-ended questions as possible and asked respondents to share memories of childhood, family, school, or relationships. Despite testing my

interview guide with several colleagues prior to administering, I found that I edited the interview guide frequently as the interviewing proceeded.

### **Limitations and Biases**

Due to the methods of data collection utilized, this study may have several limitations or biases. One is that in asking about mental health issues such as anxiety and depression and how they may or may not be related to SOR, I was inquiring about a link that many had not thought about before. Even the adults who had received treatment for anxiety or depression did not always correlate their emotional states to their Sensory Over-Responsiveness. For many, self-knowledge about SOR was relatively new despite their age (many being in their 30s and 40s before realizing that that is what they had) and therefore they were still learning about the far-reaching influences SOR can have on one's life.

Another potential bias is that I had met four of my respondents at least once prior to the interview, either because they had attended a Caregiver Support Group meeting which I co-facilitate, or a community lecture that our group had sponsored in the Fall. I did not have a primary relationship with any of the participants and participation in the study was strictly voluntary. While the personal connection likely helped in terms of their willingness to participate, I wonder if their responses were less open, especially when it came to discussing sensitive areas such as mental health. I will discuss the possible effects of these biases on my findings in Chapter V: Discussion.

### **Data Analysis**

I utilized content/theme analysis as the tool with which to organize and make sense of my data. I coded the major themes in each interview and then took note of the frequency and consistency with which each of the themes appeared. I then created a mini-synopsis of each

interview so as to imprint that in my mind before aggregating the responses. As expected, the wide breadth of the interview raised many interesting questions that need further research and it was tempting to draw conclusions and associations between various variables despite the limited sample size. I am grateful for the nature of qualitative research as I believe that this format allowed the data to come alive in the form of individual narratives which will be explicated more thoroughly in the following chapter.

## CHAPTER IV

### Findings

#### Introduction

The purpose of this qualitative study was to explore, in-depth, the lives of adults with sensory over-responsiveness, with a particular focus on the social and emotional challenges that often accompany sensory defensiveness. In addition, I asked respondents about coping mechanisms and treatments for this condition. In this chapter, I have divided my findings into six sections. The first section is a summative review of sample demographics. Section two, “Living with Sensory Over-Responsivity,” details what it looks and feels like to be over-responsive in each of eight senses. Section three highlights the various “Social and Emotional Sensitivities,” that participants have encountered in their lives: including anxiety, depression, isolation, withdrawal, lowered self-esteem, overblown empathy, deep intuition, and visual sensitivity. Section four chronicles how SOR has had an “Impact on all Facets of Life,” encompassing family, school, relationships, vocations and avocations. Section five details various “Coping Mechanisms and Treatments,” including avoidance, control, self-awareness, relaxation, humor, downtime, mental health counseling, occupational therapy, exercise, listening therapy, meditation, chiropractic, massage, journaling, and nutrition. The last section entitled, “Straight Talk,” was an opportunity for respondents to speak directly to future readers of this research as I closed each interview with the question, “What do you want others to know about



what it has been like to live as an SOR adult?” In Chapter V: Discussion, I will discuss these findings in more detail.

### **Sample Demographics**

My sample included 12 females, 1 male, and 1 transgender respondent. I conducted all of the in-person interviews between February 14<sup>th</sup>, 2013 and April 4<sup>th</sup>, 2013. Every participant was a resident of the state of Colorado. Interview length ranged from 45 to 90 minutes, with the majority approximately 60 minutes in duration. The age of respondents ranged from 19 to 52, with an average age of 33, and a median age of 32.5. In terms of ethnicity, the majority (12 out of 14), respondents identified as White, with one Asian respondent and one Latino/a respondent.

In terms of highest level of education completed, the largest percentage (50%), reported completing graduate school, followed by high school (29%), postgraduate studies (14%), and college (7%). With regard to marital status, the majority of my sample, 9 out of 14 respondents, were single, four were married, and one was divorced. In addition, five of the respondents reported having at least one child. I did not ask about parenthood as part of the demographic survey, but in the course of the interview 5 of the 14 respondents volunteered that they had children. With respect to employment status, 8 out of 14 respondents (57%), reported that they were employed for wages including self-employment. In addition, one respondent was out of work but not looking, two respondents were full-time Moms, and three respondents were college students. Lastly, in terms of household income, 29% reported household incomes greater than \$100,000, 29% reported household incomes between \$50,000 and \$74,999, 21% reported incomes less than \$24,999, and one person each reported incomes between \$25,000 to \$49,999 or \$75,000 to \$99,999. One respondent did not answer the question. I think the college students were confused by this question with some reporting their income as a student while others

reported their family's income. The breadth of occupations were varied. I spoke with an acupuncturist/therapist, several occupational therapists, several teachers, a veterinarian, a business analyst, and a Web developer. Lastly, the following table, *Table 1: Sample Demographics*, summarizes the results of the demographic survey.

Table 1

*Sample Demographics*

	<b>Range</b>	<b>Number</b>	<b>Percentages (%)</b>
<b>Age</b>	18-28	5	36%
	29-38	5	36%
	39-48	3	21%
	<u>49-58</u>	<u>1</u>	<u>7%</u>
	Total	14	100%
<b>Gender</b>	Female	12	86%
	Male	1	7%
	<u>Transgender</u>	<u>1</u>	<u>7%</u>
	Total	14	100%
<b>Ethnicity</b>	Black	0	0%
	Asian/Pac Islander	1	7%
	Hispanic/Latino	1	7%
	Multiracial	0	0%
	Native American	0	0%
	<u>White</u>	<u>12</u>	<u>86%</u>
	Total	14	100%
<b>Highest Level of Education Completed</b>	Grade school	0	0%
	High school	4	29%
	College	1	7%
	Grad school	7	50%
	<u>Post grad</u>	<u>2</u>	<u>14%</u>
	Total	14	100%
<b>Marital Status</b>	Single	9	64%
	Married	4	29%
	Separated	0	0%
	Divorced	1	7%
	<u>Widowed</u>	<u>0</u>	<u>7%</u>
	Total	14	100%
<b>Employment Status</b>	Employed	6	43%
	Self-employed	2	14%
	Out of work	1	7%
	Homemaker	2	14%
	<u>Student</u>	<u>3</u>	<u>21%</u>
	Total	14	100%
<b>Annual Household Income</b>	0-\$24,999	3	21%
	\$25,000 – \$49,999	1	7%
	\$50,000 – \$74,999	4	29%
	\$75,000 – \$99,999	1	7%
	>\$100,000	4	29%
	<u>NA</u>	<u>1</u>	<u>7%</u>
	Total	14	100%

## **Living with Sensory Over-Responsivity (SOR)**

Perhaps the most startling findings of this study revolve around the rich and detailed narratives of what life has been like as a Sensory Over-Responsive (SOR) person. It is clear from the respondents in this study that being Sensory Over-Responsive has had a far-reaching influence on every aspect of their life. As Brené Brown, a social worker, researcher, and national speaker has said, “Stories are data with a soul (Brown, 2010).” When listening to respondents’ accounts of what life was like as a child, I felt a visceral connection to their innocent and unknowing young selves. Likewise, the depth and breadth of sensitivity in the auditory, tactile, gustatory, visual, olfactory, vestibular, proprioceptive, and interoceptive senses were profound.

When asked to characterize the overall feeling of being Sensory Over-Responsive, one respondent described it this way,

It feels to me like I have a lot of information all the time. Have you heard the term neurological traffic jam? It’s like that. It’s feeling this intense amount of energy... it’s almost like I get more information from other people, but I don’t process it... the information should have flowed through me but it remains in my senses...raw information that’s kind of hovering around.

Others have characterized how different they feel from others and how our society is geared toward sensory seeking extroverts.

Our culture is accepted as sensory-seeking... especially in Boulder. You like to go outside. You're kind of extroverted. You got it going on...maybe I don't feel as accepted because I want to stay home... You run again under the radar...*It's kind of like you're more missed than celebrated* [emphasis added].

### **Life as a child.**

As a child, those with SOR were described as smart, quiet, smiley, happy, sensitive, touchy, emotional, fussy, determined, inconsolable, difficult to soothe, independent, stubborn, whiny, willful, picky, and complicated. Childhood memories were often full of worry, fear, and

confusion, about why they felt a certain way and why others were not bothered when confronted with similar situations. The following excerpts are memories from five respondents talking about how they felt and how they were perceived as a child.

I would have huge temper tantrums in the morning before school if my ponytail wasn't exactly in the center of my head because it felt weird, like leaning against stuff... Or, if my clothes felt like they were slightly too tight or slightly too scratchy, I would start screaming and crying...I could never really go to loud movies or anything like that. I cried a lot when I was little...just going to school...was really exhausting because it was such a sensory overload... And I still feel that way when I come home now [from college]...I was anxious and worried a lot of the time...I was a very picky eater my whole life...I still am...I've always been very sensitive to loud sounds and bright lights and that kind of thing and I think my Mom finally got sick of me going on about it and took me to see my psychiatrist.

I remember that overheating feeling, if clothing was uncomfortable. I did not understand what was going on with my body...I remember feeling really scared and panicked like, 'Why do I feel like I'm going to explode?' I could see that my Mom could see it but my sister would say, 'Oh, X! Stop being so difficult.' It was hard at the time. It would have been nice to know, 'Oh, you just can't be in this bright sunlight in this itchy shirt.'

I was seen as weird from preschool on. I've always been labeled as weird. It's kind of bothered me. I've been made fun of a lot. Part of the fact is that I dress in an odd way because I would not wear jeans. I would not wear certain kinds of clothes or shoes. If that happened to be completely against whatever was in style, I didn't care. I just wouldn't wear it. To this day, I don't wear makeup. I don't like how it feels.

My family started to notice things. I didn't really like to be held very much. I didn't take comfort in people holding me...I think they said that the only time that I was okay with being held was when I was sick and had to be rocked the whole time. I think otherwise I just didn't like to be held. I would not drink out of a bottle. They had to use a spoon.

As a child, what I remember most is being extremely shy and having certain anxieties. I had terrible sleep issues. If it were today's times I think my parents would have taken me to a psychiatrist but my parents did not. My mother just spent years sleep deprived and miserable.

### **A Mom's perspective.**

A welcomed addition to this research study was that one of the respondents brought her mother along to the interview for support and the mother generously agreed to participate in the

interview as well. It was helpful to hear one mother's perspective of what it was like to raise a daughter who is Sensory Over-Responsive. In the mother's narrative, she describes what other respondents in this study have confirmed. Of the 14 respondents interviewed, 12 stated that one of their coping mechanisms is to withdraw, so from the outside it might look like they are quiet, shy, and introverted. They typically do not draw attention to themselves nor cause any trouble at school so they are often overlooked.

She was my first so how would I know? She taught me a lot. My second child was so much easier than she was, but as a parent I had no idea that these little quirks were not really normal... every doctor we went to, if I brought something up, nobody ever put all of the things together, but Dr. X [a clinical psychologist], we had a nice two hour talk and all of these things fell into place. When she was a baby and she was over stimulated the only way to calm her down was to take her into the bathroom that had no windows and no noise, so it was just dark. She didn't want to bounce. She didn't want a song. She didn't want anything. I would just stand in there and hold her and she would [calm down]...Certain clothes she couldn't do. She hated mittens. She hated gloves. They have to be a certain feeling. Not wanting to wear a jacket...*Until you realize what all these little things add up to, it doesn't mean anything* [emphasis added]. Every teacher, every time, straight A student, she can look at it and know it... She was quiet. She was shy... *She was no trouble, so why would you notice* [emphasis added]? Whenever the schedule changed in junior high or high school I got the phone call, 'Mom, you have to come and get me.' Or, a counselor calling and saying, 'Please come and get your daughter.' She would be in tears [saying], 'I don't know what's going on.' In high school she never went to the assemblies or anything where there was a large group because it was too loud. That was the first time I started thinking there's something not right here because high school was social and emotional stuff where she couldn't hide it anymore. The first assembly where someone called me was because she was outside of the building...11<sup>th</sup> grade is when she finally got some help. She went on a low dose of Prozac. She told me that it just helped her to be able to sort it out more instead of just falling apart. It gave her less anxiety so she could think. And then we found a great support person at her school. She could go to X's office whether she was there or not. She could just stay there until she felt under control or maybe X would show up and was able to talk with her. She just needed a safe place and someone who understood...She just needed a dark room for five minutes.

### **Initial diagnosis of Sensory Over-Responsivity (SOR).**

While the ages of study participants ranged from 19-52, it was interesting to note that the age of respondent had little to do with: 1) when respondents first learned about Sensory

Processing Disorder and, 2) when they first realized that this was a condition that they experienced as well. Of the 14 respondents in this study, three had learned of their SOR within the last year, five had learned within the last 2-4 years, one had learned within the last 5-10 years, and five had learned about it in the last 10+ years. Time since diagnosis is important to keep in mind, as it may have had an influence on where respondents were in terms of making meaning of their SOR “label.” All the participants believed that they were born with their sensory sensitivities, except for one respondent who felt strongly that her sensitivities were heightened after she experienced a traumatic brain injury. In general, the method of discovery of SPD varied widely from learning from their children, learning through their work, and learning from an occupational therapist (OT) or mental health clinician.

#### ***Learning from their children.***

Five of my respondents were parents of children with SOR, and each of them reported that they started putting the pieces together for themselves as they were seeking treatment for their children. As they read books on SPD, attended parent education lectures, or spoke with OTs and psychologists about the condition, a common response was, “Hey, this describes me as well!” While there were many similarities between parent and child in terms of sensory sensitivities, some respondents noted that their sensory reactions appeared different from their child’s.

When we first learned about it, I would say, ‘Oh, well, I’m sensitive to sounds and clothing and smell, and I don’t like crowds but I didn’t really think much about it.’ Then the last couple of years, I’ve noticed more sensory-related things. I definitely am more closed off inside myself when these issues come up, whereas my son is more aggressive with it. There’s a big difference there...I didn’t recognize any of this before my son was diagnosed. I didn’t know it existed.

### ***Learning by doing.***

Four of the 14 study respondents are now involved in professions where they are utilizing what they know about SPD and SOR to help others through teaching, psychotherapy, and occupational therapy. Of these four, only one of them knew from an early age that they experienced sensory input differently from others and that this condition was called Sensory Processing Disorder. This group has stated that their “felt” experience of living as a SOR adult has given them a unique empathy for others with sensory processing challenges. As one teacher respondent stated, she could identify with the children in the class who were off in the corner, over-stimulated, and afraid.

I started my job [preschool teacher], 15 years ago. Within the first couple of years I started seeing kiddos who would have extreme reactions to a noise or a transition and they would just flop down on the floor... That would have been me if I had had the guts to do it as a kid. That’s me, the one in the corner who is having this emotion but you think they are fine because they are quiet and they go under the radar.

### ***Learning through an occupational therapist or mental health clinician.***

Five other respondents initially learned about SOR from an OT (not including those mothers who had learned from their child’s OT). Three others were diagnosed by a mental health professional. It is interesting that those who learned about SOR as an adult consulted a psychologist or psychiatrist first, whereas those who learned as a child consulted with an OT first. As one psychologist stated, “What starts out as sensory soon becomes behavioral (R. R. Ahn, personal communication, April 3, 2013).” One respondent described her process of awareness as follows:

I always knew that I was extra sensitive to stuff. My mom is that way too, not quite to the extent that I am. I saw a child psychiatrist when I was nine for the first time. She diagnosed me with anxiety initially. Then just a couple of years ago I went to see Dr. X [a clinical psychologist], after a friend of my mom’s whose daughter has Sensory Processing Disorder recommended it. She diagnosed me [with SOR].



*Sensory Over-Responsivity (SOR) in each of eight senses.*

The next set of findings will highlight what it looks like to be defensive or over-responsive in each of eight senses. I rank ordered the discussion of particular senses, starting with those senses which most respondents stated were the most challenging. Not surprisingly, there was a much greater awareness of the five basic external senses (auditory, tactile, taste/eating, visual, olfactory), and fewer memories of sensitivity with the three internal senses: proprioceptive (muscles/joints), vestibular (inner ear), and interoceptive (internal organs). For many respondents, their knowledge of these internal senses was vague or relatively new.

*Auditory.*

When asked which of their senses was most troublesome today, 8 out of 12 respondents chose their auditory sense. Several respondents also noted the length of time of the disturbance and how once a sound bothered them it was difficult to become unbothered. One participant stated, “ If I hear something and it bothers me, it could last for days, really.” Interestingly, three respondents talked about how difficult it was for them to stay regulated when they hear someone chewing. Upon follow up, it was clarified that it wasn’t the volume of the sound itself that was bothersome, rather it was the particular sound that was difficult to process. As one participant said, “It is distracting and upsetting when I’m listening to people chew because I don’t like hearing myself chew or sounds inside my mouth very much at all.” Another respondent detailed her difficulty tolerating the sound of others chewing and how the sound lingers with her as well.

The sound of chewing is the thing that bothers me the most...so going to the movies is really hard. I have to have popcorn if other people around me are chewing popcorn to try to override that piece. In the office if someone is eating an apple I have to leave. I can't sit at my desk and focus. A lot of us have noise cancelling headphones in the office ...that sometimes helps if someone is chewing. But, if I've already been set on edge from them chewing I can't put the headphones on because I can still hear it.

Another respondent described how her auditory sense has become more sensitive with age and how it impacts many domains of her life, including her close relationships and choice of leisure activities.

Yeah, I've gotten more so [sensitive to sound]. The sound of him [my husband] chewing drives me crazy...If I'm eating, it's okay. But, if it's just him eating and I'm sitting there, I have to leave. It's starting to be an issue. It's offensive to him. I can't sit with him while he's eating and I feel bad... I went to a concert recently and had to leave early. It was just too much. I couldn't enjoy it...The volume is always way down on my car stereo.

One respondent detailed that for her it was the unexpectedness, the volume, as well as the frequency of sounds that is challenging.

Unexpected noise, loud noise, high and low frequencies...I still hear a lot of mosquito tones. It's very distracting. And more and more movies are happily dabbling into the really low and the really high and I do like movies...I bring lots of hearing protection, but it's one of the social things that I can tolerate a little better. I think it's because everyone's focus is on the screen and it's all in the same place.

A few respondents talked about the involuntary nature of their reactions to an unexpected noise. Several said they yell or scream if surprised by a loud sound and that this response is uncontrollable.

Respondent EJ: If someone scrapes a chair next to me, I'll actually scream. That's really embarrassing. I have trouble settling after that...I can feel it. I mean, it's a vibration too, especially, if it's a really loud screech. Other people notice, for sure, but I'll actually scream.

Researcher: What would you do in a case like that? Are there things you've learned that help you settle?

Respondent EJ: Just time. I usually just try to breathe. Sometimes, if I'm embarrassed, I'll laugh...and try to get some of that energy out...

The flip side of being overly sensitive to sound is that it often means that the individual has unusually keen hearing, which was a very positive attribute for several of the study respondents. One participant noted that it has been an asset with her teaching because she can

easily pick up on what students are whispering. She has her class convinced that she has “supernatural” hearing powers and that has helped tremendously with classroom discipline. Another respondent discussed how she felt her auditory sensitivity was one of the reasons that she has excelled in school. As she says, “I can learn a lot just by listening.”

### *Tactile.*

Five out of 12 respondents chose tactile as their most over-responsive sense, while 14 of 14 cited tactile sensitivity, also known as tactile defensiveness, as being difficult to manage. Sensitivity to clothing and eating were two of the most frequently reported tactile challenges. The following comments address the difficulty of finding bearable clothing choices.

Respondent BK: I hate having tags in the back of my shirt or having wet hair on my shirt and having it get wet.

Researcher: What do you do?

Respondent BK: I change [if my hair is wet and it has gotten my shirt wet]... and I cut out the tags...before I even wear them. I hate having really tight waistbands... I can only sleep in my special sheets at home.”

I've never been able to wear anything even slightly scratchy...I thought I had an allergy when I was a kid. We just said I had an allergy, but I didn't. I would get overheated very quickly and I always felt hot...Nothing restrictive and especially not scratchy. Really, all I wear is cotton... I get that feeling. I feel very hot, angry, and irritated if I am not wearing cotton.

Interestingly, similar to what respondents stated with respect to auditory sensitivity, a number of respondents commented that once a tactile input bothered them, it was difficult to become unbothered. It's as though the sensory irritation left a lingering imprint on their brain. One respondent commented, “When I cut out the tags [from my clothing], I can still feel where it was.”

Like many conditions, the level of SOR appears to be on a spectrum. The following respondent appeared to be highly sensitive to tactile input and could perceive the slightest changes to her environment. “I loved my bedspread, but then one day when we washed it, it didn’t feel good anymore...because we washed it in a different machine. It didn’t feel the same... Then we had to get rid of it.” Avoidance appeared to be a common coping mechanism for those with tactile sensitivity. One respondent stated, “ I don’t like touching my hair or when other people’s hair touches my skin. I don’t like brushing my hair...Then I just pull it back, so I don’t have to touch it.”

While the majority of respondents had tactile senses that were over-responsive, there were three that reported under-responsivity. One Mom talked about seeking out interesting textures to touch and her love of handling clay and finger-paints. Interestingly, two of my respondents spoke about incidents of cutting as adolescents. One had a trauma history, the other did not. The one without a trauma history recounted an episode of cutting from her teen years.

Respondent WG: At one point I used a razor to try to carve into my hand and I remember at that talk [community lecture on SPD] someone saying that cutting is often a Sensory Processing Disorder symptom.

Researcher: Do you remember what feelings were associated with that behavior?

Respondent WG: ...I think I started doing it because it looked neat. I was trying to do a peace sign in my hand so I could have a scar of a peace sign, but then it felt good. I stopped fortunately before I got a scar and that was years before I ever knew what cutting was. But in retrospect was that part of it [SPD]? Maybe I need a little pain to feel things?

In this example, it is difficult to discern whether this respondent had an under-responsive tactile sense and/or a high pain threshold which is also part of the body’s interoceptive sense.

One respondent described in detail how all of her senses would feel more sensitive during times of extreme stress. She recounted a story of her extreme tactile sensitivity and how she really “took in” other people’s feelings through her fingers.

A lot comes in through my sense of touch...I would go into a room with a patient... a really sick patient and I would have to excuse myself and vomit...then it came to the point where I would make sure that I was not touching people that were really sick with my hands. I would wear gloves...I would have to have a barrier.

*Gustatory (taste) and eating.*

Ten out of 14 respondents self-defined as a “picky eater” on the screening questionnaire for this study. The most sensitive end organs for touch perception are the lips and the tongue followed by our fingertips (Abbas, 2012). Those who are extremely sensitive from a tactile perspective often have trouble eating due to the way that various textures make their mouths, lips, and tongues feel. Another challenge is that the process of eating incorporates multiple sensory inputs, including taste, tactile, olfactory, auditory, visual, and temperature. When one or more of these senses is over-responsive, it becomes difficult to eat. As one respondent detailed, “I don’t like raw vegetables. They feel scratchy in my mouth... They’re loud to crunch on... I don’t like the way it feels in my mouth when it’s cold...[raw] vegetables are always cold.”

In general, respondents did not feel that their sensory sensitivities improved with age; rather, they learned ways to cope and adapt. However, eating is one of the few sensory issues that a few respondents felt improved with time and repeated exposure. The following are two respondents talking about their early eating experiences.

When I was little, I was the pickiest eater alive...I swear to you that for 10 years, all I ate, every single day, for lunch was processed whole wheat bread with Skippy peanut butter. Jelly freaked me out. The funny thing is my Mom is a terrible cook, but it was what I knew and anything else grossed me out...I think texture is still big for me. As a kid, I never ate cheese and I didn’t eat a tomato until I was 18. I thought it was disgusting, the mushiness of the tomato.

It was the smell and for sure the texture... I would only eat white food like yogurt, milk, cheese, and noodles...The unfortunate part is you end up being constipated your whole life because of textures and foods that you can't eat; all of a sudden it affects your whole person, being constipated.

One respondent talked about how, as a child, she often would use her tongue as the preferred tool of exploration because she could better tolerate sensations through her tongue than her fingers.

Researcher: When you were young you would explore by using your tongue?

Respondent LE: When I was in school I got yelled at a lot.

Researcher: For licking?

Respondent LE: Things, but I don't even do that very much anymore.

Researcher: Why do you use your tongue?

Respondent LE: Because I don't want to touch it.

Researcher: You'd rather use your tongue than your fingers?

Respondent LE: Yes. You can learn more with your tongue. Fingers just feel things.

Researcher: What do you think your tongue gives you that your fingers do not?

Respondent LE: I can taste it. I feel better with my tongue. It feels more things... It's more sensitive than my fingertips, but I don't do that very much anymore.

Researcher: Because you got in trouble for doing it?

Respondent LE: Yes, I practice picking up stuff instead.

Researcher: Do you remember when you were a baby licking a lot of things?

Respondent LE: Yes, when I was in preschool I tasted all of the underwater toys.

One of the respondents highlighted the positive of over-responsiveness in the gustatory sense in that it has helped her with one of her favorite hobbies: cooking. She recounted the many contributions of her uncanny sense of smell and taste. "I can always taste what needs more or less of. That can be good. I like nuanced flavor."

### *Visual.*

Nine out of 14 respondents agreed with the statement on the screening questionnaire that “they are bothered by bright light.” In addition, five respondents mentioned difficulties with spot or fluorescent lighting as well. Two respondents detailed how visual overload could often lead to physical symptoms like headaches and others talked about the comfort of the dark.

I find [spot lighting] disturbing. I'll get a headache. I don't get a lot of headaches but lighting can do that to me. If it's a diffuse light, I'm better...I don't like fluorescent lighting. I notice the little filaments and if it's moving at all, with that little vibration, I'll notice that. I'm very aware of that.

I love the dark, dark, room [in our house]. You can sit in there and you can't see anything and you can't even see your own hand in front of your face. You can't even feel the air anywhere. I love it in there.

### *Olfactory.*

Over-responsiveness in the olfactory or smelling sense was cited as troublesome by 8 of the 14 interviewees. And, as stated earlier, over-responsivity to smell was often one of the reasons cited for difficulty with eating. However, a few respondents also talked about the positives of having a highly sensitive sense of smell. As described later in this chapter under “Impact of SOR on Vocations,” one respondent described in detail how her keen olfactory sense helped her “sniff out” various types of infections with her animal clients. Others cited the positives of knowing quickly if something was burning on the stove, what their parent was cooking for breakfast, or if something went sour in the refrigerator. Another respondent described how she often relied on her extra sensitive nose to help her acclimate to new situations.

When I'm trying to get familiar with a new object I sniff it, no matter what it is... I touch it, I tap it and I sniff it, even if it's lead or metal or plastic, like in non-food items, just something to get familiar.

The effect of over-responsiveness in the next three senses: proprioceptive, vestibular, and interoceptive was more difficult to discern with respondents, since these senses were generally less well known and understood.

*Proprioceptive.*

Our proprioceptive sense, also known as the “kinesthetic sense,” “position sense,” or “muscle sense,” tells us where our body and body parts are in relation to space and to one another (Kranowitz, 2005). Often those with an over-responding proprioceptive sense have poor body awareness and appear rigid, tense, and uncoordinated (Kranowitz, 2005). On my screening questionnaire the statement that addressed proprioception was, “I tire easily especially when standing or holding a particular body position.” Five out of 14 respondents marked this statement as true. A few respondents also self-described as uncoordinated and two respondents stated that they have trouble determining where their body is in space. Three respondents reported how they have trouble sleeping unless they have proprioceptive input, which for them came in the form of a weighted blanket or beanbag chair upon their legs as they fell asleep. As one respondent said, “It’s interesting because when I sleep, I like to have a 500-pound comforter on me. I like this feeling of almost having a vest on me, which I know is a sensory thing.”

*Vestibular.*

Our vestibular sense, also called our “balance and movement sense,” helps us determine whether we are sitting up or lying down. It informs us of where our head and body are in relation to the earth (Ayres, 2005). On the screening questionnaire, 6 out of 14 respondents marked “True” in response to the statement, “I become anxious or distressed when my feet leave the ground.” Many respondents also cited difficulty with motion sickness, which is also a symptom of over-responsivity in the vestibular system.



Respondent NY: Being off the ground in any capacity made me really uncomfortable...I actually have no desire to learn how to do any sports...I never learned how to roller skate or ice skate. The loss of control was very panic-inspiring to me.

Researcher: Does it still feel fearful to you?

Respondent NY: Yes, I hate amusement parks.

Researcher: Rollercoasters? Anything?

Respondent NY: I hate all of that stuff ... seesaws, even. What's weird is, I think it even got worse for me, for some reason, after pregnancy. I feel like I have a way more heightened sensitivity to being dizzy.

Interoceptive.

The final sense, which is probably the least understood of all, is the interoceptive sense.

This important sense tell us how our internal organs are feeling. It regulates functions such as hunger, thirst, digestion, body temperature, sleep, mood, heart rate, and state of arousal (Kranowitz, 2005). Many respondents spoke of interoceptive challenges by discussing their difficulties potty training as a child, regulating body temperature, or having trouble sleeping. In addition, those who were "picky eaters" as a child reported not ever feeling really hungry.

***Multi-sensory SOR is common.***

While sensitivity in one sense is troubling, over-responsivity in multiple senses can feel intolerable. There are no published data on the prevalence of SOR overall, nor the prevalence of SOR in specific senses. However, in speaking with the occupational therapists who helped me recruit for this study, they both said that their practices were full of children and adults who experience over-responsivity in multiple senses. While I set the screening criteria for this study at "over-responsivity in at least *two* senses," the distribution of senses that were over-responsive were as follows: 36% of respondents were over-responsive in at least three of their senses, 14% in at least four of their senses, 36% in at least five of their senses, and 14% in at least six of their

senses. When asked about multisensory over-responsiveness, both OTs validated that the more senses that have trouble processing input, the more difficult it is to manage. The following quote details the complexity of over-responsive tactile, taste, auditory, and interoceptive senses.

I like to be wet, but not in the pool. I don't like pools because it's cold. I don't like the ocean because it tastes bad, and it makes me feel dirty...I like to take a shower... because it's quiet and really warm.

### **Social and Emotional Challenges and Rewards**

Perhaps the most striking finding of this study was that although I did not screen for this specifically, 13 out of 14 respondents described struggling with anxiety and 12 out of 14 reported experiencing depression either as a child and/or an adult. In addition, 12 out of 14 respondents described experiences of either isolation and withdrawal either as a child and/or adult. Lastly, eleven out of 14 participants self-described as having low self-esteem as a child and/or adult. What is not clear is what accounts for this co-occurrence of SOR with anxiety and depression. Some of my respondents felt anxiety and depression were responses to being sensorily overwhelmed, while others felt those with SOR are more prone to these conditions because of their extreme sensitivity. Only one respondent did not feel that there was a link between her sensory challenges and her feelings of anxiety.

#### **Anxiety.**

Twelve out of 13 respondents drew a connection between SOR and their anxiety, talking about how a negative reaction to stimuli would often set off a cascade of negative feelings directed toward themselves. Anxiety came in many forms. Generalized anxiety, social anxiety, and fear of public speaking, were cited multiple times by respondents. One respondent clearly felt that her tactile defensiveness and anxiety were directly linked, as was her natural coping

mechanism of avoidance. I further explore avoidance and other SOR coping mechanisms later in this chapter.

My beginning was marked by anxiety. I was tactile defensive. That marked also my attachment with my mother which was avoidant and I have worked with that quite a bit - an anxious and avoidant attachment style.

One respondent described her anxiety in detail in the following passage:

Respondent BL: It's the over-thinking. The thinking starts and then you start to panic... you're worried about going to school the next day because you have this test and you're probably going to fail. Then you just keep thinking, 'I'm a failure,' and the next thing you know you're in this cycle of behavior. You just start saying these words, 'I'm ugly, I'm stupid'...and then these thoughts start to process and then you start getting anxiety like, 'I really am stupid, I can't pass this test.' You start to believe your own compulsive thoughts and the anxiety about this turn into words, which turns into who you think you are, then it turns into behaviors.

Researcher: Do you see a linkage between your sensory stuff and your anxiety?

Respondent BL: Definitely. I think whenever I was feeling physically uncomfortable, I would start to feel a pit in my stomach like something was not right with me. [I'm] not just quirky; there's something wrong with me. I don't think any of that physical stuff connected until I was out here. I knew how to withdraw. I knew how to avoid but not how to have tools to work in the moment.

Others spoke of the yearning to be “seen” and “understood” by others and how their feeling of being misunderstood often led them to feel very anxious. As one respondent stated, “I didn't feel like people got me. I was like, ‘Why isn't that sweat and the smell of gym class bothering them?’ I thought I was a little strange. I was teased a lot.”

For a few respondents, their anxiety abated somewhat after learning about SOR and how that might be the reason why they experienced strong sensory reactions.

I mean there were certain things that made so much sense. Like I would have days where I was so upset, so upset about everything that I could not calm down. I couldn't figure out why I was so upset. Finally I was like, ‘Wait a minute, so what if I go back to the last couple of times I've been really upset and look specifically at what happened? Every single time there was a loud noise, like a car honked or their engine backfired or there

was really bright light or maybe someone bumped into me and I could just feel it happen and I couldn't calm down.' Every single time there was a sensory trigger.

This respondent went on to explain how, for him, his strong reactions after experiencing a sensory trigger often looked like anxiety, depression, moodiness or irritation. A few respondents stated that anxiety was still a pressing issue for them and that, even after OT and mental health treatment, they still felt very anxious.

### **Depression.**

Anxiety and depression were the two most commonly cited social and emotional challenges among respondents in this study. Again, some saw a clear link between their SOR and depression; others did not. A few respondents spoke about how lonely and isolating it felt to not be able to tolerate physical contact, which, in turn, made them feel sad and depressed. One respondent spoke about how social contact in general made her feel depressed because she didn't know how to do it without extreme discomfort.

The depression, I know was affected by the sensory stuff...There is this physical disconnect. It isn't really comfortable [for me] hugging, or getting patted on the back...I was starting to not do very well in school and it was hard to keep focus...the level of distractions and repeated failures that came in all areas definitely contributed to the depression.

Several respondents talked about how their depression was triggered during those periods of life when they felt their lives were unpredictable or out of control. Five respondents discussed battling depression while in college. For many, the move to college was overwhelming. This respondent felt her depression was due, in part, to sensory overload and a feeling of being out of her comfort zone.

It was like the start of a downward spiral from the time I got to freshman year of college. It was a lot, moving into a new dorm, living with a person I didn't know, having to sleep in a loft, having to climb up and down to sleep. It was a nightmare and I just started to

withdraw. I felt sad and moody but again, I was always touchy so moody wasn't that far of a stretch...I remember walking around the streets of X hoping I would have a physical accident... so I could have wounds to be sad about...I thought I was going crazy because I felt so lethargic. It was a big change that was hard...I think all of that change was too much for me to process. I remember calling my parents halfway through the year and they just came and got me. They drove two hours at three in the morning and were like, 'You are not right.' I went to a psychologist the next day and [was] put on antidepressants, which was a nightmare because I was so sensitive to any drug. One made me not have an appetite and I was already skinny...One made me sleep all the time...A lot of it was depression stemming from anxiety. I think those things were combined. They would give me Xanax and that was the only thing that I felt would numb me out. It didn't help me function in the world. It helped me not feel...That was the farthest down I [had ever] spiraled. Then I found this one great therapist that's helped me through; I went on antidepressants again but these worked.

One respondent talked about the linkages between her senses, her body, and her mental health.

I remember feeling uncomfortable in my body in New York day in and day out. I found the grind of living there, especially as an 18 year-old, the first place away from home, to be very overwhelming and that definitely contributed to me feeling down because I just didn't feel comfortable in my body... If I'd gone to college in a calmer place I think I would have made the adjustment a lot easier... I was feeling very anxious and uncomfortable in New York and it turned into depression...it was too much of an assault on my senses.

Another respondent realized that her natural tendency to isolate and withdraw were not helpful responses when she was depressed. "I think when some people would seek other people, I've always drawn in. That's my tendency. I know now more how to reach out to my husband and that helps."

### **Isolation and withdrawal.**

Isolation and withdrawal were prevalent in this study with 12 out of 14 stating that they tend to isolate and withdraw. Most spoke about it as a way of being and a few more explicitly viewed this feeling and behavior as a reaction to being over stimulated through their senses. It was interesting to note that this pattern of isolation did not really change over time.

It was difficult to completely isolate myself. I really couldn't, you know, with three siblings... I wasn't ever hugely social but I probably withdrew from a friends a little bit. I remember one point when I was 19 just dropping friends because I didn't see what the point was.

### **Self esteem.**

Eleven out of 14 respondents noted that their self-esteem had been adversely affected due to their over-sensitivities. Many participants noted how quickly negative thoughts would turn inward and respondents would conclude that there was something wrong with them for having sensitive senses. The majority diligently strived to "become normal" like their peers. How parents noticed and interpreted their child's sensory sensitivities appeared to be critical to a respondent's sense of self and overall self-esteem.

I do think self-esteem would get affected by sensory stuff because one of the things I heard my whole life was, 'You're too sensitive. You're too sensitive. You're too sensitive.' I probably am too sensitive but it's annoying because it's like, 'You know what? This actually is a big deal, so stop trying to act like it's not a big deal.' It almost feels manipulative when people say you are being too sensitive.

When you have people telling you that you are willful, spoiled, and lazy all the time, that doesn't make you feel very good about yourself. Now I still have that to a certain extent but I also have some sources of positive feedback which I think helps counteract that a little bit.

Even those respondents who had achieved a great deal academically (completing graduate and post-graduate studies) and career-wise, were plagued with insecurities about their over-responsive sensory systems. The following are accounts from two respondents talking about self-image and self-esteem.

Respondent EJ: I did have good self-esteem as a child. As an adolescent, I did not...My self-esteem has definitely improved through accomplishment and that sort of thing.

Researcher: Do you see any links with the way you take in input from the world and process it as relating to your self-esteem or your self-perception?

Respondent EJ: Yeah. I think -- because I am aware that I do scream when a chair screeches or the door bangs -- I feel self-conscious that there's something wrong with me. I've always [wondered], 'Why is that bothering me? Why can't I just ignore this smell or this flashing light or the radio ... Why can't I just let that go?'

I feel very inadequate... It's a real struggle. I don't want to make a mistake. I don't want to do anything wrong, and when I do, I cleverly cover it in a way so that it is right. It wasn't because I didn't want to be wrong, it was that I didn't want to hurt anyone's feelings, and I didn't want anyone to perceive I made a mistake. I wanted to be perfect. I just didn't take on a lot of challenges sometimes if that was the case... I definitely push myself now to take on uncomfortable challenges, but the self-esteem is like, 'I don't want to get it wrong.' I don't know why that's in my head.

I witnessed in five respondents a growing awareness and acceptance of SOR and its implications on their life. This group was becoming more comfortable with saying, "This is who I am, and this is what I like to do when I have free time, even when it goes against societal norms." Conversely, others discussed the feeling of "grinning and bearing it" just to be social, to fit in, to go along with the "extrovert ideal" (Cain, 2012).

For a long time I felt counter to everything people my age do. All through college and in my early 20's, that's when everything social happens -- at night either at the bars or a loud restaurant. That age group is not looking for quiet cafes, so I would just force myself. I didn't think about it at the time as being 'a thing'... I just wanted to be with my friends, so I would just do it knowing that this is not where I would pick to go night after night. I remember feeling taxed and tired and judging myself because I didn't have a context of why I hated it so much... I'm still working on it because my family they all seek [sensory stimulation] a lot and go out a lot so I still have to try to be like, 'It's okay, this is who you are,' but I judge myself a lot like, 'They can all go out at night and I just need a lot more down time.' I have always felt bad about that... I definitely was a kid with anxiety and had depression when I was older... I always wanted to have more stamina... to be able to deal with loud parties for hours... or even stand and chat for a long time... if we're going to be standing all night, even when I was at the age when everybody was doing that, I hated it.

### **Emotional sensitivity – overlap with “The Highly Sensitive Person.”**

In the following section I will present several challenges that I did not originally have in my interview guide but noticed that many respondents discussed these as apt descriptors for

themselves. I will also present the flipside of these attributes, which, for many respondents was a great strength. Intuition and empathy are two of the characteristics that Elaine Aron as well as Susan Cain, discuss as associated with being a “Highly Sensitive Person” and “Introvert” respectively.

***Overblown empathy.***

The following are quotes from three respondents who spoke of the challenges of being an “empath,” or one who can feel someone else’s feelings with little barrier. When the feelings of others are elated and joyful, this trait can be a positive, but when others are feeling deep negative emotions, it’s often overwhelming. The first of three quotes below is from a respondent who lived with a father who had been diagnosed with bipolar disorder.

It’s like a blown up empathy basically...when you are really, really sensitive to what people are feeling. All my life I could walk into a room and be aware of how people were feeling...even if I had never met them before...Hyper-empathy. It was very strong around him [my father]. I could pretty much tell how he was feeling without being in the same room; it was like I was linked somehow. My Mom and I were both really hyper-vigilant about the way he was feeling...It was the only way to gauge what was happening next. It’s like a sensitive person living near a volcano... Sometimes I could feel him erupting even if he wasn’t talking, and other times I could tell he was barely reachable.

I was sensitive when other people would be hurt...I would feel bad...I would say that I was very intuitive as well, so when there was something that wasn’t good in a situation, even though it wasn’t verbalized, I could feel it.

I can tell when someone’s off just by looking at them... when I walk into a room I can tell if someone’s upset...the room just feels tense. I notice how they hold themselves and even if their facial expression is blank, I can see the tension.

The positive to hyper-empathy was also enumerated by several of the respondents.

Within friendships or family systems, a number of the respondents felt that their empathic natures helped them to be caring and sensitive family members, friends, or spouses. Others cited the positive of being able to gauge the feelings of another person while in a work setting like teaching, psychotherapy, and occupational therapy. As one therapist stated, “ We need more



sensory sensitive people in this arena because I think it opens people up to processing on a level that we cannot get to through words.”

***Intuitive.***

Closely related to empathy is intuition and many respondents spoke about their innate intuitive sense as an important strength in their lives. When asked what was the most rewarding aspect of being SOR, seven respondents cited their intuition. Two respondents spoke of using their intuition to help others, whether it was at home, work, or play.

I am an incredibly intuitive person, and I pick up on things. I can figure people out like nobody’s business. I can tell when somebody is bad news or has a problem and needs to be avoided...That’s all from being overly sensitive... I can pick up the frequency of somebody else.

The gift [of being SOR] is being very connected in all my senses to others...I feel like that's what I love to do. I love to figure out just the right thoughtful gift for someone or I can see when someone's uncomfortable in the room and I give them what they need.

One respondent described in detail how she utilized her intuitive sense to help a friend expand his very restricted eating repertoire.

I took really, really small steps, not forcing him to do anything, preparing two things, just a little bit of something with the offensive material in it, and then the rest was normal, changing one variable at a time...now what he eats... has quadrupled, quintupled. He still doesn’t eat what most people do, but it’s much closer to what’s normal. I kind of, instinctively, had a feel for how to do that...I have those same issues in other areas...I never wrote him off as crazy, or spoiled, or stubborn, as a lot of other people did. They would just say, ‘Well you can’t possibly know there’s mushroom blended up in there.’ He can taste it. He knows it’s there...I can, too...I’d never try to trick him like his Mom did by grating zucchini in pudding...I think, in retrospect, that it was because of my own experiences that I kind of had a feel for how to do that.

***Highly sensitive to visual imagery.***

Lastly, six respondents spoke about their extreme sensitivity to visual images such as those shown in photographs, TV shows, and movies. In particular, these six cited not being able to watch any type of visual presentation that is scary, disturbing or intense. Their response to

these images included bodily reactions such as increased heart rate and higher body temperature. Many also spoke of not being able to regulate quickly after seeing something disturbing.

Two respondents' accounts are below.

I think that the sleep problems that I described to you are because of this. When I was in second grade...there was this movie...I was terrorized by seeing the posters in the grocery store. It was called *Audrey Rose*...It was the story of some little girl, my age, who had died in a fire, and then, came back to life. Everything I'm describing to you is literally from memory, almost 40 years ago. The posters for it were pictures of this otherwise lovely girl, with blonde hair and blue eyes. Then, her hair is billowing with fire in the background...I don't know what it was, but everything about it, it struck some nerve in me that made me terrified: totally scared out of my wits, and that is when I think my sleeping nightmares started. That's why as a parent, I take it so seriously what kids are exposed to because I see what one thing did to me.

I remember this one time that I chose a movie that was supposed to be a romantic comedy and it ended up to be a film with a really disturbing scene and I shut it off but it still stayed with me...I couldn't sleep. It was so hyperarousing and it just kept replaying in my head because I'm such a visual person. When someone tells me a story I see and hear the images in my head.

### **Impact of SOR on all Facets of Life**

My findings illustrated the dramatic impact that SOR has on every facet of one's life from family to school to relationships to work/play. While sensory sensitivity was often viewed as a challenge to overcome, it was interesting to note those cases where respondents viewed their over-responsivity as an asset. Many chose professions that valued their sensitivity, or chose work where they could directly utilize their personal experience as a SOR person to help others. Others realized that their sensory over-sensitivities enabled them to have a unique perspective when working with animals, children, or adults. In most cases, relationships required more attention, as it is often difficult for tactilely over-sensitive adults to tolerate certain types of physical touch.

## **Family.**

Several of the respondents talked about feeling ostracized within their family as “the picky child that required special handling.” One of the respondents detailed how she was “singled out” as being different from her three siblings.

My older siblings were all very active, huggy, lovey, kissy, and I am not. I remember them trying to hug or touch me and I would recoil. Even to this day when we say goodnight at Christmas, everyone hugs, everyone kisses, but then they say good night [without touching] to me. I like big hugs but not a gentle hug, so I’m really specific. I grew up being called sensitive, touchy, and emotional. Those were my labels and I just thought that was me.

Another respondent spoke of how her special needs may have negatively impacted her younger sibling.

I think the hardest part has been the impact that I see it have on my family ... I definitely see that for my brother, like there was a lot of pieces that I would get more upset about than him... they were outside of the normal range...[everything] was more bothersome for me when he kind of felt, ‘Well, I’m just doing my normal thing...’

## ***Importance of parental attitudes and support.***

In discussing the role of parents in their lives, the study respondents detailed varying amounts of support and understanding from their parents and siblings. Interestingly, 11 out of 11 respondents cited that they thought that either their mother or father also had some form of Sensory Processing Disorder. However that shared experience did not always translate into parental attunement. Some respondents had incredibly attuned and supportive parents, while others had less empathic parents with more rigid parenting styles. A synonym for attuned could be “securely attached”; while I didn’t ask specific attachment questions, the importance of caregiver attachment appears paramount.

*Attuned and supportive parents.*

The attuned and supportive parents were the ones who sensed that their children did not feel comfortable and would work to alleviate the sensory overload. These parents were able to mentalize their children, not as stubborn and willful, but as scared and uncomfortable, with particular sensory inputs. One of the respondents had tried numerous treatments for her SOR due, in part, to her mother's belief in early intervention and constant search for information. She describes her mother's approach and support as follows:

My mom did a lot of research... [she] understands the brain's plasticity and ability to make changes is a lot greater when you're younger, so we did a lot of intensity then... then having my parents understand that it's not bad behavior, or to build in things for me like, 'You need to come home and get grounded,' ...those kinds of things helped a lot with the overall understanding of myself...

Another respondent spoke fondly about how her mother was very patient and attentive to her needs as a child and how she still considers her mother a close confidant forty years later.

She was always very catering to anything and everything. She lived for her kids. Whatever we needed, she provided...I would say hair brushing would be the exception. I didn't want my hair brushed at all. So, eventually, we just cut it really short. She was [very accommodating] for me and my sister.

Lastly, one respondent reported that it was her parents who have helped bolster her self-esteem and sense that she can handle the challenges associated with being Sensory Over-Responsive. "My parents have been incredibly supportive even if they don't totally understand everything...I don't think I would have been able to deal if I didn't feel like I had their support on the other end."

*Non-attuned parents.*

Several other respondents described what it was like to grow up with little parental or family support for their sensitivities. These respondents expressed feeling unseen and unheard within their family system. Often they would put up a front as if it didn't matter, when, in reality,

they did want to try a sensory challenging activity, but they were too scared. One respondent reported, “I would like to have been challenged more and not stressed... I was so scared but I was just like ‘I didn’t want to do it anyway.’ That was my coping mechanism: not interested.”

It was particularly challenging for those respondents who felt that their sensory profile was opposite from their siblings and parents or if their family norms did not include open communication about emotions and feelings. Three respondents described their families’ diverse reactions to their SOR.

It was not okay to have big feelings in my family...I was scared but I didn't want to say I was scared because they'd say, ‘You're just emotional or you're so touchy.’ At the basis was a physical thing...a physical uncomfortableness...now they embrace my uniqueness. I explain to them some unique things about highly sensitive people...

I think as a kid I must have had adaptive mechanisms because it just wasn’t tolerated in my family...My father had a big temper, he was very scary and would get really angry...You just had to deal and put up and shut up.

To this day they still ascribe these really calculated intentions, but I am just not that calculated...This is really how I feel. I’m not adding a value judgment to it. The fact that I can hear that noise doesn’t necessarily mean it’s bad or good... Especially my Dad, [he] always thinks that I’ve got these premeditated things that I’m doing just to annoy him...That’s just not how I am. I think that, at this point, he would have figured that out. In my family, there’s not a whole lot of tolerance for aberrations from the norm... On the one hand, I think it’s been good because it’s forced me to learn how to adapt to a lot of things. On the other hand, it’s been really frustrating because I feel like my parents don’t understand me. I think they go through phases where they really try, or they think they’re trying. They’re unwilling to let go of these preconceived notions. Without that, I don’t think it’s really possible... they’ve vacillated between trying to discipline me into shape and trying to figure out something.

### **School.**

In general, school was a challenging experience for many of the respondents. Many detailed how misunderstood they felt throughout their school years--or how, in some instances, they were the victims of bullying or insensitive behavior by other children. For three

respondents, being around other people in a school environment was overly stimulating. A narrative of one respondent's school experience follows:

Respondent AT: In grade school, I would react very strongly to touch so they found it funny to kick me in the shins and poke me in the back or smack me on the head with rulers and pens...and that was one of the reasons why I got pulled out of public school...from 4<sup>th</sup> to 8<sup>th</sup> grade I went to a private school and then back to public high school. X high school is in an old building and the halls are narrow and there's like 2000 students there and there were always human traffic jams...So the whole experience was hard and classrooms were always kind of difficult because there's people; even when they were focusing in class they shifted around. They whisper under their breath. They write. They cough.

Researcher: All these things you're describing, did it make you feel a certain way?

Respondent AT: Kind of threatened or distracted a lot...or just disrupted. I think one of the worst ones I've ever been in was in college... I'd usually try to sit in the front, but it was a test day and all the front seats were taken. They had stadium seating... and I could not take the test because people shifted or went down the stairs and I was sitting all the way in the back so all the vibrations came right up.

One respondent's mother spoke about the adaptations that her daughter has learned in order to tolerate the visual, auditory, and physical challenge, of having 60+ kids in a college lecture.

She used to take her notes right outside the door so as not to deal with the overwhelm of being in a class with 60 other students. She would ace all of her tests but then her professor marked her down for not being in class. Then she worked with the disabilities office at her university and now they walk her to all of her classes and get her set up and introduce her to the professors which is working much better.

### ***Giftedness.***

Multiple respondents in this study reported being identified as "talented and gifted" when they were younger. One respondent skipped a grade and then another before being moved back to just one grade of acceleration. When asked about her giftedness, another respondent reported that her keen ability to focus and interpret multiple streams of data has helped her in school and now at work.

If the environment is good, I can hyper-focus, and that's gotten me through a lot like a very challenging school. I don't multitask well. But, I can focus on one thing very

well...I wonder if it's just that you take more in and maybe there's more connections [in your brain].

Another gifted respondent talked about how her elementary school's system for achievement did not take into account her sensory sensitivity or shy temperament.

I had one element that seemed to work well for me, which was learning. I started learning very quickly and my teacher thought I was very accelerated and they asked me to do things on the spot. Of course, being a shy, sensory-sensitive child I couldn't read a word [when put on the spot].

### **Friends and relationships.**

In general, this group of respondents reported that they tended to have a few close friends and preferred one-on-one interaction to a group social setting. Two respondents stated a clear preference for online friends where they could interact via one channel and control the amount of stimuli received. As one participant stated, "When I first discovered that I could spend time in online games and talk to people, it was the first time where I felt I could interact with people in a way that didn't overwhelm me." And for a few, social interaction was extremely difficult. In addition, a few respondents reported that physical intimacy was challenging due to tactile and auditory sensitivity.

One young respondent detailed the multiple sensory challenges of being in relationship with others, and the felt sense of being misunderstood by her peers.

It was definitely difficult for me to make friends and stay in a group or with other people for very long...kids are just loud and noisy and smelly and it was difficult being around other kids for eight hours a day...I guess I can never really socialize for too long because it's pretty tiring...and pretty stimulating having to talk and be close to people and stuff. So I think they probably thought I was being snobbish because I didn't really want to talk to people very long.

Another respondent discussed how his insecurities and anxiety made it difficult for him to make friends.

Respondent RS: Making friends was definitely difficult...just initializing it, coming up front and meeting them as well.

Researcher: What made it hard for you?

Respondent RS: Nervousness I guess. Fear of failure... and I didn't really know how to approach it because I would see someone and I'd see that we had similar interests or something, and then I just wouldn't know how to proceed from there.

Researcher: What helped you with that?

Respondent RS: More confidence in myself. Going for it and not really worrying about what would happen afterward. Getting that initial step out of the way, and then dealing with whatever came next.

Other respondents have learned how to create close and long-lasting friendships where they have felt "seen" and understood. Several spoke about the importance of learning how to communicate their particular sensory needs to those who are close to them. "I have a good friend who still teases me about not liking hugs but it didn't affect our relationship." A few of the respondents have practiced telling others about their sensory needs – one puts the blame squarely on herself while another asks friends to not misinterpret her actions.

I do self-deprecate. I'm weird. Scents bother me. My colleague was wearing a new perfume and I said, 'I'm sorry. You can't wear that around me. I can't handle it.' I put it on me for sure. I do say, 'I'm sensitive to smells or sounds or that sort of thing.' I will use that word [sensitive] for sure.

I just say, 'Oh, I'm just very sensitive and certain things bother me more than would other people so, if I seem withdrawn, or if I'm not in the conversation, it's not anything that you have done; it's just that I'm getting overwhelmed.'

Both respondents felt that their friends and colleagues responded positively to their direct addressing of the issue.

A few participants worried about being able to communicate their needs adequately to their partners. One respondent, in discussing relationships, detailed how her former boyfriend would interpret her sensory needs as a reflection of his shortcomings.



He kept taking it personally like, 'I can't make you comfortable.' It takes a pretty special person to understand me and not take it personally and find humor in, 'Yeah, you're quirky. You're crazy but you have learned enough tools.'

### **Vocations and avocations.**

It was interesting to note the breadth of careers that the SOR respondents in this study chose and how their sensory sensitivities have helped or hindered them in their professions. Six of the 10 respondents who are currently working are in the "helping" professions as a veterinarian, occupational therapist, therapist, acupuncturist, and teacher. Two respondents are full-time mothers, one works for a non-profit, and one is a computer programmer. One respondent who works with animals detailed how her highly sensitive olfactory sense, combined with sharp intuition, has proven to be extremely beneficial in her work.

I'll go in a room and say, 'What's that smell?' and eventually I'll identify it. I smell things about my patients. I smell yeast. I smell bacterial infections...It's strange, but in my work, I think it has helped...I would also say I'm more intuitive than a lot of people and that's also helped with my work. My technician will go in the room and ask questions and we're really not getting anywhere. I go in and I know how to guide the questions to get an answer...I always thought I was just a good listener but maybe it's something else. Maybe I'm more aware of changes and the way people are thinking.

Six of my respondents work with sensory-sensitive children and adults either as a teacher, occupational therapist, acupuncturist, or psychotherapist, and each of them described how helpful it has been to be able to relate with what it is like to experience Sensory Over-Responsivity. These SOR adults can often discern when a child's behavior is in response to sensory over-stimulation versus a willful behavior. A teacher respondent described her work in the classroom as follows:

The most rewarding part of it has been that I feel I have an intuitive understanding of the kids that I work with. I know what they are experiencing. I also feel that I'm more in tune with the environment like, 'Oh that clock is ticking over there or the lights are

buzzing, or that person just walked in.' I'm more perceptive of how that can impact their functioning.

### ***SOR parents helping their SOR children.***

For the five respondents who have children with SPD, their journey of self-awareness has given them a unique level of empathy and understanding for their children, especially when it comes to behavior. One mother expressed the difficulty of decoding her children's behavior since one appears to be more of a sensory seeker while the other is more sensorily over-responsive. This mother intuitively can understand what her SOR child needs but was confused by her sensory seeking child who constantly craves input and motion to feel organized in her body. Another mother stated that she feels fortunate to have "connected the dots" for herself and wants to ensure that her daughter's self-esteem is not compromised by how she interprets input through her senses. Yet another mother reports the following:

I think I have greater empathy in certain situations than my husband with my son. That seems to really help him. More discipline does not help when I know that he needs someone to help him understand and help him get through a difficult moment.

### ***Creating a comfortable work environment.***

Some respondents discussed the importance of creating an environment at work that would meet their sensory needs. Temperature, light, sound, visuals, and smell, are all critical inputs for a SOR person. Many respondents talked about how they have had to advocate for themselves in order to be able to create an optimal work environment. Again, self-awareness is an important first step. Once people are aware of their sensory sensitivities and triggers, they can then evaluate various environments more critically. One of the college students in my study described her environmental decisions this way:

I like to sit in a spot in the classroom where there aren't bright lights shining down on me. I find that certain textures of chairs are really annoying, so I try to find ones that

aren't so much. The fabric ones are just disturbingly soft. I like the wooden ones better...I can only take four classes a semester; otherwise, I get totally overwhelmed by just being there physically...I didn't live in the dorms or anything because it was way too much. I was there for a night and it was way too loud.

## **Coping Mechanisms and Treatments**

### **SOR is not out-grown.**

One of the theories surrounding SPD and SOR is that one can outgrow the condition.

When asked this question, all 14 respondents unanimously replied, except for eating issues, that they didn't think they had outgrown any of their sensory sensitivities; rather, they had developed coping strategies which enabled them to better handle their sensory challenges. Many felt that their sensory sensitivities had worsened with age. As one mother reported, "I think I struggle with all the same things [sensory sensitivities]; I just am in control of my life now. As a kid I was dragged along so I was constantly exhausted from all the demands."

### **Coping mechanisms.**

Humans are unparalleled in our ability to develop adaptations or coping mechanisms to minimize the impact of intolerable situations. For SOR adults, these strategies range from: avoiding unpleasant sensory stimuli, controlling challenging situations, and utilizing self-regulating tools after sensorily arousing exposures.

#### ***Avoidance.***

As children, many respondents quickly learned how to avoid the stimuli that did not feel good to them. When given a choice, they opted out of situations that they perceived as either too loud, too fast, too smelly, or too touchy. If the music was too loud, they would cover their ears or leave the room. If there were too many people crowded together they chose to stand apart, often in a quiet corner. If their pants had seams and tags, they would wear cotton leggings or

sweatpants instead. If their pasta did not look inviting, they would not even try one bite.

Avoidance is often the primary line of defense for a young child because it works and it's easy (sometimes). But a lifetime full of avoidance can feel stagnant. One respondent described the ironic dilemma of an avoidant strategy, "What you want the most you avoid. On top of it you become like a butterfly flickering your wings and you can't get anywhere."

### ***Control through planning.***

Many SOR adults realized what their individual tolerance level was for particularly sensory challenging situations such as going to a party, a trip to New York City, or shopping at a crowded mall. Rather than avoiding, they often used planning as a way to control or manage expected chaos. One respondent talked about the value of knowing your sensory limits and what to do if you can't control the situation.

If someone is having a party on a Saturday, then I need my Friday open because I know now from experience, that if I do things two nights in a row I'm going to be a wreck. Not only that, but I need things to be quiet and calm right before, because if I'm going to go into something that's going to be stimulating, I need it to be in small doses. You can get in situations where ... things come up that you can't plan for. I have earplugs I always carry with me. They don't do much, but sometimes they help a little. I usually have something that is fairly distracting with me like ... Sudoku or something like that, crossword puzzles... That's something that helps me.

Another respondent talked about the importance of control, and the safety that control provided when the world felt unsure.

Respondent EJ: Oh gosh, when I was young I would worry about everything. I would schedule my day down to the minute... I was very organized... I would plan everything to make sure that things went just a certain way.

Researcher: Why do you think that was?

Respondent EJ: Maybe it was a way to control my environment. I wonder, because I see it a lot in my son--a certain amount of control that he needs to feel more comfortable. I think I did that for a long time.

Overall, respondents expressed that dealing with Sensory Over-Responsivity was much easier as an adult than a child, due in part to the fact that as an adult one has more control over participating or not in certain experiences. As a child, one is bounded by parental expectations and the family rhythm.

I think when you grow up and can control your environment, it becomes a lot easier. So it's not to say that when I walk into a cocktail party I still don't feel that way [overstimulated] but I know that it's a choice. I am going because I want to socialize and then in two hours I'll go home. I still feel uncomfortable in a lot of the same situations but I have a broader view now...I'm choosing to be here and it's not going to be my whole life and I can tolerate it. My parents are very, 'Go, go, go,' so as a kid I think I was constantly pushed past what I was comfortable with just because that was their lifestyle. They had plans all weekend long. They never really wanted down time...I live my life differently. If we have plans one night, then I know I want to chill close to home the next day.

### *Self-awareness.*

Several respondents talked about the importance of tuning into their body and listening to sensory cues as a mechanism for coping with sensory overload. For some, a quick nap was the answer. For others, it was turning off the lights or heading home to a safe and controlled environment. One respondent noted how empowering it was to realize she could change her environment and make herself feel better.

Learning more about breathing and tuning into what I'm feeling ...like my toes are cold, my sock has a wrinkle, my pants are too tight. My heart is palpitating. I feel like I'm sweating. My hair is irritating me on my forehead so breathe. I need a glass of water. Learning that changing the environment is the most important thing for me. It helps a lot.

Many participants reported that it was an important milestone when they realized how much their physical environment contributed to their overall feelings of arousal and well-being. Notably, two respondents who had formerly lived in New York City (NYC), drew similar conclusions between their physical environment and their overall mental health.

I tried to go to school there [NYC] but I felt like I was trapped in a Vegas casino all day. I didn't identify it [then] as to why I felt down and didn't like New York, but now, looking back, I still get the same feeling when I go to NYC. It's like, 'Brace yourself: you're going to New York it's going to be an assault of the senses' ... that's how I feel when I'm there...It's the coolest place ever, and I want to like it but I just feel like it's cacophony and no space. I feel really anxious, I feel like I can't talk to people if there's a ton of background noise. I don't like trying to connect with friends in crowded places. It just taxes me, but that's obviously how everybody there lives and connects.

I do feel this need a lot, which I don't remember feeling 10 or 20 years ago ... to go home and sit in my house. I'm totally happy alone, in silence...in my house. I see the mountains. I have all of this glass in my house, so there's a lot of natural light. Every day, I'm so happy I live here because it's so much better for me. Honking and ambulances ... In New York City, you hear an ambulance every 10 seconds -- what that has got to do to your nervous system, I just don't know.

### ***Relaxation and breathing.***

Many of the respondents cited deep breathing, taking warm showers or baths, listening to peaceful music, meditation, and massage, as important coping mechanisms. One of the respondents spoke very highly of a sensory re-patterning massage that was designed to soothe the mind. Visualization techniques learned with a psychologist proved to be very helpful for some of my respondents, particularly with respect to reducing feelings of anxiety and fear. One respondent spoke about the power of visualization as a coping technique throughout her life.

I was eight years old and the babysitter let us watch the movie, *Halloween*, which is a super intense movie. In the movie the five-year-old boy kills the entire family and so I developed ritual behaviors around going to bed because I was so fearful from the images that I saw. The rest of my siblings saw it and they were fine. Finally my parents brought me to a psychologist and she worked with me with breathing and putting myself to sleep doing visualization. I used it all throughout [my life], even college. If I couldn't sleep at night...I would do this deep breathing, walking upstairs to a door and, when I opened the door, it was this beautiful whatever it was. I would smell beautiful things and I would see beautiful things and that helped me through grade school, middle school, and high school.

### *Use of humor.*

Upon reflection, one of my respondents realized that her wit and sense of humor has been one of the ways that she has dealt with her specific sensitivities. She realized at an early age that she seemed to have more trouble than others with certain stimuli, so she learned that if she made fun of herself first than others didn't need to.

If my clothing felt uncomfortable, I couldn't focus on what I was doing ... or if I was smelling food in the hallway... I would be distracted and uncomfortable. I think playing games with friends, anything fast paced or unpredictable with balls or things like that, I didn't want to do. I think I got creative and I started developing a sense of humor, self deprecating stuff to counteract [my sensitivities]...Using humor was a huge gift. By being funny, people looked past my quirksiness.

### *Downtime.*

Several respondents discussed the importance of having downtime – either while awake or a quick nap to rejuvenate after being over-stimulated. One mother extolled the virtue of napping for those with SPD.

Costco is invented to kill people who have sensory processing issues because of the warehouse, the fluorescent lights, the overabundance ... I feel like a loser saying this but I was drained from the experience. Yesterday, after the Costco debacle, I thought, 'I haven't slept well. Maybe I ought to try and take a nap before I pick the kids up from school.' I had 45 minutes...It was a great way of processing toxic sensory overload...It's so funny. This is the person who wanted nothing more than to live in New York City. Now, I'm the happiest person alive to take a nap. To me, it seems like the greatest luxury. Wake up, and it's quiet...I could feel the difference. I could feel a shift in my body...my son can be very trying on your nerves. He's just that kind of a kid. Yesterday, he was having a really difficult day, and I was fascinated by the fact that it didn't really start to get to me until 7:30 at night, which a lot times, it'll get to me within half-an-hour... I think napping is the secret for people with Sensory Processing Disorder.

Another respondent talked about the importance of sleeping and her need for good quality sleep in order to stay regulated and calm.

I loved sleeping in and if I was awoken before my time, it would set off my whole day. Sleep was such an important piece of the plan... Not necessarily a lot of sleep, just good quality sleep. Six hours is not a lot for me like last night, but I had a humidifier on, soft

blankets, dark. Solid sleep and it's fine...It builds up so much that it affects me days later [not getting good sleep].

### **Treatments for SOR - what has helped?**

Treatment was one of the original focuses of this research and it was very interesting to hear from the six adults who received sensory integration treatment in the form of occupational therapy either as a child and/or an adult. What is even more interesting is to talk to the 14 out of 14 respondents who sought out psychotherapy for their anxiety, depression, or difficulty dealing with a new transition in their life. Only one respondent stated that she had sought out mental health treatment specifically for SOR. Depending on the clinician's knowledge about SPD, most respondents were not even asked about their sensory profile or history. For some, it was the mental health clinician who first diagnosed the possibility of SPD; for others, it was the occupational therapist. I was impressed with the breadth of treatments that many of these adults have explored in their attempts to live more comfortably with SOR. In addition, the question of what worked is tenuous, as four of my respondents had received OT as children and had very little memory of OT and whether or not it "worked" for them. I was only able to sense that, in general, they liked going to therapy and that their parents felt that the OT was helpful.

#### ***Mental health counseling.***

For many of the respondents there was not a clear linkage between their SOR and their mental health issues. When asked, many thought there likely was a connection but admitted that this was a relatively new belief. Interestingly, a few respondents noted that there was a lack of knowledge around sensory issues among the mental health clinicians that had they initially consulted. One of my respondents detailed her experience with a psychologist who wasn't aware of Sensory Processing Disorder.



Yes. I did go to a psychologist once...I brought up sensory integration stuff and he hadn't heard about it. Then, the next session I assumed he had looked it up or asked one of his friends. He shifted around a lot and then he said, 'Well, that sensory integrative stuff, isn't that a childhood disease?' I thought, well it started when I was a child, so I said, 'Yes, I guess so.' I didn't consider at the time that he probably meant limited to childhood... So, I didn't go back. I was too confused by that point and the guy didn't really seem to listen. At the end of that session I had a lot of other problems to go over, but he said, 'Well, I think you're doing pretty well, so why don't you just call me if you have any issues.' It was pretty much that: 'Yes, don't come back.'

The majority of respondents had favorable experiences with therapists who helped them with their presenting issues at the time. One respondent spoke of how transformative her therapy was in helping her tune into her feelings before they mushroomed into larger issues.

My current therapist started connecting for me that I avoid feeling things because it's too much... my thoughts turn into anxiety, which then makes me feel depressed. She told me, even if it's not comfortable you have to tune in like, 'I'm really hungry, my clothes are really uncomfortable, I'm surrounded by loud noise and it's super bright but I don't know why I'm agitated; I'll just put my sunglasses on. I'm going to bring a hat. I'm going to step outside.' Once I started tuning into my feelings, then I realized what little things were bothering me that were turning into emotions. By tuning into that, it helped me take care of those things...you can solve so many problems. Why did I just freak out and have this fight with my boyfriend over this surprise? It wasn't that it wasn't great. It was that I was uncomfortable. It was this loud place with lots of lights and had I known that, I would've been prepared to go in...

Two other respondents also felt that counseling or therapy was helpful to them.

Yeah, I think the people I talked to were helpful in helping me feel more empowered, that I had the answers, and just to have someone to talk to that wasn't my Mom [was helpful]...I remember it being a positive experience.

I guess talking with someone about things that I would normally never talk about, exposing me to things, learning to identify how you're feeling and why, and how to fix things if I'm feeling badly...learning how to take cues from what's going on around me, seeing if they're affecting my emotions or feelings.

Another respondent talked about her growth mindset and how she has come to realize that what she needs is to constantly be challenging but not stressing herself. She has learned

through experience that she doesn't want to miss out on certain things just because she feels sensorily uncomfortable. As she says, "You need to keep doing that [challenging yourself] or you just go home and watch your favorite TV shows on your really cozy couch that you love so much."

### ***Occupational therapy.***

As stated earlier, 6 of 14 participants had undergone occupational therapy (OT) treatment for their sensory processing challenges. Of these six, three had received OT treatment both as a child and an adult, one received OT only as a child, one received OT only as an adolescent, and one only received OT as an adult. Those who had received OT as a child retained vague memories of playing with balls, swinging on swings, or pushing chairs down a hallway. Overall, those who experienced OT as a child felt that it was a positive experience in that they liked their OTs but they weren't sure of the overall impact of the treatment. Two of my respondents did not realize until their recent work with an OT, that they had, in fact, received treatment for sensory integration when they were a child.

### ***Brushing was helpful.***

A common protocol in occupational therapy is the use of the Wilbarger Brushing protocol. The theory behind the protocol is that frequent brushing with a plastic surgical brush on the arms, legs, and back, followed by joint compressions desensitizes those who are tactile sensitive and helps their bodies feel more organized. One of my respondents felt this tool was one of the most effective things that he has learned in occupational therapy.

I would do the brushing and I would feel a dramatic difference right away. If I did the brushing for a couple of days, I would start to feel normal. I would start to not be overwhelmed by loud noises, be able to tolerate stress better, and not feel so anxious all the time... The way I described it was that it was like a classical concert, you're sitting in the seats waiting for them to start and they're all tuning their instruments ...but it sounds like discord...that was before I brushed. Once I've been brushing for a while it was like

the instruments made the same noises but they made sense... I could feel all the same things but it made sense... We also tried joint compression, which was helpful and made a difference.

This same respondent also felt that the brushing helped wake up his physical side and allowed him to engage and tolerate more physical activity.

When I started doing the brushing, with my first occupational therapist, it was suddenly like I had this intense desire to do physical things... I started running on a treadmill. I found that was really helpful for me in terms of draining a lot of my excess energy. It was such a huge difference. Suddenly I was as physically aware as I am mentally... I wanted to be as physically active as I am mentally. Typically, I am more mentally active and physically sedentary and just out of shape and kind of overwhelmed. I really enjoyed engaging with myself physically. I kept going to classes [Aikido] for months and I really enjoyed challenging myself.

Perhaps one of the strongest endorsements for occupational therapy came from a teacher respondent who had learned several OT classroom exercises designed to help Sensory Over-Responsive children settle in the classroom. She reported that the use of OT exercises made a dramatic difference with her students.

All of a sudden the one who's in the corner and it's too loud, 'Let's go and do something to get our engine revved up but it's something really nice. We're swinging, we're swinging.' You come back in and all of a sudden they're focused, they're engaged, they're talking to people.

### ***Exercise.***

Exercise and movement was cited by 9 out of 14 respondents as an important coping mechanism. However, some respondents were challenged in either their vestibular and/or proprioceptive senses making coordination difficult. Other respondents mentioned useful exercise choices including: walking, hiking, running, swimming, basketball, soccer, Aikido, and yoga .

### ***Listening therapy.***

Two study respondents had tried Integrated Listening System (iLs) therapy, which is a multi-sensory program designed to improve emotional regulation while helping the brain process sensory information. Both participants who had tried iLs felt there were significant benefits to this type of therapy. One respondent explained how her listening therapy worked:

Respondent AT: I'd be listening with headphones. Certain frequencies would be enhanced to try to get your hearing attenuation in more of a bell curve. My response to frequencies is kind of spiky...Also there was a vibration pad at the top of the head ...and it would vibrate with the sound, but a fraction of a second before everything and just like a very slight vibration. But the idea was to give a signal to let your ear and listening know that there was sound coming. So it would be a vibration which would trigger the listen-up kind of thing...They also did reading aloud...and the therapy was always good, like quiet arts and games to engage different centers of the brain.

Researcher: What did you think of all that?

Respondent AT: That seemed to help quite a bit. I did it for quite a while...a couple of times a week. My parents were very happy. They said it made quite a difference. I think my grades improved a lot after that. One thing that I noticed, during the session at the beginning I couldn't tell when the music had stopped...like a half-hour would go by and I would not have noticed...But then even that got better. So there was some improvement in school.

Researcher: Improvement in your ability to attend to auditory instruction?

Respondent AT: Yes it was. I'm trying to think if I really noticed specific things. I was a kid, I don't remember...But I think it was a bit easier.

### ***Meditation.***

Two respondents spoke at length about the importance of their daily meditation practice in keeping them in balance from a sensory perspective. The first spoke about a very difficult period in her life and how she attributes some of the difficulty due to the fact that she had abandoned daily meditation during this stressful time. As she reported,

When I first started working there, I would meditate for an hour or so every morning...And then I became so tired and worn down that I didn't continue...I was

spending half of my time in X and I was spending all of my other time just trying to restore myself enough to be able to go back to work on Monday. It was not a good life.

Another respondent spoke about how she had incorporated meditation into her life from an early age.

I got my transcendental meditation word when I was seven or eight so meditation has always been a part of the process...with transcendental meditation, you get a word, and you say that word over and over again, and you do it for however many minutes of how old you are until you're 20, and then you try to do 20 minutes a day of that meditation piece. My Mom has always meditated, and my Dad has also...sometimes my Mom would say, 'I think you need to take some time to meditate or do something like that.' It's typically what I try to do in the morning if it's 4:30 or 5:00 and it's not quite time to get up, I'll do a meditation and try to calm my mind.

### ***Chiropractic and massage.***

Five out of 14 respondents talked about the fact that chiropractic and massage could be helpful but that the practitioners needed to be wary of their tactile sensitivities or the experience was overwhelming. One respondent detailed her experiences with chiropractic.

Well, I'm pretty sure it was just too much for me, because the guy was pretty quick, but I'd come out really dizzy; things would look kind of funny and I'd be stumbling around. I didn't go too long to that guy but several years ago I did try another chiropractor down in Denver and I told her I had a lot of sensitivities. She started out very gentle, but I still got dizzy, stumbling afterwards and then she was like, 'Okay, that's too much.' So then... she used a tiny little stick that kind of smacks a little bit, but that was enough for my body to respond. And I was actually okay with that one, and more responsive, and it was working to slowly desensitize me which was kind of nice. I never fully got up to her typical level but she was able to do more.

### ***Journaling.***

For some, journaling was an effective way to release anxious energy and negative cognitions. One respondent described how journaling helped her improve not only her sensory symptoms but her anxious and depressive symptoms as well.

Journaling was immensely helpful. I was flowing the energy out and it would leave me...I started to go to this really peaceful place where I could focus and get stuff done.

I think the journaling may, at some level, be a more powerful tool than the brushing...I only did it for three months but things changed dramatically...I really never talked to people in class at school, but I started to make friends in class easily...It was like I gained control of myself...I reflect constantly internally, but it never gets any better... When I journal, it goes away.

### ***Nutritional intervention.***

Three out of 14 respondents detailed trying some type of nutritional intervention in order to improve their sensory sensitivities. Some examples of various diets included: gluten-free, dairy-free, high-protein, and high-lipid. Results were mixed, with some saying that they felt marginally better, but no one felt that diet alone significantly reduced their sensory over-sensitivities. One respondent noted, “It was just a little bit [better]...It kind of felt like a drop in the bucket.”

### **Straight Talk: What Do You Want Others to Know**

This final section is a compilation of responses to my final interview question which was, “What would you like readers of this research to know?” I was impressed and inspired by the earnestness of their reflections. What follows is a series of direct quotes from the study respondents.

#### **SOR is real.**

It’s a real thing. I see it in my son and in my family. I think there's a lot of doubt out there, that that person is just being sensitive...I'm hoping with research that we'll learn more about why certain people are so sensitive.

I guess that it's an actual thing and that [it] can be very difficult, and to just try to be more understanding and not tell people to just not be so sensitive about stuff, because I've heard that a lot. Saying someone is too sensitive doesn't really help.

For parents: your kid is not trying to be difficult. These experiences are very real to your kid, it is how they experience the world.

### **SOR is not a choice.**

It's not something you choose. It's not a question of willpower to just block it out, or don't think about it. It's not a conscious decision to...be difficult and make everyone's lives complicated...If you don't figure out a way to control it, it controls you...It's not a question of discipline. It's not something that you can punish out of somebody. Be aware that not everyone experiences things the same way, and that there isn't a right or wrong way to experience things...It may not be how you experience it, but why do you have to attach a judgment to it? It's just different.

I'd rather be faking it or just be able to adjust. To just say, 'Yes, nothing bothers me.' Stand up straight, go forward and just deal, because you can. Right? Right. But then, I have tried normal activity rates and activity patterns. It lasts a couple of days and then a hard crash.

### **Different is not bad.**

For people who feel like they have [SOR] too, that you're not alone and you will find your coping ways. You don't have to be an extroverted person and you don't have to like going to concerts. That's what I've struggled with. I want to be able to like those things or be in certain environments, but I just can't.

It's like living on another frequency really. It has its downsides but it also has its ups.

### **You're okay.**

If I were talking to a kid [with SPD] I would just make sure that they knew that it is normal and that they are okay. It's perfectly fine not to eat a certain food or to not do something.

For other SOR adults: be kind to yourself and be accepting.

### **Go for it.**

Have more confidence in yourself. If you want to do something or try something, just do it, even if you don't want to in the moment -- yeah, especially if that's the case. Just get out, try new things, and don't worry too much about the consequences.

### **There's hope.**

I guess one of the pieces is that I turned out okay. I have a successful career and I have successful relationships...I feel like I'm in a really great place in my life and I'm really happy, and so I think that any parents that read this, I think that there is a lack of research about this. They always want to know, 'Well, what is my kid going to be like...five years from now, 10 years from now?' -- those kind of things, and so I think in the 'Asperger's

world,' there are a lot of adults that have written books, and those pieces help give families hope and an understanding of what their kid could look like down the road. So, I hope people that read this know that there is hope down the road, and that there is a different way to look at [your] kids.

## **Summary**

In the following chapter, I will summarize conclusions about key findings, discuss study limitations, and offer specific action steps for SOR individuals, parents, mental health professionals, teachers and medical professions. Also included are recommended thoughts for further research.



## **CHAPTER V**

### **Discussion**

#### **Introduction**

The purpose of this study was to look deeply at the lives of 14 Sensory Over-Responsive (SOR) adults to understand what it has been like to live with highly responsive senses, with a particular focus on accompanying social and emotional challenges such as anxiety and depression. I also explored coping mechanisms and treatments for this condition.

This research study utilized qualitative research methods as the means with which to explore this nascent and under-researched field. In this chapter, I will review key findings and compare them with current literature on SPD and SOR, discuss strengths and limitations of my research study, and close with a call to action for SOR adults, mental health clinicians, parents, teachers and medical professionals. Specifically, I will focus on the importance of: increasing awareness and understanding of SPD and SOR, continuing focused research, and validating what works in terms of occupational therapy and mental health treatments.

#### **Key Findings**

**SOR is a real and chronic neurological condition with a genetic basis.**

Due to the relatively low level of awareness regarding SPD and its subset, SOR, there are many who do not believe that there is such a condition. While my screening criteria were taken from the Adolescent/Adult Sensory Profile, an important diagnostic tool for occupational

therapists, my seven questions alone were not sufficient to constitute a diagnosis of SOR (Brown & Dunn, 2002). However, 9 out of 14 respondents were “officially” diagnosed by either an OT or a psychologist utilizing a full battery of sensory integration tests.

The enduring nature of sensory challenges was confirmed by all of the respondents. This finding supports current research showing that sensory sensitivities continued from infancy through elementary school (Ben-Sasson et al., 2010). With the notable exception of eating difficulties, study respondents felt that their sensory sensitivities had continued throughout their lives, with a few reporting increased sensory sensitivity with age. In addition, all five of the mothers in this study confirmed that their SOR children had exhibited signs of sensory defensiveness since birth.

Study participants also confirmed the research that suggests there is a genetic basis to SPD as 11 out of 11 respondents cited that either their mother or father or both exhibited signs of Sensory Processing Disorder as well.

**The breadth and severity of SOR symptoms presents on a spectrum but is not necessarily related to Autism Spectrum Disorder.**

I was struck by the level of daily impairment reported by respondents who, by many other measures such as academic achievement, career success, household income, and quality of relationships, would have been classified as highly functioning. Level of impairment is a difficult qualifier; what constitutes impairment? And, in what domains should we look for impairment? In a recent training presentation that I delivered to 60 teachers at the University of Colorado, Boulder, I entitled my presentation: “SPD: The Hidden Diagnosis,” because often the distress associated with SPD is unseen. SOR adults often suffer silently or in isolation (Heller, 2003).

Of the 14 respondents who participated in this study, two had been given diagnoses of either Asperger's or Autism Spectrum Disorder, and when I looked at their reporting of sensory challenges they did, indeed, report having difficulty in multiple senses, but they were not alone. As reported earlier in the Findings chapter, 7 out of 14 respondents reported having over-responsivity in five or more of their senses. I certainly would not have classified all of these seven as meeting criteria for Autism Spectrum Disorder. Likewise, the two respondents who had been diagnosed with Asperger's and Autism Spectrum Disorder, reported that their level of sensory impairment was pretty severe but, again, there were a number of respondents who were not diagnosed with Autism Spectrum Disorder who reported equally disabling sensory sensitivities.

**SOR affects all aspects of life.**

At its core, sensory processing describes how people receive input from their eight senses, interpret sensory input, and then mobilize to respond to this input (Ahn, 2012). So it is not surprising that a disruption in this process in one or more senses would have a far-reaching influence on a person's daily life. As one occupational therapist commented, "SPD creates a misattunement between the self and others (A. do Valle, personal communication, March 28, 2013)". This misattunement plays out in many relational spheres including family, friends, school and work.

**SOR and anxiety/depression co-occur – the link is unclear.**

In this study, 13 out of 14 SOR respondents reported having chronic or multiple experiences with anxiety and depression throughout their life. When asked, the majority of respondents felt that there was a link between their sensory sensitivities and their anxiety/depression, with one respondent unsure. Many respondents recounted examples of how

their anxiety would often manifest as a reaction to sensory overload. Others reported feeling anxious some or most of their life.

### **Occupational therapy and mental health counseling can help.**

For those who had received OT or mental health counseling as an adult, they were unanimously positive about the help and relief that both of these types of treatment provided. One respondent, in particular, felt that “brushing” was a very helpful tool for regulating bodily arousal levels. For the four respondents who had received OT as a young child (before the age of 10), perceived impact was less clear because of their limited memories. For those cases, it might have been more helpful to interview their parents regarding their perceived sense of the effectiveness of early intervention.

Thirteen out of 14 respondents had engaged in therapy with a mental health professional as an adult and the majority felt that their therapy was helpful in addressing their presenting problems at the time. Twelve of 13 respondents believed that their feelings of anxiety or depression were linked to how they receive and interpret sensory stimuli in their bodies. However, they did not originally seek counseling for their SOR, rather they sought out therapy for their anxiety or depression.

### **The importance of early intervention and parental attachment.**

It is interesting to note that the one respondent who did not report experiencing anxiety and depression, was the one who had received the earliest and the most numerous interventions for her SPD. This respondent reports that her mother, who was a medical professional, was very active in researching possible treatments and that she, the daughter, engaged in many treatments for her SOR including: occupational therapy, mental health counseling, integrated listening therapy, acupuncture, meditation, therapeutic riding, nutritional intervention and massage. I

know that it is statistically unsound to draw any conclusions from a sample of one, but I did think this relationship was suggestive of the importance of early, aggressive treatment in bypassing internalized, negative cognitions.

In addition, I found that the nine respondents who spoke of a secure attachment or close attunement with a parent, and/or a supportive family system, appeared to have struggled less with social and emotional issues such as anxiety, depression, isolation, withdrawal, and lowered self-esteem. Again, it was difficult to measure, but when I summarized the content and tone of all the interviews I did sense an inverse relationship between parental attachment and anxiety/depression. As I discuss later under “Continue Research,” this area requires further exploration.

### **Research Study Strengths and Limitations**

#### **Strengths.**

##### ***Flexibility.***

The advantages of a qualitative research study are similar, I think, to the advantages of psychodynamic treatment versus a manualized treatment. In a qualitative study I had the freedom and the flexibility to follow the respondent’s lead and not be tied to a prescriptive interview guide. Each interview was slightly different and I added and deleted questions as I progressed.

##### ***Importance of the non-verbal.***

Another helpful advantage of in-person interviews over quantitative research, is that I was able to take note of all the non-verbal, affective messages as well as the verbal communication that added a helpful dimension to respondents’ narratives. In summarizing the interviews, I thought back to the subjective experience of each interview; how did it feel to sit

with this person as s/he was telling the story? Did the words match the affect? I was fortunate to have conducted all of my interviews in-person, though, I was prepared for a phone or FaceTime interview if needed. Making sense of Sensory Processing Disorder is very complex, so I think I would have had difficulty characterizing a life experience via a quantitative study. There is nothing more powerful than hearing a participant narrate his/her own life story.

***Use of feeling self.***

I also utilized my strong intuitive and feeling perception to make sense of respondents' stories and I often felt that I could feel a respondent's joy, shame, or pain in recounting a story. This sensitive sense was helpful in guiding the interview, as I could feel when there was more to be said on a particular topic. When our conversation veered to more sensitive topics such as anxiety or depression, I could feel when respondents felt less open and I could adjust my responses accordingly.

***Conducive environment for a SOR respondent.***

In addition, I utilized my knowledge of SOR and my personal sensory sensitivities to ensure that our interview room was comfortable for a sensory sensitive adult. I lit the office dimly with a side lamp instead of the buzzing, overhead florescent light. I turned off the standard noise-cancelling machines and space heater knowing that those sounds could be distracting, and during the interview itself I followed my respondent's lead in terms of voice volume, eye contact, and physical proximity. I encouraged respondents to "make themselves comfortable," which, for some, was sitting cross-legged on a cushion on the floor, and for others, it was relaxing on the couch. I tried also to be mindful of the respondents' level of activation and offered frequent rest or water breaks.

***My personal passion.***

Another strength of my study was my deep and passionate interest in this topic. In my recruiting letter I shared that I had a Sensory Over-Responsive nine-year old son; what I didn't mention is that I also met the diagnostic criteria for SOR as well. I often disclosed this during the interview but not always. My sense was that study respondents enjoyed the experience of sitting with someone who was riveted to their story and who could empathize both as a SOR adult, as well as a mother of a SOR child.

**Limitations.**

***My personal passion.***

My personal passion proved to be both a strength *and* limitation for this study. I wonder if respondents may have been influenced by my enthusiasm. I know that I consciously tried to avoid leading questions, but as some of my transcriptions showed, I was not always successful. In my efforts to create a comfortable and supportive interview environment, I may have shared too much of my personal experience with respondents who may or may not have had a similar experience. In retrospect, I should have worked harder to be more of a supportive yet neutral interviewer.

***Sample selection.***

As noted earlier in the Methodology chapter, one of the limitations of this study was the fact that I had met four of the respondents during my role as a co-facilitator of a monthly SPD Caregiver Support Group. I did not have a primary relationship with any of the four respondents. However, I noticed that when we were discussing difficult topics such as anxiety and depression, there appeared to be less openness and fluidity around these topics. In general, I found the majority of the respondents to be less comfortable recalling memories in this arena, but I wonder

how my support group facilitator role may have influenced the four respondents' responses. If I were to repeat this study I would expand recruiting nationwide to find 14 respondents whom I had never met so as to minimize any potential bias.

*Imperfect picture.*

While I knew this was the nature of qualitative research, I found myself frustrated by the inability to draw solid conclusions from this study. Perhaps that is my inner impatience with the lack of research overall in this field. While this group of 14 reported sensory processing challenges in at least two of their senses, their similarities ended there. Members in this cohort also experienced significant abuse, loss, alcoholism, eating disorders, traumatic brain injury, congenital hearing loss, divorce, post partum depression, ADHD, mood disorders, and PTSD. Of course, all of these factors will contribute to the state of a person's mental health -- making correlations and linkages with sensory profile and mental health even more difficult. Likewise, biological/genetic dispositions will leave an imprint but we should not minimize the impact and influence of family, school, friends, community, medical issues, and life events.

**The Call to Action – What Can We Do?**

Like any good research study, this work has unturned many new stones to pick up and examine in the Sensory Processing Disorder field. My generous respondents have implored us to wake up and pay attention to their stories. They have cried out to us as individuals, as mental health clinicians, as parents, as teachers, and medical professionals, asking us to learn more about SOR, to reframe what we do know, and to think hard about the multi-faceted impact that SOR has on someone's life. They are asking for our understanding, our empathy and our action. It is up to us to take the next step.



While the December, 2012, decision to not include SPD in DSM-5 as a stand-alone disorder is very disappointing, just the mere inclusion of hypo-or hyper-sensory symptoms is a positive first step. I believe that, like autism, which had very little awareness and research funding 20 years ago, SPD has the potential to “rise above the fray,” carried along by the millions of people who experience Sensory Processing Dysfunction. There are many things that we, as individuals, can do to increase general awareness of SOR and its far-reaching implications. Some of these initiatives are longer term in nature and others more short term.

**Increase awareness and understanding.**

The first step is to increase overall awareness of SPD and SOR, particularly among individuals, parents, mental health clinicians, medical professionals, and teachers. As Margaret Mead, American anthropologist, once said, “Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has.” Personally, I have seen a rapid increase in the number of websites, blogs, books and articles on SPD over the last eight years. Dr. Lucy Jane Miller, founder of the S.T.A.R. center and the SPD Foundation, and one of the leading researchers in SPD, recently wrote that the SPD Foundation receives over 85,000 daily hits to their website (L. J. Miller, personal communication, December 4, 2012). Awareness has been growing but it needs to continue at an accelerated rate.

*Among SOR individuals.*

*Accentuate the positives.*

Like the repositioning that is going on with temperaments such as introversion, (one need only look at the infectious popularity of Susan Cain’s 2012 book, *Quiet: The Power of Introverts in a World that Can’t Stop Talking*, which quickly rose to #2 on the *New York Times* bestseller list), SPD and SOR could benefit from a similar reframe. Later in this chapter under,

“Continue Research,” I will discuss in detail my belief that many of the studies that look at highly reactive/inhibited adults, highly sensitive adults, or introverts are, in fact, talking about people who are over-responsive in multiple senses. Because our world is governed by highly extroverted, energetic, charismatic social beings, anything less than that appears weak or ineffective. Likewise, the media have colluded in portraying success as an outgoing, high-energy, and sociable individual who appears to be at ease in all environments. What I want SOR adults to know is that having highly sensitive senses can be a tremendous asset. Remember the veterinarian who spoke about her uncanny ability to smell a yeast infection? The acupuncturist who could feel pain and sickness through her fingers? And, the teacher who intuitively knew when to challenge and when to support her over-responsive preschoolers? SOR adults are uniquely positioned to utilize their over-responsive senses to be able to help others.

Likewise, the high incidence of giftedness within the SOR population is not an accident. Many respondents spoke about their amazing ability to focus (once the environment was right), and how they felt as if they took in a lot more from their senses than a non-highly-sensitive person. Several respondents also cited heightened creativity and the unique ability to recognize nuances in art, food, music, and writing, as gifts. Lastly, a number of respondents reported that they were loyal and thoughtful friends who utilized their deep feeling sense to meet their friends’ non-verbal needs.

*Co-occurrence of social and emotional challenges is expected.*

As 13 out of 14 respondents reported, they had either multiple or chronic struggles with anxiety and depression throughout their life. Given what we have learned about SOR, these results are not surprising. However we should also put into practice what we have learned from these respondents, to know that there are many coping mechanisms and treatments that can help

alleviate the feelings of sensory overload. As various respondents spoke about their learning process of discovering what has helped them deal with sensory overload, I sensed a very real and growing level of self-confidence and feeling of empowerment.

*It's not too late for help.*

I was struck by the marked difference between the treatments that parents would try for their children versus themselves. It was as if there was an unconscious acceptance among parents that they had muddled along this far, that they didn't need to explore occupational therapy or mental health therapy for themselves. One of my respondents did contact me several weeks after our interview to ask for a referral for an integrated listening therapist, as we had spent the focus of her interview talking about her severe auditory challenges which had never been treated. Her son, on the other hand, had tried many different therapies for his sensory processing issues including OT, mental health, medication, nutritional intervention, and therapeutic riding.

*Know thyself.*

Perhaps the corollaries to "know thyself" are to "love thyself" and "be gentle to thyself." As one respondent reported, she felt like she had been really hard on herself her whole life until finally, in her 40s, she learned that there was a neurological basis to all of her quirks. That realization was the beginning of a blossoming of her self-esteem. As she has said, learning about SPD helped normalize a lot of her confusing feelings.

A grounded self-awareness and understanding of one's sensory sensitivities is essential as one thinks about school, work, play, and relationships. Adulthood gives highly sensitive people an opportunity to exhibit more control and choice than childhood, and self-awareness is a critical step to making thoughtful choices.

*Among clinical social workers and all mental health professionals.*

I am committed to helping to increase awareness among the mental health community. Why is it that SPD is not mentioned in our hallowed schools of psychiatry, psychology and social work? I continue to be amazed at the lack of familiarity with SPD and SOR among mental health clinicians when I know that approximately 5%-17% of their caseloads (extrapolating childhood incidence into adulthood) report having Sensory Processing Dysfunction (Ahn et al., 2004; Ben-Sasson et al. 2009). At minimum, sensory processing should be part of every biopsychosocial assessment with specific questions tailored around how a person receives, interprets, and takes action, in response to stimuli in each of their eight senses.

*Relationship to sense of self and self-esteem.*

As clinicians we spend a great deal of time helping clients unravel the many influencers and shapers of self-esteem. What we know from current research and from the respondents in this study, is that how we make sense of sensory input is a core brain function. When this process of receiving sensory input, interpreting sensory input, and mobilizing behavioral and motor responses is malfunctioning, we know that it creates conflict both intra-and inter-psychically. Often, sensory sensitive people develop anxiety or depression as a result of their sensory overload. Their body and brain do not feel right but they look at others who appear unbothered and they start to feel that something is very wrong with them. This feeling then becomes repeated over and over again until it becomes a neuronal pathway that is hard to undo.

*Relationship to attachment.*

Likewise, there is research that highlights the difficulty that adults with tactile defensiveness have in creating secure attachments (Heller, 2003). Because attachment in infancy

relies so much upon tactile sensation, a baby with tactile over-responsivity will often act disturbed when a mother tries to snuggle or soothe and then, depending on the mother's reaction to the baby's reaction, a mother often escalates a baby's discomfort leading to further misattunement between parent and child. This cycle of misattunement can lead to difficulties in forming secure attachments in infancy that can continue throughout childhood. As clinical social workers, it is imperative to understand our clients' attachment experiences in light of their sensory profile.

*Relationship to trauma.*

As stated in the research review, there are many who believe that the brain of an over-stimulated sensory sensitive person looks very similar to the brain of an adult who has experienced some type of traumatic event. There are a few studies that look at how SOR triggers the amygdala and the limbic system to prepare for fight, flight, or freeze (Schaaf et al., 2010). Many respondents talked about how difficult it was to become "unbothered" after being triggered in their senses – the analogy is similar to the lingering effects of being in a freeze state. A chronic state of hyperarousal is not good for our brains as our bodies are flooded with cortisol (Heller, 2003). Just as we often use brain models to highlight what goes on during trauma, it might also be helpful to talk about the similarities of a trauma brain and an SPD brain to our SOR clients.

*Need for policy.*

An important end result of increased awareness and understanding is the creation of policy. For those with SPD, I fear the wait for policy will be a lengthy one. While there is a current furor over the usefulness of DSM-5, I think that insurance companies will continue to use this guide until handed a suitable replacement. And since SPD was not recognized as a distinct

disorder in DSM-5, I think it will continue to be difficult, for children or adults with SPD only, to access special accommodations in school, unless they also have a concurrent DSM-5 diagnosis. I think of the college student respondent who sat outside her lecture hall to take notes because she could not tolerate the bright, noisy, smelly lecture hall and how her college experience could have been so much richer if she had received classroom accommodations on her first day of school. Likewise, I look at the reality of treatments for SPD and see a marked divide between those who have the resources to pay for weekly occupational therapy treatments and those who do not. Most insurance companies will not cover the cost of occupational therapy if SPD is the only diagnosis. Without policy validating that SPD is a stand-alone disorder that creates significant impairment in daily functioning, SPD, like many other diagnoses, will exist as a disorder that only the wealthy can afford to treat.

**Among parents.**

*Look behind the behavior.*

An increased awareness and understanding of SPD and SOR should lead parents to wonder: what are the underlying needs driving my child's behavior? With a thorough understanding of SPD and its many subtypes, parents can then work with their children to uncover specific sensory triggers and then create coping mechanisms to deal with challenging situations. As Dr. Jerome Kagan emphasized in an interview with Susan Cain for her book, *Quiet: The Power of Introverts in a World That Can't Stop Talking*, "every behavior has more than one cause" (Cain, 2012, p. 107). The single most important piece of advice for a parent of a sensory sensitive child is to ask them to pause before responding to a child's big emotion and to mentalize their child given what they know about their child's sensory sensitivities. What may look like willful, disobedient behavior, may, in fact, be a child's way of communicating that s/he

is in sensory overload. As one of our respondents had stated in the Findings chapter, it was very hurtful to her that her father believed that she had “calculated intentions” to annoy him. As she said, “I am not that calculated: this is how I really feel.”

*Help your child to reframe his/her experience.*

As a parent, the reframing or repositioning of sensory processing challenges from a negative to a positive is critical. Think about the importance of creating positive introjects that your child will then incorporate into his or her sense of self. While you can’t control the societal messages that your child hears, you can be an important voice that conveys, “You are amazingly special since you can hear everything around yourself, or feel how other people are feeling, or taste the difference between a walnut and a peanut.” As several of our respondents reported, it’s important to continue this open dialogue with your children throughout their lives and to help them make sense of their sensory challenges. Two of the study participants had experienced OT as a young child but had little memory of the experience or why they had needed OT.

Now that my son is nine years old I realize that he has little memory of the extensive feeding therapy that he experienced from age three to five. I have begun the important process of “telling the story” of when he was a baby and how he did not like to eat. I am careful to accentuate his strengths in his life story. I tell him, “You were a very special baby – you could feel certain textures in your mouth and with your fingers that no one else could. You knew at an early age what felt good and what did not, and you did not like to try new foods. You went to feeding school (that’s what we called his weekly feeding group with a feeding psychologist and OT) in Denver when you were little to help you expand the number of foods that you would eat.” As he gets older, my husband and I will continue to help him make sense of his ongoing auditory and tactile sensitivities and gently encourage him to try new experiences.

*Among teachers.*

The tools to increase awareness and understanding of SPD among teachers is similar to those of mental health and medical professionals. The first step needs to be education. Within the study of child and human development, time needs to be devoted to learning about Sensory Processing Disorder. Likewise, teachers could benefit from learning self-regulation strategies that will help all of the kids in their classroom, not just the sensory over-or under-responsive. Exercises such as deep breathing, singing, and blowing bubbles, help children regulate their systems if they feel over- or under-aroused. Likewise, exercises that stimulate both the left and right sides of the brain, such as bilateral tapping while singing or counting, cross-crawling on the ground, or drawing figure eights in the air, utilize both hemispheres of the brain and produce a calming and organizing effect.

Other than parents, preschool teachers are often the first professionals to notice that a child may be struggling with sensory input -- or that certain reactions appear disproportionate in relation to the precipitating event. Similarly to the advice given to parents, I would encourage teachers to look behind the behavior to understand a child's need. As one of the teacher respondents cautioned, "Pay attention to the easy kids too; they are often the ones that are struggling internally."

*Among medical professionals.*

In order to increase awareness among medical professionals, there need to be some significant changes in perception within the fields of pediatrics and neurology. The American Academy of Pediatrics issued a position paper in 2012 stating that, "because there is no universally accepted framework for diagnosis, sensory processing disorder generally should not be diagnosed" (American Academy of Pediatrics, 2012, p. 1186). The AAP goes on to say that



sensory issues are often deficits found in developmental and behavioral disorders and that pediatricians should refer out to child psychiatrists or child psychologists. We need pediatricians and neurologists to believe that SPD is real and distinct, and I'm not sure they will get on board without the research. As I discuss in the next paragraph, scientific research is a much needed but longer-term endeavor. My belief is that the SPD movement will have to be consumer-led or parent-led, as medical professionals will likely not take much action until more research is published. On the other hand, perhaps SPD will seep into the medical field as more studies confirm the relationship between SOR and various autoimmune disorders such as fibromyalgia, irritable bowel syndrome, and rheumatoid arthritis. For those who believe that the state of Sensory Over-Responsiveness creates a chronically hyper-aroused limbic system, there is evidence to suggest that one of the long-term effects of this is an increase in autoimmune disorders.

**Continue research.**

Although longer term in nature, it is imperative that research into this under-researched field continue and that mental health professionals continue to get involved in this important arena. The majority of published studies have come from occupational therapists but there is a clear need for more specific and multidisciplinary scientific work.

***Focus on neuroscience.***

When I looked through published research and asked the experts that I know, "What is different about the brain of an adult who is SOR?" There were few answers. While we know what parts of the brain are involved in processing input from the senses, we still don't know what looks different when individuals are either sensory under- or over-responsive. This focus on the brain and the nervous system could also tell us whether an SOR brain is similar to that of a

traumatized brain. A few experts have posited that the nervous system of someone with SOR looks as if they are in survival mode, either fighting, fleeing, or freezing (Heller, 2003).

***Learning from autism.***

Currently, there is a SPD workgroup consisting of over 30 researchers worldwide focusing on various research areas within SPD. This represents major growth from even 10 years ago. Looking at autism research as a bellwether, I think it may still require a number of years, but my hope is that the research approach in SPD follows that of autism research. We need to codify what we have and then bolster the number of studies that look at biology, neuroscience, and genetics. Perhaps SPD researchers should collaborate with autism researchers to look more closely at specific sensory challenges. Chantal Sicile-Kira is an advocate and award-winning author and speaker on autism. In her most recent book, *Autism Life Skills: From Communication and Safety to Self-Esteem and More - 10 Essential Abilities Every Child Needs and Deserves to Learn* (Penguin 2008), Sicile-Kira interviewed autistic teens and adults of varying ability levels. She reported that “Making sense of the world, understanding what their senses are telling them...is what most adults on the autism spectrum convey as the most important skill they needed to learn as children” (Sicile-Kira, 2008, p. 3).

***Need for prospective, longitudinal studies.***

Lastly, there is a huge need for prospective, longitudinal studies that would focus on the effectiveness of various treatments for SPD as well as the overall life of someone with SPD. There are many who think of SPD as a childhood disorder only and there is extremely low awareness that adults have SPD as well. It would be compelling to study not only the biology and trajectory of brain development in those with SPD from birth through adulthood, but also the environmental, social, and emotional impact as well. A prospective longitudinal study would

either validate or dispel the idea that one can outgrow SOR. Likewise, it is also important to look at the effects of early OT and mental health interventions over time.

***Is it a matter of words?***

In a perfect research world I would take Jerome Kagan's criteria for Inhibition/High-Responsivity, Elaine Aron's 27-item Highly Sensitive Person scale, and Susan Cain's 20-question Introvert-Extrovert spectrum quiz, and combine them together to create one research instrument that looks at temperament and personality traits such as shyness, introversion, and sensitivity. If you compared the three surveys, I believe you would find a significant overlap among the questions asked. After validating this self-report tool, I would then add on a self-report survey modeled after the Adult Sensory profile developed by Winnie Dunn that looks at sensitivity in each of the eight senses. What I believe would be found (after validation of this combined research instrument through a large-scale quantitative study), is that there is a significant correlation between those who report over-responsivity in multiple senses and those who are deemed highly-reactive, highly sensitive, or introverted. In fact, I believe that our language confounds what we are talking about. What Jerome Kagan calls inhibited/highly-reactive, Elaine Aron calls highly sensitive, and Susan Cain calls introverted, I am calling Sensory Over-Responsive (SOR). And, I believe there is a connection between being over-responsive in one or more of the eight senses and a propensity to exhibit personality and temperament traits that are associated with those who are highly sensitive or introverted.

**Continue exploring and validating what works in treatment.**

***Need for an integrated approach.***

From my dual perspective as a Mom of a nine-year-old son with SOR, and as a SOR adult, I feel that OT and mental health need to work more closely together for the benefit of their

SPD clients. Both disciplines focus on empowering their clients to cope, confront, and ultimately change, but so much could be gained by a sharing of information between the two fields. Ideally, there would be joint sessions where a client is performing exercises that are helping to organize over-responsive senses while talking through what it is that makes him/her anxious. OT and mental health would both benefit by understanding the goals, process, and tools of the other. The lines between the two professions are blurred. For example, when you think of a SOR client who is very shy and over-responsive to auditory and tactile input, and whose primary coping mechanism is avoidance – what would be the best way to work with this client? Self-regulating tools are in the domain of both an OT and a psychologist, although OTs have access to more specific vestibular and proprioceptive exercises that are regulating and calming. In order to make progress, I think it's important that the treatment plans between an OT and therapist are well coordinated so as to maximize treatment benefit. In addition, study respondents have suggested there is a benefit to many complementary therapies including: nutrition, mindfulness, acupuncture, therapeutic massage, and biofeedback. What makes the most sense is a coordinated delivery of these services and explicit measuring of progress so as to ensure the most improvement or gain in functioning. The goal in treatment would be not to just cope but to thrive.

*Feeding therapy as a model of integration.*

One area where OT and mental health have come together, along with pediatrics and nutrition, is in a team approach to helping children with feeding issues. Utilizing what they have learned about the importance of repetition and continued exposure from habituation research, certain feeding therapies incorporate this learning into their program as they continually expose children to new and different foods. Particular focus is on presenting new foods with a slight

alteration in texture, color, smell, taste, temperature, and visual presentation, than a preferred food. A key goal of feeding therapy is to change the child's relationship to food. What had often become a time of tension and conflict, is now reframed as a time to explore and play in a supportive, non-judging way.

When my son attended feeding school as a toddler, he would first start with a half hour warm up in the occupational therapy gym where various obstacle courses would be set up to help his body get organized and ready to eat. He would then sit with a small group of peers in a chair that was especially designed to support his "core" while he was eating. Some of his peers wore weighted vests or blankets, others wore weights around their ankles, and still others sat on bumpy cushions, depending on their need for proprioceptive input. Each week a speech language therapist as well as an occupational therapist would work with the small group to try various new foods. While the kids were eating, parents would sit behind a one-way mirror listening to an educational lecture from the feeding psychologist. Personally, I thought the team approach was very effective. I appreciated having multiple perspectives on my son and I liked how the team worked together to achieve specific goals around feeding and eating. And the best part was that my son thought feeding school was fun!

### ***Mental health.***

I feel that this integrated model of mental health with occupational therapy would translate well into other areas of focus such as helping children feel less anxious at school, helping children navigate new social situations, or helping kids negotiate separation while in college. While there are some, there are not many mental health professionals who fully understand SPD and SOR, and the accompanying preponderance of anxiety and depression within this population. I interviewed one of the clinical psychologists in my community who has

specialized in working with sensory children and adults for the last 25 years and she admits that she is still tweaking the formula of what works in terms of mental health treatment. The challenge, she reports, is that each case is unique with a distinct sensory profile and varied mental health challenges. She incorporates a learning model of change with her clients. Since those with SOR are likely to avoid those situations that are challenging, Dr. X encourages her clients to try new things and build new neuronal pathways in a safe and titrated way.

### ***Mindfulness and meditation.***

Judging from the positive reaction from the respondents that had engaged in some type of mindfulness practice, I think that meditation and/or other mindfulness practices could and should be incorporated into the treatment for SPD. The choice of mindfulness practice should be guided by the client's particular sensory sensitivities. I think of one of the respondents who had talked about how helpful visualization practice was to her in helping her manage childhood anxieties, and I think that that played well with her keen visual and creative sense. Likewise, the respondents who talked about having uncanny senses of smell might react favorably to practices that incorporate calming scents as part of the process. And lastly, because meditation is a quiet and solitary activity, it is often well tolerated by those with tactile and auditory defensiveness.

### ***Occupational therapy.***

One of the occupational therapists that I interviewed for this study told me that she has seen significant changes in the way OT is implemented with sensory children over the last 30 years. There appears to be more of a focus on intensity and in training parents to recognize and respond to symptoms of sensory over-or under-stimulation. OTs are taking more of a holistic view trying to look at all of the client's presenting issues and which can be addressed through OT. While adult treatment is still nascent, a few OTs have relayed that they are also seeing more

adults come in for treatment. As one of the study respondents stated, “OT works, it’s just hard to do it everyday.” I interviewed one of the OTs in my community about why there weren’t more SOR adults in treatment and she made the case for OT for everyone.

I think every human being benefits from having a rhythmic daily pace that meets all of their basic needs. In today’s world we have to look at the environmental structure of where you are and what kind of school you attend... every single human being benefits from knowing what works for them to self-soothe in a productive manner (C. Gibbons, personal communication, March 4, 2013).

***Don’t delay.***

The challenge is upon us now. Those of us who have been diagnosed with SPD, or have children with SPD, are unwilling to wait until all of the research is funded, conducted and then published. We are willing to learn from others and their life narratives. I think there may be a lot of promise with alternative brain-based therapies such as neurofeedback but again there is little science -- just anecdotal evidence at this point. Social media and the Web are our friends, as they allow instantaneous access to each other’s experiences on what has worked and why. Become a researcher and contributor – share what has worked for you or your child. Join an in-person or online support group and learn from others who see the world as you do.

And for those adults who are Sensorily Over-Responsive (SOR), and still testing the waters outside their comfort zone, I borrow from Mark Twain in saying,

Twenty years from now you will be more disappointed by the things that you didn’t do than by the ones you did. So throw off the bowlines. Sail away from the safe harbor... Explore. Dream. Discover.

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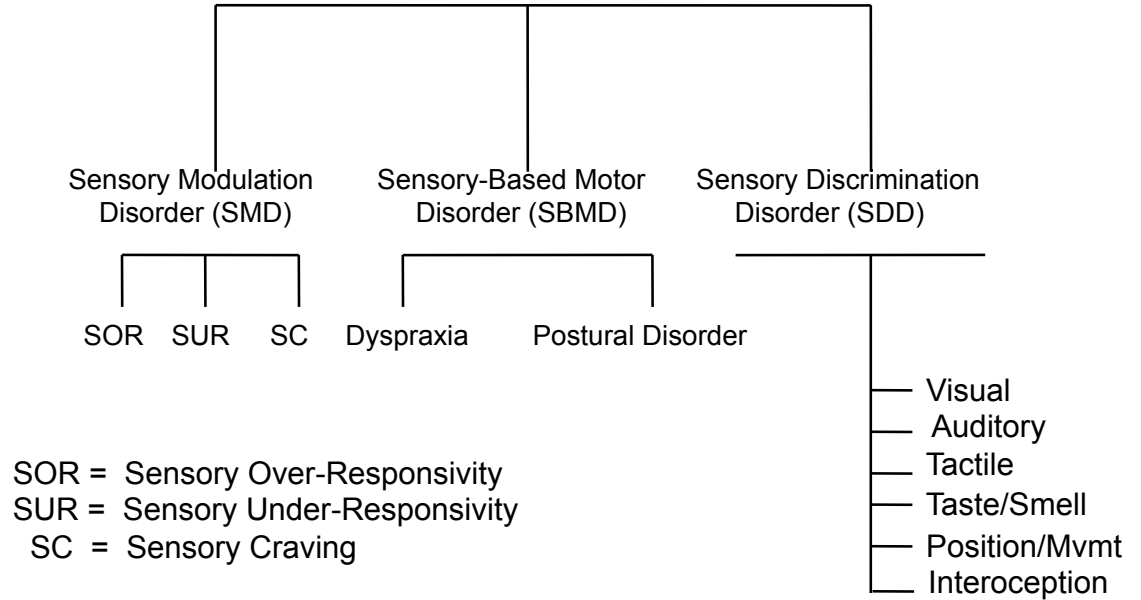
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**Appendix A : Sensory Processing Disorder and Its Subtypes**

# Sensory Processing Disorder (SPD)



Miller, LJ 2007

## Appendix B : Study Qualification Screener

### Sensory Processing Disorder Research Study

*Please read the following statements and indicate True or False as to whether or not the statement describes you:*

1. I am 18 years old or older. (True/False)
2. I do not have a diagnosis of Autism Spectrum Disorder or Asperger's Syndrome. (True/False)

*If you answered "True" to Questions 1 and 2, please proceed to Question 3. If not, you are not eligible for this study. Thank you for your interest.*

---

3. I am sensitive to certain fabrics (e.g. particular about shirts or bedding). (True/False)
4. I am a picky eater especially regarding food textures. (True/False)
5. I become anxious or distressed when my feet leave the ground. (True/False)
6. I can't work with background noise on (e.g. a radio or fan). (True/False)
7. I often hold my hands over my ears to protect my ears from sound. (True/False)
8. I am bothered by bright lights after others have adapted to the light. (True/False)
9. I tire easily especially when standing or holding a particular body position. (True/False)

*If you answered "True" to at least TWO of the statements numbered 3-9, then you are eligible for participation in a research study exploring the experiences of adults with Sensory Over-Responsiveness with a particular focus on treatments for this condition.*

**Appendix C: Demographic Survey**  
**Sensory Processing Disorder Research Study**

- 1) What is your age? \_\_\_\_\_
- 2) What is your gender?
- i.  Female
  - ii.  Male
  - iii.  Transgender
  - iv.  Prefer not to answer
- 3) What is your ethnicity?
- i.  African American/Black
  - ii.  Asian/Pacific Islander
  - iii.  Hispanic/Latino
  - iv.  Multiracial
  - v.  Native American
  - vi.  White
  - vii.  Not listed (please specify)
  - viii.  Prefer not to answer
- 4) What is the highest level of education that you have completed?
- i.  Grade school (grades K-8)
  - ii.  High school
  - iii.  College
  - iv.  Graduate school
  - v.  Post graduate school
- 5) What is your marital status?
- i.  Single, never married
  - ii.  Married or domestic partnership
  - iii.  Separated
  - iv.  Divorced
  - v.  Widowed
  - vi.  Other
- 6) What is your employment status?
- i.  Employed for wages
  - ii.  Self-employed
  - iii.  Out of work and looking for work
  - iv.  Out of work but not currently looking for work
  - v.  A homemaker
  - vi.  A student
  - vii.  Military
  - viii.  Other
- 7) What is your annual household income?
- i.  0-\$24,999
  - ii.  \$25,000 - \$49,999
  - iii.  \$50,000 - \$74,999
  - iv.  \$75,000 - \$99,999
  - v.  > \$100,000

**Appendix D: Human Subjects Review Approval Letter**  
**Sensory Processing Disorder Research Study**



School for Social Work  
Smith College  
Northampton, Massachusetts 01063  
T (413) 585-7950 F (413) 585-7994

January 31, 2013

Sarah Ahn

Dear Sarah,

Thank you for making all the requested changes to your Human Subjects Review application. Your project is now approved by the Human Subjects Review Committee.

*Please note the following requirements:*

**Consent Forms:** All subjects should be given a copy of the consent form.

**Maintaining Data:** You must retain all data and other documents for at least three (3) years past completion of the research activity.

*In addition, these requirements may also be applicable:*

**Amendments:** If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

**Renewal:** You are required to apply for renewal of approval every year for as long as the study is active.

**Completion:** You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Good luck with your interesting project.

Sincerely,

A handwritten signature in cursive script that reads "Marsha Kline Pruett PhD".

Marsha Kline Pruett, M.S., Ph.D., M.S.L.  
Vice Chair, Human Subjects Review Committee

CC: Gael McCarthy, Research Advisor



## Appendix E: Recruitment Letter

### Sensory Processing Disorder Research Study

March 1, 2013

Dear Potential Participant,

Hello, my name is Sarah Ahn. I am the mother of a nine-year-old boy with Sensory Processing Disorder and also a Master's level Social Work student at Smith College School for Social Work in Northampton, MA. I am conducting a qualitative research study to learn more about Sensory Processing Disorder and specifically, about the lives of adults, 18+ years of age or older, who are sensory over-responsive. In particular, I will be interviewing participants to learn from them about how their sensory sensitivity may have had an impact throughout their life. The goals of this research study are to increase awareness of what it is like to live with Sensory Over-Responsiveness and to shed light on effective treatments for those with Sensory Processing Disorder.

I am writing to you because you have been recommended to me as someone who might be interested in participating in this study. I hope that you will consider participating in my research. The process would consist of a short demographic questionnaire and a 60-minute interview, conducted either in-person, via Skype or FaceTime, or over the phone. In-person interviews will be conducted in my office at the Boulder Institute of Psychotherapy and Research at XXXX. **All participants will be given a \$25 gift card to either Target or Amazon to thank them for their time.** All interview questions will be provided in advance of the interview along with an Informed Consent form. The Human Subjects Review Committee of Smith College School for Social Work has approved this study.

Thank you for your time, I hope that you will consider participating in this study. On the next two pages you will find a short screening questionnaire, which will determine if you might be eligible for this study. If you have any questions, please feel free to contact me at XXXX or XXXX.

Kind regards,

Sarah Ahn  
Masters of Social Work Candidate, 2013

## Appendix F: Informed Consent

### Sensory Processing Disorder Research Study

February 12, 2013

Dear Potential Participant,

Hello, my name is Sarah Ahn. I am a mother of a nine-year old boy with Sensory Processing Disorder and also a Master's level Social Work student at the Smith College School for Social Work in Northampton, MA. I am currently conducting a qualitative research study to learn more about Sensory Processing Disorder (SPD) and specifically, about the lives of adults who are Sensorial Over-Responsive. In particular, I will be looking at how sensory integration treatment(s) may or may not be helpful in improving sensory processing symptoms. I will also be looking at the relationship between Sensory Over-Responsiveness and conditions such as anxiety and depression. The purpose of this study is to contribute to the knowledge about what works in helping those with Sensory Over-Responsiveness. This study will be presented as a thesis and may be used in future presentations and publications.

Your participation in my study is voluntary. Eligible participants will be adults, 18 and older, whose primary diagnosis is Sensory Over-Responsiveness in at least two of their senses. I am asking you to participate in a 60-minute interview with me either in-person, over the phone, or using video technology such as Skype or FaceTime. You will also be asked to complete a short demographic questionnaire that will be used to describe the participant sample. I will ask you specific questions about your experience with various sensory integration treatments including but not limited to: occupational therapy, mental health treatments, neurofeedback, and brain integration therapy. Our interview will be audio-recorded and then transcribed by me via transcription software and/or via a contracted transcriber who will have signed a pledge of confidentiality.

Risks in participating in this study are minimal. Participation in this study may bring up difficult feelings with regards to your experience of living with Sensory Processing Disorder. If you feel that you would like additional support, I have provided a list of mental health resources at the end of this letter. I have also noted which of these resources offer services on a sliding scale based on household income. I will provide you a preview list of questions prior to our interview so you can familiarize yourself with the range of possible questions. Please know that you can decline to answer any questions at any time. Benefits of participation may include: sharing your unique experience of what it is has been like to live with Sensory Over-Responsiveness and providing valuable input into what you feel has worked or not in terms of treatment. **As a thank you for participating in this study, you can choose between a \$25 gift card to Target or Amazon.**

In addition, your confidentiality will be protected. All in-person interviews will be conducted in my private office at the Boulder Institute of Psychotherapy and Research, XXXX. Any communication via email will be secure as both of my personal computers are password-protected as is my email. My research advisor will have access to the data only after any identifying information has been removed. In any publications or presentations the data will be

presented as a whole, in brief illustrative quotes or vignettes with no accompanying, identifying data. All computer data will be kept in password-protected files and any paper-based data will be kept in a locked file drawer for a period of three years as required by Federal guidelines. After that time, if the data are no longer needed for research purposes they will be destroyed. If they are needed for research purposes the data will continue to be kept secured for as long as they are needed, and when they are no longer needed they will be destroyed.

If you choose to participate, you may withdraw from the interview at any point and you may choose not to answer any or all of the questions in our interview. Furthermore, for up to three weeks following the interview you may contact me by phone at XXXX, or email: XXXX, and have your interview transcript and any demographic data deleted. If you have any additional questions, please feel free to contact me directly at XXXX, or email: XXXX. Should you have any concerns about your rights or any aspect of the study, you are encouraged to contact me or the Chair of the Smith College School for Social Work Human Subjects Review Committee at (413) 585-7974.

**YOUR SIGNATURE INDICATES THAT YOU HAVE READ AND UNDERSTAND THE ABOVE INFORMATION AND THAT YOU HAVE HAD THE OPPORTUNITY TO ASK QUESTIONS ABOUT THE STUDY, YOUR PARTICIPATION, AND YOUR RIGHTS AND THAT YOU AGREE TO PARTICIPATE IN THE STUDY.**

Participant's Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Investigator's Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Please keep a copy of this form for your records.

Thank you for your time and your participation in this study.

Kind regards,

Sarah K. Ahn

#### Counseling Resources

1. XXX\*
2. XXX\*
3. XXX

\*Offers sliding scale fee based on household income

## **Appendix G: Preview Interview Questions**

### **Sensory Processing Disorder Research Study**

This preview is provided for you so that you have a chance to familiarize yourself with the types of questions that I will ask you if you are willing to participate in an interview. You will be asked questions that fall roughly into two categories:

1. Personal Experience with Sensory Processing Disorder and Sensory Over - Responsiveness
2. Sensory Integration or Sensory Processing Treatments

The following questions will form the basis of our interview:

#### ***Personal Experience with Sensory Processing Disorder and Sensory Over-Responsiveness***

1. How did you first learn or realize that you had Sensory Processing Disorder? How did you first learn or realize that you were Sensory Over-Responsive?
2. How old were you at the time?
3. What do the terms: Sensory Processing Disorder and Sensory Over-Responsiveness mean to you?
4. Can you tell me how your body and senses feel as a result of your Sensory Processing Disorder and Sensory Over-Responsiveness?
5. Can you describe what it has been like for you to live with Sensory Processing Disorder?
6. What types of changes have you had to make to your life or your life routines, if any, as a result of your sensory processing issues? (e.g. You avoid places that may be too loud like a crowded restaurant or you avoid visually-stimulating environments)
7. As a child or adolescent, did any of the following apply to you? If yes, for how long did you experience this behavior or condition?
  - a. Aggressive behavior – physically injurious or hurtful behavior toward others
  - b. Feeling withdrawn – did not initiate contact with others
  - c. Feeling isolated – liked to be alone most of the time
  - d. Feeling depressed – lack of energy or interest in life
  - e. Feeling anxious – uneasy and worried
  - f. Having low self esteem – a below average opinion of yourself
  - g. Inflexible behavior – unwilling to change or compromise
  - h. Difficulty concentrating or focusing
  - i. Other – please elaborate

8. Currently, do you exhibit any of the following behaviors or conditions?
  - a. Aggressive behavior– physically injurious or hurtful behavior toward others
  - b. Feeling withdrawn – not initiating contact with others
  - c. Feeling isolated – liking to be alone most of the time
  - d. Feeling depressed – lack of energy or interest in life
  - e. Feeling anxious – uneasy and worried
  - f. Having low self esteem – a below average opinion of yourself
  - g. Inflexible behavior– unwilling to change or compromise
  - h. Difficulty concentrating or focusing
  - i. Other – please elaborate
  
9. Do you believe that these challenges are associated with having Sensory Over-Responsiveness, why or why not?

### ***Sensory Integration Treatments***

10. What types of treatments have you engaged in to treat your Sensory Over-Responsiveness? (Occupational therapy, Speech language therapy, Feeding therapy, Nutrition therapy, Brain integration, Mental health treatment and/or counseling, Other)
  - a. For each type of treatment – please explain how long each treatment was and if concurrent with other therapies - which ones. (For example, did you have occupational therapy and speech language therapy at the same time? If so, for how many months was it concurrent? How long was the total therapy?)
  
11. Which, if any, of the therapies do you feel improved your physical symptoms of Sensory Over-Responsiveness? (Some examples of physical symptoms include: sensitivity to visual stimuli, oral stimuli, sound and touch, including inability to tolerate light, eat various textured foods, inability to tolerate loud environments like a restaurant or party, inability to wear certain textured clothing)
  - a. Of those treatments that improved your physical symptoms of Sensory Over-Responsiveness, what specifically felt different as a result of treatment?
  - b. Of those therapies that you felt didn't work, why do you say that?
  
12. Which, if any, of the therapies do you feel improved the ***social*** or ***emotional*** challenges associated with Sensory Over-Responsiveness? (e.g. some people report feeling aggressive, withdrawn, isolated, depressed, anxious, low self esteem, inflexible, difficulty concentrating or focusing)
  - a. Of those treatments that improved your ***social*** and ***emotional*** symptoms of Sensory Over-Responsiveness, what specifically felt different as a result of treatment?
  
13. Of those therapies that you felt didn't work, why do you say that?

Appendix H: Recruiting Flyer

Sensory Processing Disorder Research Study

# *Are You Sensitive to Sensory Input?*

- *Are you 18 years of age or older?*
- *Have you been diagnosed with Sensory Processing Disorder?*
- *Have you undergone occupational therapy treatment for at least six months?*

If you can answer “yes” to all of the questions above and have not been diagnosed with Asperger’s Syndrome or Autism Spectrum Disorder, you may be eligible to receive a \$25 gift card to Target or Amazon!

As part of a research study for the Smith College School of Social Work, I am asking participants to share their stories on how sensory sensitivity may affect a person’s life. Participants will complete a short demographic survey followed by a 60-minute in-person, video, or phone interview.

To see if you qualify for this study please contact the principal investigator, Sarah Ahn at XXXX or XXXX. Thank you!

**Appendix I: Transcriber Confidentiality Agreement**  
**Sensory Processing Disorder Research Study**

**Confidentiality Agreement**  
**Transcription Services**

I, kimberly Nip, transcriptionist, agree to maintain full confidentiality in regards to any and all audiotapes and documentation received from Sarah K. Ahn related to her master's thesis on Sensory Processing Disorder. Furthermore, I agree:

1. To hold in strictest confidence the identification of any individual that may be inadvertently revealed during the transcription of audio-taped interviews, or in any associated documents;
2. To not make copies of any audiotapes or computerized files of the transcribed interview texts, unless specifically requested to do so by Sarah K. Ahn;
3. To store all study-related audiotapes and materials in a safe, secure location as long as they are in my possession;
4. To return all audiotapes and study-related documents to Sarah K. Ahn in a complete and timely manner;
5. To delete all electronic files containing study-related documents from my computer hard drive and any backup devices.

I am aware that I can be held legally liable for any breach of this confidentiality agreement, and for any harm incurred by individuals if I disclose identifiable information contained in the audiotapes and/or files to which I will have access.

Transcriber's name (printed) kimberly NIP

Transcriber's signature kimberly Nip

Date 3/16/13

## Appendix J: Interview Guide

### Sensory Processing Disorder Research Study

#### Part One: Personal Experience with Sensory Processing Disorder and Sensory Over-Responsiveness

1. How did you first learn or realize that you had Sensory Processing Disorder? How did you first learn or realize that you were Sensory Over-Responsive? How old were you at the time?
2. Do you see SOR in your siblings? Parents?
3. What do the terms: Sensory Processing Disorder and Sensory Over-Responsiveness mean to you?
4. Can you tell me how your body and senses feel as a result of your Sensory Processing Disorder and Sensory Over-Responsiveness?
  - a. Have these feelings changed over time? If so, how?
  - b. Probe on eating habits, sleeping habits, motion sickness, watching visuals in movies, intuitive sense, potty training, cutting, interesting habits/quirks that you may have that you think may or may not be associated with sensory?
  - c. What senses are most challenging today? And overall, what is most challenging about being a sensory sensitive person?
  - d. What is most rewarding about being a sensory sensitive person?
5. Can you describe what it has been like for you to live with Sensory Processing Disorder?  
*(Additional probes, if needed)*
  - a. How has it affected, if at all, your performance in school? Talk specifically about the various schools that you may have attended....
  - b. How has it affected, if at all, your work life?
  - c. How has it affected, if at all, your relationships with your primary caregivers or family members – do you feel that your parents and family were supportive of your sensory needs growing up? Please elaborate....
  - d. How has it affected, if at all, your relationships with your friends?



- e. How has it affected, if at all, your relationships with your significant other, if applicable?
  - f. How has it affected if at all your physical health?
6. What types of changes have you had to make, if any, as a result of your sensory processing issues? (e.g. *You avoid places that may be too loud like a crowded restaurant or you avoid visually-stimulating environments*)
  7. Do you think you grow out of SOR or just learn adaptive skills?
  8. How have you learned to take care of your sensory needs? (or, how do you know when you are in your “just right” zone of arousal/stimulation) – what works to get you there? (e.g. quiet time, napping, massage, acupuncture, meditation, exercise, special stuffie or blankie)
  9. As a child or adolescent, did any of the following apply to you? What 3 words would parents use to describe you as a child/adolescent? If yes, for how long did you experience this behavior or condition? How were you described as a baby? Do any particular stories or memories stand out from a sensory perspective?
    - a. Aggressive behavior– physically injurious or harmful behavior toward others
    - b. Feeling withdrawn – did not initiate contact with others
    - c. Feeling isolated – liked to be alone most of the time
    - d. Feeling depressed – lack of energy or interest in life
    - e. Feeling anxious – uneasy and worried
    - f. Having low self esteem – a below average opinion of yourself
    - g. Inflexible behavior – unwilling to change or compromise
    - h. Difficulty concentrating or focusing
    - i. Other- please elaborate

What did those behaviors look like? What memories do you have around these behaviors? What memories do your parents have around these feelings?

10. Currently, do you exhibit any of the following behaviors or conditions? If yes, ask them to put on a scale from 1-10...and how that might compare to child or teenager. What 3 words would spouse/best friend use to describe you today? Would you consider yourself an introvert or extrovert? Intuitive?
  - a. Aggressive behavior– physically injurious or harmful behavior toward others
  - b. Feeling withdrawn – did not initiate contact with others
  - c. Feeling isolated – liked to be alone most of the time
  - d. Feeling depressed – lack of energy or interest in life

- e. Feeling anxious – uneasy and worried
  - f. Having low self esteem – a below average opinion of yourself
  - g. Inflexible behavior – unwilling to change or compromise
  - h. Difficulty concentrating or focusing
  - i. Other- please elaborate
11. Do you believe that these challenges are associated with having Sensory Over-Responsiveness, why or why not?
12. What do you say to people when you want them to understand your sensory issues?
13. What do you want others to know about what it has been like to live as an SOR adult? (Use as closing question)

### **Part Two: Sensory Integration Treatments**

14. What types of treatments have you engaged in to treat your Sensory Over-Responsiveness? (Occupational therapy, Speech language therapy, Feeding therapy, Nutrition therapy, Brain integration, Mental health treatment and/or counseling, Other) – Massage/Acupuncture/Meditation – what makes your sensory stuff feel better??
- a. For each type of treatment – please explain for how long each treatment was conducted, and if concurrent with other therapies - which ones. *(For example, did you have occupational therapy and speech language therapy at the same time? If so for how many months was it concurrent? How long was the total therapy?)*
15. Which, if any, of the therapies do you feel improved your **physical** symptoms of Sensory Over-Responsiveness?
- a. Of those treatments that improved your physical symptoms of Sensory Over-Responsiveness, what specifically felt different about yourself as a result of treatment? *Probe as needed.*
  - b. Of those therapies that you felt didn't work, why do you say that?
16. Which, if any, of the therapies do you feel improved the **social or emotional** challenges associated with Sensory Over-Responsiveness? *(e.g. some people report feeling aggressive, withdrawn, isolated, depressed, anxious, low self esteem, inflexible, difficulty concentrating or focusing.)*
- a. Of those treatments that improved your social and emotional symptoms of Sensory Over-Responsiveness, what specifically felt different about yourself as a result of treatment? *Probe as needed.*
  - b. Of those therapies that you felt didn't work, why do you say that?