2016-6

Sensory processing disorder, invalidating childhood environments, and mental health outcomes in adulthood

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Recommended Citation

Ross, Emma, "Sensory processing disorder, invalidating childhood environments, and mental health outcomes in adulthood" (2016). Masters Thesis, Smith College, Northampton, MA.
https://scholarworks.smith.edu/theses/1765

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Sensory Processing Disorder,
Invalidating Childhood
Environments, and
Mental Health Outcomes
In Adulthood

ABSTRACT

This study examined the interpersonal and mental health outcomes of children

with sensory processing difficulties or Sensory Processing Disorder (SPD). SPD occurs

when the ways in which we interpret sensory input in over-sensitive or under-sensitive

ways. This can create a variety of difficulties, including impairment in the areas of touch,

taste/smell, auditory, visual, proprioceptor, vestibular, and activity level/emotional

reactivity. Previous studies have focused on the biological underpinnings of SPD,

however few have looked at the interpersonal relationships of children with sensory

processing difficulties as well as the mental health outcomes as those children mature

into adults.

Methods: This mixed methods study employed snowball and convenience sampling

methods via an online, English language survey. Participants identified which sensory

symptoms they experienced as a child, whether or not they have a mental health

diagnosis, and assessed their childhood interpersonal relationships with

parents/caregivers, teachers, and peers using a modified version of the Invalidating

Childhood Environment Scale (ICES).

Findings: There were several statistically significant results. Participants with a greater

number of sensory processing symptoms were more likely to have a mental health

diagnosis ($t(166)=3.108$, $p=.002$, two-tailed). A moderate, positive correlation was found

between number of sensory processing symptoms and level of invalidating environment (r =.578, p=.000). Participants with a greater number of sensory processing symptoms were more likely to have grown up in an invalidating environment (t(158)=3.668, p=.000, two-tailed). These results indicate a need for more psychoeducation for parents/caregivers and teachers, as well as additional treatment interventions for children with SPD.

SENSORY PROCESSING DISORDER, INVALIDATING CHILDHOOD

ENVIRONMENTS, AND MENTAL HEALTH OUTCOMES IN ADULTHOOD

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June 2016

ACKNOWLEDGEMENTS

My sincerest thanks to the following for their help, guidance, and support throughout this process:

Rob Eschmann
Jill Harvey
Aviva Jacobstein
Jean LaTerz
Gael McCarthy
Dennis Miehls
Victoria Mountford
Diane Philipp
Marjorie Postal
Mariel Stadick
Ellen Yack
Sally Wright
The York University PCS Intern Cohort 2015-2016

My parents, Eileen Steinberger and Don Ross
My brother and sister-in-law, John and Lauren Ross

Thank you to the participants in this study for sharing your experiences.

This thesis is dedicated to my husband, Nate Gilmore – you helped in every way imaginable, but most importantly, you kept me laughing, as you always do.

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CHAPTER I

Introduction

This study examines the impact of sensory processing difficulties on childhood development, particularly in terms of interpersonal relationships with parents/caregivers, teachers, and peers. This study also explores how sensory processing difficulties and invalidating or unsupportive childhood environments (as defined by the participants) impact mental health outcomes as these children develop into adults. This was achieved through surveying adults, asking them to reflect on their sensory processing difficulties in childhood, as well as how the adults and peers in their lives responded to their sensory needs. This introductory chapter explores a case study describing the impact of sensory processing difficulties, defines sensory processing difficulties and sensory processing disorder (SPD), and discusses some of the relevant literature around how sensory processing difficulties manifest in children at the biological, social, and psychological levels.

For my first Master's of Social Work placement, I interned within an interdisciplinary team working with preschoolers and their families. We did attachment-based psychological assessments and treatment interventions. These children presented with a variety of issues such as difficulty sitting still in school or at daycare, violent outbursts, and separation anxiety, among others. During that year and with the guidance of our clinical lead, I became aware of a variety of sensory sensitivities that the children exhibited. Taylor, a fictional young girl I discuss below, is a classic example of many of the cases I witnessed.

Taylor is a two-year-old girl who loves story time, drawing, and petting the family dog. Taylor is also currently on the brink of being kicked out of daycare due to her behaviour towards other students, which is described by staff as "aggressive" and "violent." Taylor will oftentimes punch or kick other children if they get close to her, seemingly unprovoked by anything the other child said or did. Taylor's parents also struggle with managing her behaviour at home, as Taylor objects to routines such as bathing and dressing. When forced to bathe, particularly if her hair needs to be washed, Taylor will throw tantrums. If her clothes are made out of denim or wool, she will shriek, frightening her parents and her older sister, Annie. Taylor hates being in loud environments, including going to the movies or being in large crowds, and when exposed to such situations she will often hold her hands over her ears and cry. Taylor is also an exceptionally picky eater, making meal times another area of contention for the family. While their paediatrician, family, and friends reassure Taylor's parents that oppositional behaviour is normal in a two-year-old, Taylor's parents feel overwhelmed by her behaviour and worry that about that this is not "just a phase." Taylor's parents find themselves having less and less patience for her antics, and often reflect on how Annie was such an easy child in comparison to Taylor.

While Taylor's situation may sound like a case of the "terrible twos," many professionals would recognize Taylor's symptoms as indicative of sensory sensitivities and potentially a Sensory Processing Disorder (SPD). The SPD Foundation defines the disorder as "a condition that exists when sensory signals don't get organized into appropriate responses" (SPD Foundation, 2016). They go on to describe how "A person with SPD finds it difficult to process and act upon information received through the senses, which creates challenges in performing countless everyday tasks. Motor clumsiness, behavioral problems, anxiety, depression, school failure, and other impacts may result if the disorder is not treated effectively" (SPD Foundation,

2016). We interpret sensory information constantly, adjusting our behavior to fall in line with our understanding of various sensory input (e.g. we have the awareness to avoid obstacles in our path such as tables, chairs, or other pedestrians; we hug someone at a pressure that feels comforting without squeezing so hard as to hurt them; etc.). When sensory input feels overwhelming or underwhelming, we also have automatic processes that help us adjust (e.g. we place our hands over our ears when a siren passes; we take a walk and stretch our legs when we notice they become stiff; etc.). If our sensory processing capabilities went offline, the world could become extremely loud or far too silent, bright to the point of being unable to see, or we could wake up with unexplained bruises from walking into objects, among many other outcomes that would make it difficult to impossible to function.

Ahn, Miller, Milberger, and McIntosh (2004) performed a study to determine the prevalence of SPD within a "typically developing" population, finding that somewhere between 5.3% and 13.7% of children meet the criteria for SPD (p. 287). The fact that this many children who have not been otherwise identified as having Autism Spectrum Disorders (ASD) or Attention-Deficit-Hyperactivity-Disorder (ADHD) qualify as meeting the criteria for SPD is alarming considering the lack of current awareness about SPD and the potential severity of the difficulties children face while struggling with SPD. Furthermore, Ahn et al. (2004) cite other studies that have explored SPD in populations of children with another known disability, discovering that the rates of SPD "are reported to be as high as 40%-88%" (Adrien et al., 1993; Dhalgren & Gillberg, 1989; Kientz & Dunn, 1997; Ornitz, Guthrie, & Farley, 1977; Talay-Ongan & Wood, 2000; as cited in Ahn et al, 2004, p. 287). Clearly whether children have known disabilities or not, SPD impacts a large portion of the population and there is little-to-no education or support around sensory processing difficulties.

In the case of Taylor, she experiences sensory sensitivity (e.g., feeling pain and extreme discomfort through light touch such as bathing or wearing certain fabrics), however other individuals may experience sensation seeking behaviours (e.g., crashing into others), and some may experience a combination of the two. These ends of the SPD spectrum may referred to as a child being hyper-sensitive or hypo-sensitive to sensory input, but may also be referred to as being Sensory Over-Responsive (SOR), Sensory Under-Responsive (SUR), and there is a potential third category of Sensory Craving (SC) (Walbam, 2013; SPD Foundation, 2016). While the symptoms that a person with SPD may experience vary dramatically, there is evidence that those with SPD present with similar neurological markers (Chang, Owen, Desai, Hill, Arnett, Harris, Marco, & Mukherjee, 2014; Owen, et al., 2013).

In spite of compelling evidence about brain structure and SPD, there is still scepticism among members of the mental health community as to whether or not SPD should be given its own diagnosis (American Academy of Pediatrics (AAP), 2012). The recent release of the DSM-V redefined many diagnoses, including ASD, ADHD, schizophrenia, bipolar disorders, and depressive disorders, among others (American Psychiatric Association, 2013). Occupational therapists and other mental health professionals fought to get SPD included in the DSM-V as a stand-alone diagnosis. The benefits of a diagnosis being included in the DSM are undeniable, including insurance coverage for treatment, access to funding for research, and an increase in psychoeducational resources. As Wittchen states while discussing the pros of the DSM-V: "Ensuring common procedures and a common language regarding diagnostic labels, definitions, and rules allows improved communication and is regarded as the essential basis for and the link between research, education, everyday practice, and the healthcare system." (Rief & Martin, 2013, p. 283). Those fighting for SPD to be included in the DSM-V did not meet their goal, with

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opponents arguing that SPD describes a set of symptoms inherent in ASD or ADHD rather than its own unique classification (Ahn, 2013, p. 2). Similar arguments were put forth for exclusion from the DSM-IV (Ben-Sasson, Carter, & Briggs-Gowan, 2009, p. 706).

Many argue that the DSM-V chose wrongly to not include SPD, and there is some compelling research to support this theory (Chang et al., 2014; Owen et al., 2013). This research explores the neurological differences between SPD and ASD, and has found differences in brain functions based on these two diagnoses. A study by Chang, Owen, Desai, Hill, Arnett, Harris, Marco, and Mukherjee (2014) found that, while children with ASD and SPD function similarly in terms of sensory processing, their brains register social and emotional interactions differently. This lack of recognition contributes vastly to the challenges children with SPD face, including an absence of resources and rampant misinformation spreading amongst mental healthcare and healthcare providers about treatment procedures for sensory processing difficulties (Chang et al., 2014, p. 1). In addition, the relative scarcity of information about SPD contributes to decreased empathy towards children who exhibit signs of SPD, as they are solely recognized as having behavioral issues (placing the blame on the child) rather than a disorder (phenomenologically holding the child) (Rass, 2003 p. 288).

While several studies examine the brain structure and functioning of children with SPD, few look at the interplay of this biological function within the context of interpersonal relationships. The few studies that do look at attachment or interpersonal relationships of children with SPD find they experience greater struggles than their peers (Gourley, Wind, Henniger, & Chintz, 2012; Carter, Ben-Sasson, & Briggs-Gowan, 2012). As Liss, Timmel, Baxley, and Killingsworth (2005) state: "highly sensitive people are not necessarily prone to more negative emotional states, but that they may be more sensitive to negative parental

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environments" (Aron & Aron, 1997 as cited by Liss et al., 2005, p. 1430). This study implies that children with SPD are particularly vulnerable to interpersonal strife. There is also evidence in other studies that psychoeducation and sensory interventions could greatly enhance the parent-child dyadic relationship. As Cohn, May-Benson, and Teasdale (2010) state: "Parents of children with SPD have reported challenges…and that understanding their children's behavior from a sensory processing perspective has contributed to their parental sense of competence" (p. 172). I posit that this could hold true across multiple interpersonal relationships, including with teachers, school administrators, and peers.

If research regarding interpersonal difficulties and SPD is lacking, there is an even greater dearth of research that examines the mental health outcomes of children with SPD. There is, however, evidence that suggests that there is a greater risk of psychological difficulties arising throughout childhood (Liss et al, 2005; Brindle et al, 2015; Koenig & Rudney, 2010; Rass, 2003). While there is some limited literature on the mental health status of children as they struggle with SPD, there is even more limited research looking at the mental health outcomes as these children mature into adulthood. The study by Liss et al. (2005) noted: "Sensory processing sensitivity was strongly related to anxiety…Sensory processing sensitivity appears to be appears to be an independent risk factor for the experience of psychological distress above and beyond parental experiences" (p. 1437). Clearly the psychological impact of SPD needs to be further explored in order to determine how SPD affects an individual in terms of the biological implications, interpersonal relationships, and psychological wellbeing throughout the lifespan.

Current Study

This study examines the interpersonal relationships in childhood and mental health outcomes in adulthood of individuals with sensory processing difficulties or Sensory Processing

Disorder (SPD). The survey encouraged individuals to reflect on their own childhood experiences with sensory processing as well as their childhood relationships with caregivers, teachers, and peers. The research presented combines the biological component of sensory processing, the psychological component of mental health diagnosis, and the social component of interpersonal relationships. This provides a more thorough and complete picture of what children with SPD face and what life with SPD looks like beyond the neurobiological level. This study seeks answers about the concrete implications of SPD and hopes to begin to answer the questions that individuals with SPD and their loved ones have grappled with for years.

Sensory processing difficulties have the potential to impact all aspects of a child's life, including their relationships with parents/caregivers, teachers, and peers. Sensory sensitivities could be the reason for children struggling to listen in class, having tantrums at bedtime, refusing hygiene routines, being uncoordinated in gym class, as well as expressing shyness and/or anxiety. These are the kinds of behaviors adults may pathologize, label with diagnoses, and medicate. These are also the kinds of behaviors that children may ridicule and bully. While sensory sensitivities are clearly not the only cause of these issues, considering that somewhere between 5.3%-13.7% of children in the U.S. are recognized as experiencing sensory processing difficulties, it seems likely that it plays a role in the ways children struggle, and understanding these sensory processing difficulties may also be the key to creating effective interventions to help them succeed (Ahn et al, 2004).

CHAPTER 2

Literature Review

The current literature on Sensory Processing Disorder (SPD), though relatively scarce, demonstrates that children with SPD experience difficulties in all realms, including at home, school, and with peers. As Gourley, Wind, Henninger & Chinitz (2012) state: "children with poor sensory regulation demonstrate a wide variety of difficulties across many domains including externalizing behaviour problems, internalizing behaviour problems, difficulties in emotional and attention regulation, and difficulties in many daily activities" (p. 913). While the research on SPD is limited, it is critical to social workers as they engage with children in schools, child protective services, agency settings, and therapeutic milieus (Walbam, 2013). Social workers need to have more information about SPD and how it may create difficulties for children in these and other settings. As Walbam (2013) states, "Since up to three million children in the United States have SPD, social workers are likely already in contact with these children, whether or not they know it" (p. 62). I posit that, likewise, social workers engage with those children who were impacted by SPD when they grow up to become adults, whose experiences with SPD possibly contribute to the development of other mental illnesses. Understanding the specific ways in which SPD impacts child development and relationships in childhood is paramount to viewing clients of any age through a phenomenological, biopsychosocial lens.

This literature review explores the work that has been done so far, examining how children with SPD develop and the biological, social, and psychological implications of SPD

across the lifespan. This chapter is divided into six sections. The first section discusses the

biological implications of SPD, the second the social implications, and the third the

psychological implications. The fourth section focuses specifically on attachment, invalidating

environments, and SPD. The fifth section examines how sensory processing difficulties co-occur

with other mental health illnesses including Autism Spectrum Disorder (ASD), as well as the (ill-

advised) decision to exclude SPD from the DSM-V. In the sixth section, I look at the parallels

between experiences of SPD and the construct of ableism.

Biological Implications

Clinicians primarily understand sensory integration as being rooted in biological

processes, as "the organization of sensation for use…[t]he brain locates, sorts, and orders

sensations" (Ayres, 1983, p. 5). The initial development of our sensory processing capabilities

takes place in utero. As Mitchell, Moore, Roberts, Hatchel, and Brown (2015) state in their

review of the literature on the neurological implications of SPD, "The majority of neurosensory

development usually occurs in the last 16-20 [weeks] of gestation. Premature birth could

therefore preclude much of the typical development of sensory systems that occurs in utero,

resulting in difficulty processing sensory input and in one or more types of SPD" (Graven &

Browne, 2008; as cited in Mitchell et al., 2015, p. 2). This clearly points to a neurobiological

root of our sensory processing capabilities. Responding to the biological implications of SPD,

studies have begun to explore the brain function and structure of children with SPD compared to

typically developing children, finding distinct neurobiological markers using EEG technology

(Yeo et al., 2003; Schaaf et al., 2010; Davies & Gavin, 2007; Gavin et al., 2011; as cited in

Gourley et al., 2012, p. 913). Another study by Owen, Marco, Desai, Fourie, Harris, Hill, Arnett,

& Mukherjee (2013) confirmed differences at the neurological level, focusing on white matter in

the brain. This study determined that children with SPD have differences in brain structure, primarily "reduced posterior white matter microstructural integrity…[this] correlates directly with the atypical sensory behaviour" (Owen et al., 2013, p. 850). These studies confirm that neurological differences directly impact a person's sensory input function. In addition, it is well understood that these neurological differences impact a child's emotional experience of certain situations. As Walbam (2013) states: "the limbic system takes the sensory experience of being hugged…and attributes emotion to that experience. A child who is hyper-sensitive may experience a hug as painful or frightening, while a hypo-sensitive child may experience the same hug as insufficient" (p. 64).

These neurobiological studies that examine SPD are surely valuable, however the dominance of this single view fails to fully capture the picture of SPD. There are many reasons why this is problematic, not the least of which is that it limits our ability to treat SPD as the complex disorder that it is, one that is constantly evolving throughout the life of the child. As Mitchell et al. (2015) cited: "Wickremasinghe and colleagues (2013) noted a trend toward increasing frequency of atypical Sensory Profile scores with increasing age; therefore, they argued, SPD may increase in severity or become more evident as children age" (p. 9). The fact that SPD changes across a person's lifespan leaves questions of what additional factors other than biology play a role in how our sensory processing capabilities shift over time. Furthermore, this begs the question: what does SPD grow into over time? To better understand SPD, we must examine it through a biopsychosocial framework, taking into account how a child's neurological wiring interacts with the environment and the outcomes this creates.

Social Implications

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Socializing and play in children has been shown to be of the utmost importance for a variety of reasons. As Russell and Lester (2010) state, "Play is about creating a world in which…children are in control and can seek out uncertainty in order to triumph over it…In this way, children develop a repertoire of flexible responses to situations they create and encounter" (p. x). Children with SPD, however, demonstrate a number of differences in terms of the ways that they choose to or are able to play. Cosbey, Johnston, and Dunn (2010) did a study that examined the differences in terms of how children with and without SPD play, finding a number of differences, including that "[children with SPD] reported that most of their social activities took place with immediate family or alone, unlike their peers, who reported more involvement with extended family and friends" (p. 470). More research needs to be done on why this difference exists. Is it that certain types of play (e.g. where children are up and moving versus sitting still) are more comfortable or enjoyable for children with SPD? Or is it that children with SPD are ostracized from their others and therefore have a smaller social world? Walbam (2013) notes: "[stimulus seeking or avoiding] behaviours may be distracting to the child and others, and may impact important social or learning experiences"(p. 65). While Cosbey et al. (2010) demonstrate the differences of the play style and preference of children with SPD, their recommendations are problematic, such as when they state: "Children with SPD should be encouraged to identify peers who demonstrate similar play preferences (e.g. active versus sedentary play) and similar activity preferences to facilitate positive interactions by minimizing the differences between the children's play behaviours" (p. 470). While children are likely to self-select into groupings that promote this concept, facilitating the isolation of these children away from certain peers limits the social world of the child with SPD instead of expanding it. The child with SPD may be left out of play often and, as Cosbey et al. (2010) state: "The

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persistent absence of play may disrupt emotion-regulation systems, which in turn will diminish children's physical, social and cognitive competence"(p. x). Another solution could be to incorporate sensory interventions that allow children with SPD to play comfortably when possible in both active and sedentary play settings. This would be valuable both for children with SPD and those without, teaching tolerance for multiple ways of playing and encouraging a different set of interpersonal skills. Currently, however, as Koenig & Rudney (2010) note: "The studies provide evidence to suggest that children with difficulty processing and integrating sensory information show decreased quality and quantity of play skills and social participation" (p. 432).

In addition to the ways that SPD may impact a child's socialization with peers, it also has an impact on their performance in school settings. As Cosbey et al. (2010) state: "Identification of SPD is generally through observation of behavioural difficulties such as responding to touch aggressively, withdrawing from or failing to respond to sensory input, and seeking out additional sensory input through hyperactivity"(p. 463). These sorts of behaviours correlate in the school environment to children who "make noises, fidget, touch things or people, and act impulsively" (Walbam, 2013, p. 65). Based on the standardized curriculum that most children are exposed to, these kinds of the behaviours have little space in a classroom and children who behave this way will likely be labelled "troublemakers" and struggle to meet the learning expectations of their peers. Maxam and Henderson (2013) explored the attitudes of teachers in a Northeastern high school towards students with invisible disabilities similar to SPD, finding that "most of the teachers feel ill-equipped to handle these students in their already overcrowded classes and insist that valuable class time is often 'wasted' tending to the needs of these students" (p. 74). When educators recognize that they view spending time and energy on students with specific needs as

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"wasted" time, this suggests that they are struggling to maintain empathy and compassion for these students, and this, in turn, impacts student performance. As the literature reviewed by Koenig & Rudney (2010) states: "children and adolescents with difficulties processing and integrating sensory information showed lower participation in school activities; children from diagnostic groups associated with difficulties processing and integrating sensory information demonstrated decreased academic achievement and attention and were at a higher risk for learning difficulties"(p. 436-7). While the ways that children are socialized in both school and peer settings play an important role both in their experiences of sensory processing, the question still remains how the interaction of a neurobiological phenomenon with social implications impacts a child psychologically.

Psychological Implications

The literature indicates that SPD impacts emotional processing in and of itself, in addition to the stressors brought on by lacking ability or comfort in participating in normative childhood activities. Brindle, Moulding, Bakker & Nedeljkovic (2015) state: "Research suggests that individuals who are sensitive to sensory stimuli are more likely to experience negative psychological symptoms such as depression, trait and state anxiety, and stress" (Aron & Aron, 1997; Bakker & Moulding, 2012; Liss, Timmel, Baxley & Killingsworth, 2005; as cited in Brindle, et al., 2015, p. 214). Brindle et al. (2015) note that it is unlikely that the cause of these negative psychological symptoms is rooted in the neurobiological differences of those with SPD, but rather that it is a result of the environment (Liss et al., 2005; as cited in Brindle et al., 2015, p. 214-5). They go on to posit that increasing emotion regulation skills in children with SPD could mediate the impact of negative psychological symptoms including depression, anxiety and stress (Brindle et al., 2015, p. 215). Koenig and Rudney (2010) succinctly address how

children's SPD may impact them, stating: "For children with deficits in motor planning and coordination, their participation in school and play activities is compromised, which has implications for social and emotional well-being" (Koenig & Rudney, 2010, p. 437). Walbam (2013) also recognized the psychological impact of SPD, stating: "Children with SPD may feel discouraged, depressed, or anxious. The child may have a poor self-image, and may feel that they are unable to have fun like their peers" (p. 67). Rass (2013) specifically explored the impact of sensory processing difficulties on children's self esteem. In addition to poor self-esteem, we see other psychological implications resulting from certain traits of SPD, including that "physical coordination difficulties were significantly related to loneliness" (Koenig & Rudney, 2010 p. 432).

While we can summarize the psychological consequences of SPD at the peer and school level easily, more complex are the difficulties that arise in the parent-child attachment relationship as a result of SPD. Parenting a child with SPD raises unique issues for the parent and, as Rass (2003) states: "These children [with sensory processing difficulties] cannot use their parents as empathic selfobjects because these parents cannot sufficiently mirror and offer adequate selfobject experiences and, therefore, cannot be used as idealizable selfobjects" (p. 302). Understanding how the parent-child relationship is impacted by SPD is of the utmost importance to understanding the full scope of how SPD impacts a child psychologically.

Attachment Style, Invalidating Environments, and SPD

An important component of lifelong psychological health is attachment style. Or, as Bowlby (1997) stated: "the ability to establish attachments to other persons (either in the role of the person seeking support and comfort, or of the person providing both of these), is regarded as a fundamental characteristic of an effectively functioning personality and of psychic health"

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(Bowlby, 1997, p. 20 as cited in Kurth, 2013, p. 16). These early parent-child relationships are often centered around sensory-based interactions, including touch (e.g. cuddling and rocking), nursing, visual stimuli (e.g. mirroring infant affect), and sound (e.g. cooing). If a child does not respond positively to these interventions it can have deleterious effects on parental feelings of bonding and competence (McGeorge, Milne, Cotton, & Whelan, 2015; Cohn, May-Benson, & Teasdale, 2010). As Cohn, May-Benson, and Teasdale (2010) state: "The variability and unpredictability of behaviours of children with SPD may be frustrating for parents and contribute to their decreased parental sense of Satisfaction…it is understandable that parents may feel less satisfied because the social value of their parental role is vulnerable." (p. 179). Likewise, sensory intervention may be indicated for parents and infants who are struggling with sensory processing in the context of attachment. As McGeorge et al. (2015) state: "Helping mothers understand their infant's sensory processing and the interaction with their own sensory processing may provide a nonjudgmental and practical focus for therapeutic interventions" (p. 284). The evidence of attachment theory and parental reflective functioning indicates that these beginnings of an insecure attachment will resonate across a child's lifetime (Katznelson, 2014, p. 115). While I theorize that sensory processing difficulties will have an impact on a child's attachment style towards their parent and vice versa, there is limited literature that focuses directly on this topic.

Some studies, however, have begun to examine the link between attachment style and SPD, including the study by Jerome & Liss (2004), where they hypothesized that "sensory processing style may be one temperamental component of attachment style" (p. 1343). They also discuss how sensory processing challenges may contribute to how children interact in the world, with sensation-seeking children longing for relationships and sensory-sensitive children

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coming across as shy (Jerome & Liss, 2004, p. 1343). In spite of an understanding that these children interact with the world and that conceptualizing SPD solely as a biological phenomenon is inadequate, minimal research has been done to explore the interactions with caregivers, teachers, and peers. These findings by Jerome and Liss (2004) indicate that those with sensory sensitivities have anxieties in the context of relationships, whereas those with sensory seeking behaviours were more likely to seek emotional support and want to vent emotions (p. 1350). This study is promising and examines this previously unexplored interaction; however, they endorse that much more research is needed to draw conclusions.

The impact of being raised in an invalidating environment correlates with the development of eating disorders, depression, anxiety, and Borderline Personality Disorder (Haslam et al., 2007; Liss et al., 2005; Linehan, 1993). Given these well-documented correlations, it stands to reason that invalidating environments, whether real or perceived by the sensitive child with SPD, are a risk factor in terms of developing mental illness in later life. This notion is particularly important in the context of sensory processing, as the child's sensory experiences may appear unsubstantiated by the parent or caregiver, but feel exceptionally real to the child. Likewise, the environment may feel warm and nurturing to the parent, but may be lacking the necessary attunement to sensory needs the child requires for the development of a secure attachment.

If a correlation exists between SPD, invalidating environments, and later psychological distress or mental health diagnosis, preventative measures could be put in place with families where children have SPD. Liss et al. (2005) have explored sensory processing and how it interacts with or adds to negative parenting styles, stating: "Sensory processing sensitivity was strongly related to both depression and anxiety and contributed unique variance above and

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beyond parental factors for both forms of psychological distress" (p. 1438). The interaction

between parenting style, SPD, and mental health outcomes in adulthood seem evident; however,

the Liss et al. (2005) study looks at parents who are described as providing "cold and uncaring"

environments rather than invalidating ones (p. 1438). The difference between neglectful and

uncaring environments and invalidating environments is an essential distinction in this research,

as one implies malintent, while the other phenomenologically holds the family. I operationalize

invalidating environments as coming from a place of misguided reassurance (e.g. "you're okay,

I'm only touching you lightly") rather than from a more insensitive place (e.g. "there's no way

this hurts, you're way too sensitive"). This distinction depathologizes parents who invalidate,

and it is more akin to how microaggressions erode a person's sense of self slowly over time.

Co-Occurring Mental Illness and the DSM-V Debate

Much of the research surrounding sensory processing difficulties focuses on sensory

processing as a part of ASD. The reasons for this are manifest, given that individuals with ASD

often present with sensory processing difficulties and benefit from sensory-based interventions.

As Schaaf, Toth-Cohen, Johnson, Outten, and Benevides (2011) state: "It is estimated that over

80 percent of individuals with autism demonstrate behaviors that may be related to poor sensory

modulation" (p. 374). While the research on Autism provides some insight into how our sensory

processing capabilities impact our interactions with the world, assuming that sensory processing

difficulties are a symptom of ASD leaves a large gap in the research. Given the prevalence of

sensory processing difficulties in individuals with ASD, it makes sense why clinicians would

make the false assumption that sensory processing is solely a symptom of ASD or other

developmental disabilities. This logic led to the exclusion of SPD as a distinct diagnosis in the

DSM-V. The reason behind this exclusion is that SPD is not its own distinct category and is best

designated as a symptom of other developmental disorders, such as ASD. Even the American

Academy of Pediatrics (AAP) released this statement: "the [AAP] recommends that pediatricians

not use sensory processing disorder as an independent diagnosis. When sensory problems are

present, health care providers should consider other developmental disorders, including autism

spectrum disorders, [ADHD], developmental coordination disorder and anxiety disorder" (AAP,

2012). One journalism article by Beth Arky sums up the concerns, noting: "The mental health

establishment doesn't acknowledge SPD as a distinct disorder because it isn't convinced that

SPD is the best possible way to understand, and approach, those symptoms. And it's dissatisfied

with evidence that the treatment gets real, measurable results" (Arky, The Child Mind Institute,

2016). This appears to me to be a chicken-egg situation: if SPD was a discrete diagnosis, SPD

organizations would receive more funding to research and find evidence (which occupational

therapists who work on the front lines most closely with SPD believe exists) to support the

assertion that SPD is unique. However, the fact that there is no diagnosis leads to there being

limited funding with which to find the evidence that the medical community requests to make

SPD a distinct diagnosis.

The occupational therapy community recognizes sensory integration challenges as a

distinct diagnostic category and one that has real implications for the children who are impacted

by it, including associations with insecure attachment relationships and as a response to

childhood trauma (American Occupational Therapy Association, 1987; Champagne, Koomar &

Olson, 2010). Miller, Anzalone, Lane, Cermak, and Osten (2007) note that diagnostic manuals

other than the DSM-V chose to include SPD as a unique diagnosis with sub-classifications,

including the Psychodynamic Diagnostic Manual, the Diagnostic Manual for Infancy and Early

Childhood, and the Diagnostic Classification of Mental Health and Developmental Disorders of

Infancy and Early Childhood, Revised (p. 135). The Diagnostic Classification of Mental Health and Developmental Disorders of Infancy and Early Childhood was developed because "Existing classification systems, such as the [DSM] provided insufficient coverage of syndromes of early childhood that needed clinical attention. Nor did DSM pay adequate attention to the developmental features of mental health disorders that are typically first diagnosed in infancy and early childhood" (Zero to Three, 2005, p. 36). This manual includes multiple classifications of sensory processing difficulties, including sensory seeking/impulsive, sensory food aversions, and regulation disorders of sensory processing (Zero to Three, 2005, p. 37). Sensory processing difficulties are more often documented in children than adults, and it seems likely that diagnostic manuals whose sole focus is on children and are developed by children's mental health practitioners would pay more attention to sensory processing as a distinct category (Ahn, 2013, p. 4). While the fight to be included in the DSM-V may be over, among mental health communities in which sensory processing is considered a diagnosis (e.g. children's mental health practitioners, occupational therapists, etc.) it continues to be a source of debate as to how further classification should occur. Miller et al., (2007) propose a multiple categories, delineating the difference between hyper-sensitive (Sensory Over-Responsive or SOR), hypo-sensitive (Sensory Under-Responsive or SUR), and Sensory Seeking/Craving (SS); while other components of their proposed diagnostic categories include multiple disorder classifications such as Sensory Discrimination Disorder (SDD), Sensory-Based Motor Disorder (SBMD), and Sensory Modulation Disorder (SMD) all as distinct categories with different treatment needs and recommendations (Miller et al., 2007, p. 137).

In spite of this support and the research that is going into understand SPD in increasing levels of complexity, the DSM-V continues to hold considerable weight in the U.S. mental health

community and leaving SPD out was a mistake that heavily impacts the lives of children and their families. There is compelling evidence to support that other diagnostic manuals chose correctly to include SPD and that the DSM-V made a significant error in the decision to exclude SPD.

As previously discussed, the research that best refutes the argument that SPD is not a distinct diagnosis focuses on the neurological differences between SPD and ASD. The study by Chang, et al. (2014) measured the white matter brain functioning of children with ASD and children who meet the criteria for SPD, but not ASD, noting differences in how these children register emotional stimuli, but similarities in how they register sensory stimuli. The implications of this misclassification, as Chang et al. (2015) state, are that "Children with SPD remain critically underserved with regard to their developmental challenges in our society due to the lack of a diagnostic label recognized in the current DSM 5 manual"(p. 1). This occurs in spite of a lack of research that targets the question of potential differences between these two populations, leading to further targeting the behaviors children with SPD display rather recognizing the source of these behaviors. The study by Owen et al. (2013) confirms that the structural differences they found in the brains of children with SPD differ from others, stating that: "From a clinical perspective, these findings suggest that children with SPD have a specific imaging biomarker for their clinical disorder…suggest[ing] that this disorder may be distinct from other overlapping clinical diagnoses, specifically attention deficit hyperactivity disorder and autism" (p. 850).

While the symptomology of SPD may appear similar to that of ASD, ADHD, or other learning or developmental disabilities, neurological evidence suggests that SPD is a distinct diagnostic category. This has serious implications for social workers. Walbam (2013) addresses

this, noting that the similar symptomology (as well as the lack of a distinct diagnostic category) "puts clinicians at risk of attributing the social, emotional, and behavioral difficulties associated with SPD to other disorders" (p. 65). Lacking a distinct SPD diagnosis has many consequences for families and children who suffer from SPD. Occupational therapy is already a treatment modality that is often not covered by insurance policies, but without a diagnosis insurance coverage becomes impossible in the U.S. and other countries.

Ableism

In talking about SPD and invalidating environments, it is essential to examine the lens through which these microaggressions occur: ableism. Ableism is described as how those with disabilities or other differences are othered in the world. As Wendell (1996) states: "if the cultural concept of the 'normal' body is a young, healthy, energetic, pain-free body with all parts present and a maximum range of graceful movement, then experiences of the negative body need not be confronted and understood. They belong to those with disabilities and illnesses, who are marginalized, not 'ordinary' people, not 'us'" (p. 91). In an ableist society, everyone is expected to be able to meet certain requirements and the child with SPD is blamed for their inability to function in a bright, loud, and painful world. The messages that children, as well as caregivers and teachers, receive is that something is wrong with the child with SPD, which would contribute to invalidation of the child's experience. Rass (2003) explores this concept as well, stating: "Children with slight disabilities, whose neurological deficiencies are difficult to detect and are undiagnosed, are considered intact and therefore experience indifference and unempathic surroundings" (p. 288). This concept of how children may experience an invalidating environment while struggling with SPD is a piece of ableism, as it is the expectation that "intact" children will have the abilities to participate in prescribed ways in their home and school

environments. Even the dedication of the seminal work on sensory integration theory by Ayres (1986) reinforces the sense of SPD as a problem lying within the child, stating "To Parents of Children with Problems and Children with Problems." By locating the problem of sensory difficulties solely in the child, the larger societal impact upon the child is negated, further eroding the child's sense of self. Maxam and Henderson (2013) look at what educators can do to improve conditions for students struggling with invisible disabilities that cause behavioral challenges in schools, stating: "The success of students with disabilities depends to a large extent on willingness and ability of their instructors to accept them and provide accessible instruction, engagement, and assessment so that they can participate more equitably" (p. 78). Reframing the problem as something that can be solved through innovative parenting and teaching methods takes the onus off the child to "fix" their neurological differences (perhaps through medication to treat behavioural difficulties) and instead approaches the situation collaboratively (Blum, 2007, p. 204).

SPD is largely an invisible disability, meaning that a person cannot determine that a child has SPD simply by a brief visual observation and the physical evidence is not readily seen (Crastnopol, 2009, p. 474). This also has implications for access to treatment, as well as empathy from others. Rass (2003) points to the concept of invisible versus visible disability, stating: "Up until recently, only people with clear handicaps in motor skills or sensory integration disorders have been receiving adequate treatment. The treatment appears to be dependent on the degree of visibility of these handicaps and/or the alertness of the environment" (p. 288). In recognizing the ways that children with SPD and their families are impacted by ableism throughout this research, we can further conceptualize the problem as lying at the societal level rather than locating the

problem in the child with SPD, or in the parenting skills of the child's caregivers, but rather as a system that currently does not adequately meet the needs of children with SPD and their families.

Summary

My research aims to examine whether or not children with SPD are at a greater risk of experiencing psychological distress or developing mental illness in later life. I theorize that children with SPD are at greater risk of having their experiences invalidated by their caregivers, and of being raised in an invalidating environment. Haslam, Mountford, Meyer, & Waller (2007) define the invalidating environment, stating: "Such an environment can be defined as one where there is a poor fit between the environment and the child's temperament, where the child's personal experiences are not validated by caregivers, and where communication of emotions is either ignored or punished" (p. 314). Given that the experiences of children with SPD fall outside of the realm of normative child development, it would follow that parents and other caregivers would naturally have less of an innate understanding and attunement for this distress.

As clinical social workers will frequently be the initial clinician working with clients struggling with SPD, it is imperative for social workers to be able to identify SPD, to have accurate information about the relational impact of SPD, as well as the long-term psychological consequences that may be associated with SPD (Walbam, 2013). If an association exists between SPD, invalidating environments, and later psychological distress or mental health diagnosis, preventative measures could be put in place with families where children experience SPD. Likewise, this research could contribute to new treatment methods for adults with psychological distress or mental illness, as incorporating more sensory-based interventions may treat underlying sensory challenges that have gone unaddressed with previous treatment modalities. Clearly the outcomes of this research are directly related to clinical social work, as it

will provide social workers with additional information and tools that could lead to preventative treatment as well as the formation of new treatment modalities.

This study offers a new way of approaching SPD, and sensory difficulties in general. In undertaking this research, I hope to further dive into the work that the field has only begun to touch upon. As Jermone & Liss (2004) state: "The construct of sensory processing could prove to be a valuable tool in assessing the risk of the development of certain psychological disorders, and in enhancing our understanding of a wide variety of psychological traits" (p. 1350-1). This study contributes to and expands upon our current understanding of SPD and how this biologically based phenomenon interacts relationally within homes, schools, and peer groups. Furthermore, while some studies have begun to examine SPD without traits of ASD present, few have examined the long-term mental health outcomes of growing up with SPD, as well as the ways in which this impacts our attachment style and other relationships, including those with caregivers, teachers, and peers.

CHAPTER 3

Methodology

This chapter describes the methodology used in this study. This study explores if sensory processing difficulties, as defined by the participant, are associated with invalidating experiences in childhood, and if these processing difficulties are a predictor for emotional or psychological stress in adulthood. Jerome and Liss (2004) noted a link between sensory processing capabilities and attachment style, while Brindle et al. (2015) focused on the correlation between sensory sensitivity and emotional or psychological distress. This study takes their work and expands upon it, looking at whether or not SPD is associated with both tenuous attachment relationships in childhood as well as a higher vulnerability towards developing mental illness in adulthood.

Research Method and Design

As there is currently limited research in this area, this is an exploratory study design. This is a mixed methods study, combining a quantitative survey and a series of text boxes in which participants have the option of writing qualitative narratives about their experiences. Curry, Nembhard, and Bradley (2009) discuss the advantages of qualitative research when they state: "Qualitative methods can be used to understand complex social processes [and] to capture essential aspects of a phenomenon from the perspective of study participants" (p. 1442). In the case of this study, giving participants the opportunity to state in their own words the prevalence or lack thereof of their experiences with sensory processing difficulties and invalidating

environments allows for further exploration of experiences with SPD, as research on this topic remains in its infancy.

The survey was completed online via Survey Monkey, so responses are anonymous and encrypted; therefore, I have no way of knowing who submitted which responses. There is evidence that "making a source anonymous encourages the individual to tell the truth and disclose sensitive personal information that they would otherwise hide" (Novak, 2014, p. 41). The hope in this anonymous survey was to both protect the participants while creating conditions under which participants felt comfortable sharing wholly truthful responses. As Novak (2014) points out as well, sometimes anonymity can have the opposite impact, leading participants to not be accountable for their responses (p. 41). In addition to having anonymity, the subject matter of the survey is relatively benign, which may increase the validity of the responses.

The survey will give participants a modified version of Yack, Aquilla and Sutton's (2015) checklist (see Appendix D for full version) to self-report which sensory processing difficulties they experienced as children (e.g. over-react to unexpected touch or avoids light touch). Permission to use and modify this sensory processing checklist was obtained from Ellen Yack, a prominent occupational therapist based in Toronto, ON. Yack uses this checklist both in her book co-written with Aquilla and Sutton, as well as in her occupational therapy practice (Ellen Yack and Associates).

This checklist is followed by a series of Likert scale questions, designed to determine how supportive the participant's environment was in relation to these difficulties in the areas of home, school, and peer groups (e.g. my caregiver helped me by teaching me ways to be comfortable even when I was experiencing challenges). This section was developed based on the

Invalidating Childhood Environment Scale (ICES) (See Appendix E for full version), developed by Mountford, Corstorphine, Tomlinson, and Waller (2007). Permission to use and modify this scale was obtained from Dr. Victoria Mountford, the principle author of ICES and a clinical psychologist based in London, UK. The ICES operationally defines invalidating environment using Linehan's (1993) work as a guide. Mountford et al. (2007) describe the invalidating environment as: "as one in which the communication of emotion is ignored or responded to negatively. Displays of negative affect or individualism are not tolerated, whilst high value is attached to being happy, never giving up, and believing in the power of 'positive mental attitude' in overcoming adversity" (p. 49). The term "invalidating environment" is a general term that has different meanings to each individual, but the ICES measures these scales via eight themes derived from Linehan's (1993) work: "ignore thoughts and judgments; ignore emotions; negate thoughts and judgments; negate emotions; over-react to emotions; overestimate problem solving; over-react to thoughts and judgments; oversimplify problems" (Mountford et al., 2007, p. 50-1).

Participants were given the opportunity to write free-form narratives about their experiences, which were coded thematically (e.g., Please reflect on how your parents responded to your sensory needs throughout your childhood). In this qualitative section, participants may have chosen to go into the specifics of what their childhood environment was like both in terms of being supportive and being invalidating to the participant. However, if individuals did not elaborate, "invalidating environments" were measured based solely on how they are operationally defined with the ICES rather than on how the participants may define their own environment.

Sample

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The criteria for participants to qualify for this study was to be over the age of 18, to be able to read and write in English, and to be able to complete a computer-based survey. The goal of the broad inclusion criteria was to have a sample large enough to encompass both the sample of interest (individuals with sensory processing difficulties or SPD), as well as a comparison group (those with no or minimal indicators of sensory processing difficulties). This comparison group will help determine whether there is a difference in the childhood experiences of people with and without sensory processing difficulties. Because of the extremely broad inclusion criteria, I used non-probability methods including convenience sampling and snowball sampling. I used social media outlets such as Facebook to advertise my study, as well as posting my survey on various mental health related forums in order to obtain enough respondents who have sought mental health treatment or have a mental health diagnosis. I requested that participants find at least one other person to send the survey to.

The survey collected demographic data to analyze as separate variables, including gender, age, socioeconomic status, and identified race and/or ethnicity. In addition to these demographic questions, participants were also asked whether or not they have ever had a diagnosis of ASD, as well as whether or not they were ever tested for ASD. The goal of these questions is to ascertain whether or not participants may have difficulties with sensory processing as a symptom of ASD as opposed to SPD. I will discuss the importance of this distinction further in the Discussion chapter. Finally, participants were asked whether or not they have sought counseling for emotional or psychological distress, and whether they have ever received a mental health diagnosis. Mental health diagnosis was another variable against which I examined differences in sensory processing difficulties and invalidating or supportive childhood experiences within three categories of interpersonal relationships (caregivers, teachers, peers).

Ethics and Safeguards

Participants were informed that the purpose of the study was to understand if there was an association between sensory processing difficulties in childhood, relationships in childhood, and the eventual development of emotional or psychological distress in later life. Participants were also informed that their participation in the study is completely voluntary and that they have the option to choose not to participate at any time until they submit their survey. Surveys are collected via Survey Monkey, meaning that all responses are anonymous and encrypted, so there is no way of determining who submitted which responses. The hope with these anonymous results is to mitigate the social desirability response set as well as protect the confidentiality of participants. However, there is still a possibility that social desirability could have impacted the following results.

Participants were given all of this information in an informed consent document (see Appendix B) after determining whether or not they qualify for the survey, but prior to answering any survey questions. Participants were informed that, by consenting to participate in the survey they were indicating that they had read and understood all of the above information including the risks and benefits of participating in the survey. Participants were advised that if they experienced discomfort they could search for a psychologist through the American Psychological Association website (www.apa.org), for a social worker through their local National Association for Social Workers (NASW) chapter (https://www.socialworkers.org/), or contact the Crisis Call Center via phone (1800-273-8255) or text (Text "ANSWER" to 839863).

Data Collection

Data was collected via online survey from February 9th, 2016 to February 28th, 2016. Requests for participation were submitted to my personal Facebook and Facebook groups I am a

member of, as well as to several mental health-based SubReddits, including those for anxiety, depression, BPD, SPD, and Mental Health. Early on in the data collection process, it became clear that many participants were not completing the survey in its entirety and appeared to become fatigued due to the length of the survey, closing out before getting to the questions about mental health diagnosis. I sought permission from the Smith College School for Social Work Human Subjects Review Committee to modify the order of the questions in order to ensure that participants who began the study were answering that crucial question (see Appendix A for HSR Committee letters of approval). Following this, participants appeared more likely to answer the necessary questions, ending with over 150 respondents who completed the quantitative portions of the survey in its entirety.

Data Analysis

Marjorie Postal, a data analyst at the Smith College School for Social Work, analyzed the quantitative data that the Survey Monkey survey gathered. The Excel spreadsheet downloaded from Survey Monkey was converted into the software program SPSS in order to analyze the data. T-tests were used to analyze whether participants with a higher mean number of sensory processing symptoms were more likely to have a mental health diagnosis. Likewise, T-tests were used to determine whether or not having a higher rating of invalidating environments was associated with having a mental health diagnosis. A Pearson correlation was run in order to determine if there was a correlation between the number of sensory processing items a person checked off and their self-report of an invalidating environment. I analyzed the qualitative findings using content analysis, searching for themes within the narrative responses. These results will be discussed in the Findings chapter, which follows.

CHAPTER 4

Findings

This study examined whether or not there is an association between sensory processing difficulties and invalidating environments in childhood and the mental health outcomes of adults. I assessed this by administering an online survey, designed to determine degree of sensory processing difficulties in childhood, level of invalidation in childhood environments (with caregivers, teachers, and peers), and the mental health outcomes in adulthood. This study found statistically significant results, demonstrating positive correlations between sensory processing difficulties and invalidating environments, as well as a significantly higher number of sensory processing difficulties in those with mental health diagnoses than without, and significantly higher self-report results of invalidating environments in participants with mental health diagnoses than those without.

The findings as described in this chapter detail the following: demographics of survey participants, including gender identity, age, race/ethnicity, and socioeconomic status; sensory processing difficulties experienced between the ages of 4-12; whether or not the participant has received a mental health diagnosis and whether or not they have been diagnosed with or tested for any Autism Spectrum Disorder (ASD) including Asperger's; and level of invalidating environment including with caregivers, teachers, and peers. Finally, this chapter details the overall correlational findings of this study.

Participant Demographics

Data was used from 292 participants (out of 360 participants who clicked on the survey), indicating an overall response rate of 81.1%. Participants had the option to not answer any given question and, as such, each question has a different number of participants who chose to complete that given question. The inclusion criteria for this survey was extremely broad (any adult over the age of 18 with the ability to complete an English language, computer-based survey). In addition, data was collected using convenience and snowball sampling methods, contributing to a skewed data sample with the majority of participants identifying as white females under the age of 35 making $40,000 dollars per year or less.

The sample had limited diversity in terms of gender identity, with the vast majority of participants identifying as female. The question of gender identity had a response rate of 55.1% with 22 (13.7%) identifying as male; 126 (78.3%) identifying as female; 3 (1.9%) identifying as transgender; 4 (2.5%) identifying as genderqueer; and 6 (3.7%) identifying as a gender that was not listed above ("other"). See Table 1.

Table 1: Demographics - Gender

Gender					
Male	**Female**	**Transgender**	**Genderqueer**	**Other**	**Total**
22	126	3	4	6	161
13.7%	78.3%	1.9%	2.5%	3.7%	

Participant age in this study trended towards younger age groups, with the majority of participants identify as being between the ages of 18-24 and 25-34. This question had a response rate of 55.1% with 47 participants (29.2%) between the ages of 18-24; 89 (55.3%) between the ages of 25-34; 17 (10.6%) between the ages of 35-44; 6 (3.7%) between the ages of 45-54; 2 (1.2%) between the ages of 55-64 and 0 (0.0%) participants over the age of 65. See Table 2.

Table 2: Demographics – Age

Age						
18-24	25-34	35-44	45-54	55-64	65+	Total
47	89	17	6	2	0	161
29.2%	55.3%	10.6%	3.7%	1.2%	0.0%	

Diversity in terms of race and/or ethnicity in this study was also limited, with the vast majority of participants identifying as white. Participants were able to "check all that apply" in terms of race/ethnicity, allowing participants who identify with multiple racial or ethnic groups to select any combination of options. This question had a response rate of 55.1% with 145 (90.1%) identifying as white; 7 (4.3%) identifying as Hispanic or Latino; 1 (0.6%) identifying as Black; 2 (1.2%) identifying as Native or Aboriginal; 9 (5.6%) identifying as Asian or Pacific Islander; 3 (1.9%) identifying as South Asian or Indian; 1 (0.6%) identifying as Middle Eastern; and 5 (3.1%) identifying with another race or ethnicity not listed above ("other").

Table 3: Demographics – Race

Race								
White	Hispanic/ Latino	Black	Native or Aboriginal	Asian or Pacific Islander	South Asian or Indian	Middle Eastern	Other	Total
145	7	1	2	9	3	1	5	161
90.1%	4.3%	0.6%	1.2%	5.6%	1.9%	0.6%	3.1%	

The majority of participants in this sample identified as making less than $40,000 annually. The response rate for this question was 54.8%, with 49 (30.6%) identifying as making less than $20,000 annually; 28 (17.5%) identifying as making between $20,000-$40,000 annually; 29 (18.1%) identifying as making between $40,000-$60,000 annually; 17 (10.6%) identifying as making between $60,000-$80,000 annually; 10 (6.3%) identifying as making between $80,000-$100,000 annually; 15 (9.4%) identifying as making more than $100,000

annually; and 12 (7.5%) identifying as making an amount not listed above (e.g. Student; Unemployed; etc.). See Table 4. Figure 1 outlines all demographic information. I believe the demographics of the survey participants impacted the study results in several ways. Primarily, the lack of diversity across all demographic categories measured leads this data to have low generalizability. The implications of the demographics are discussed in detail in the following Discussion chapter.

Table 4: Demographics – Socioeconomic Status

Socioeconomic Status							
Less Than $20,000	$20,000-$40,000	$40,000-$60,000	$60,000-$80,000	$80,000-$100,000	More Than $100,000	Other	Total
49	28	29	17	10	15	12	160
30.6%	17.5%	18.1%	10.6%	6.3%	9.4%	7.5%	

History of Mental Health Diagnoses and Treatment

The primary questions in these sections were about whether or not individuals have accessed counseling services at some point during their lives, as well as whether or not they have ever received a mental health diagnosis. The question of accessing professional help for psychological or emotional distress had a response rate of 68.2% with 153 (76.9%) answering "Yes" and 46 (23.1%) answering "No." See Table 5 below.

Table 5 – Accessed Professional Help

Sought Professional Help/Counselling		
Yes	No	Total
153	46	199
76.9%	23.1%	

The question of having received a mental health diagnosis had a response rate of 67.5% with 115 (58.4%) answering "Yes;" 58 (29.4%) answering "No;" and 24 (12.2%) answering "N/A." See Table 6.

Figure 1 – Demographics

Gender

- Male
- Female
- Transgender
- Genderqueer
- Other

Age

- 18-24
- 25-34
- 35-44
- 45-54
- 55-64
- 65+

Race

- White
- Hispanic/ Latino
- Black
- Native or Aboriginal
- Asian or Pacific Islander
- South Asian or Indian
- Middle Eastern
- Other

Socioeconomic Status

- Less Than $20,000
- $20,000-$40,000
- $40,000-$60,000
- $60,000-$80,000
- $80,000-$100,000
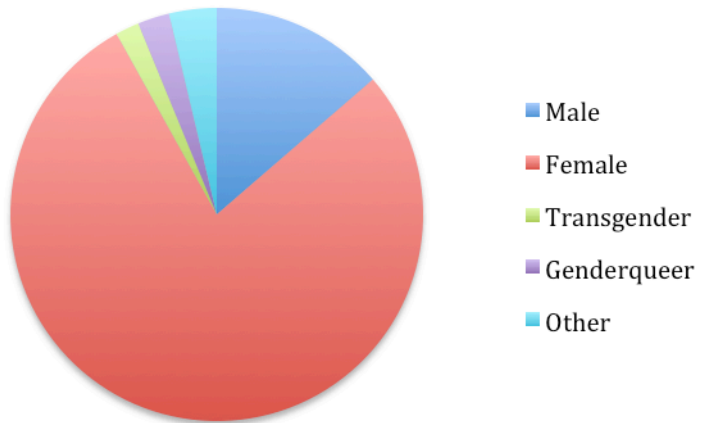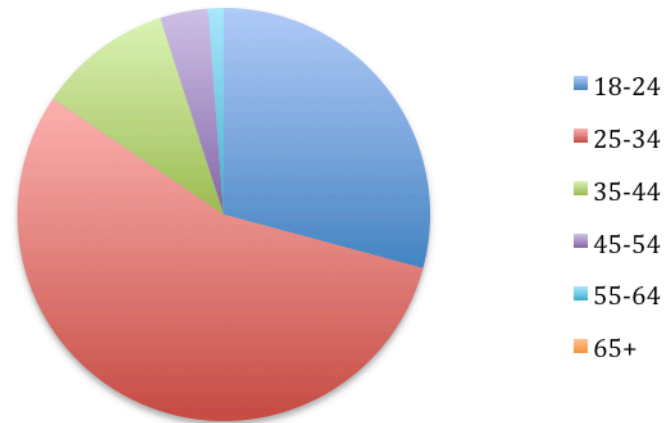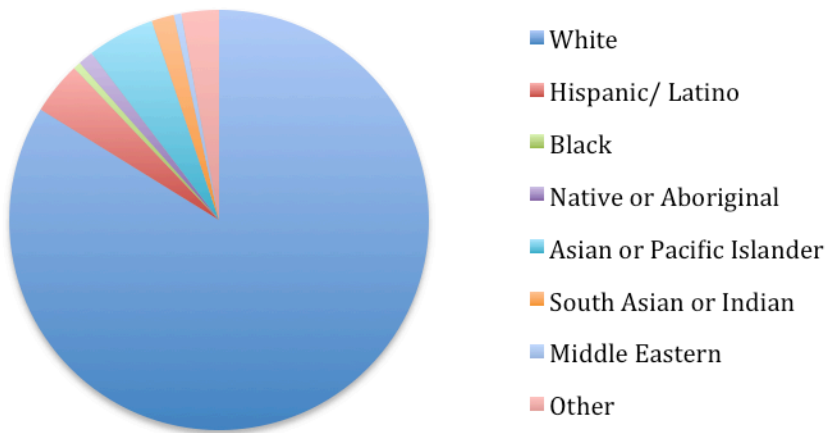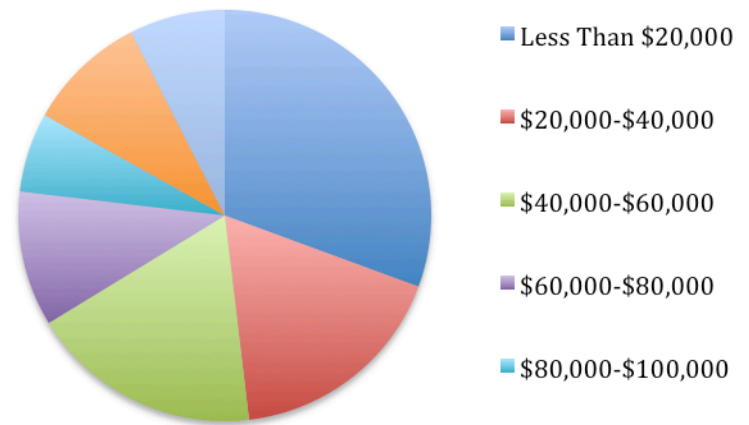
Table 6 – Received a Mental Health Diagnosis

Received Mental Health Diagnosis			
Yes	No	N/A	Total
115	58	24	197
58.4%	29.4%	12.2%	

Participants were asked to designate which mental health diagnoses they have received. The response rate for this question was 38.7%. The question was asked as a qualitative narrative, leading to some interpretation of the results as many participants listed multiple diagnoses, some stated that they feel as though they meet some diagnostic criteria, and others stated that their diagnosis has evolved over time. If participants stated that they felt they have been misdiagnosed, I did not count their result for that diagnostic category; however if a participant listed multiple diagnoses or an evolution of their diagnoses, I counted them for each category. See Table 7 for these results. The responses were as are listed: 68 (60.2%) of those participants stated they have been diagnosed with an anxiety disorder, including social anxiety as well as panic disorder; 72 (63.7%) stated they have been diagnosed with a depressive disorder, including Major Depressive Disorder (MDD) and Dysthymia; 17 (15.0%) stated they have been diagnosed with Borderline Personality Disorder (BPD); 13 (11.5%) stated they have been diagnosed with Attention Deficit Disorder (ADD) or Attention-Deficit Hyperactivity Disorder (ADHD); 12 (10.6%) stated they have been diagnosed with Post-Traumatic Stress Disorder (PTSD); 10 (8.8%) stated they have been diagnosed with a Bipolar Disorder or "Manic-Depression;" 9 (8.0%) stated they have been diagnosed with Obsessive-Compulsive Disorder (OCD); 6 (5.3%) stated they have been diagnosed with an eating disorder or Body Dysmorphic Disorder (BDD); 2 (1.8%) stated they have been diagnosed with an Autism Spectrum Disorder (ASD) including

Asperger's; and 10 (8.8%) stated they have been diagnosed with another type of mental health

diagnosis.

Table 7 – Mental Health Diagnosis (Qualitative Responses)

Mental Health Diagnoses (Qualitative)										
Anxiety	Depression	BPD	ADD/ ADHD	PTSD	Bipolar Disorder	OCD	Eating Disorder	ASD	Other	Total
68	72	17	13	12	10	9	6	2	10	113
60.2%	63.7%	15.0%	11.5%	10.6%	8.8%	8.0%	5.3%	1.8%	8.8%	

Participants shared their mental health diagnoses in narrative form. This led to some

unexpected commentary on individual feelings about how the medical and mental health

community's interpretation of symptoms in the form of diagnosis impacted them. Here are some

examples of these narratives, the implications of which will be discussed further in the

Discussion chapter:

> "After a single visit as a teen I was diagnosed with "severe depression, possible manic depression"

> "ADHD. I have told many professionals that I believe I have Autism spectrum disorder, but because my communication skills are so good (learned by observing my mother) and I make excellent eye contact (also learned by observing her and only in adulthood realized that it is too much sometimes for me, energetically, to make eye contact so much). So they're wrong. It's exhausting that they don't believe me. One person recently I think believed me, but I doubt there is an official diagnosis"

> "First clinical depression, then bipolar type 2, now bpd. I don't know what's next"

> "Major Depressive Disorder, Generalized Anxiety Disorder; mainly different mood and anxiety disorders that I stopped keeping track of such labels."

Participants were also asked whether not they have ever been tested for and if they have

been diagnosed with Autism, Asperger's, or any Autism Spectrum Disorder (ASD). This

question had a response rate of 55.1% with 6 (3.7%) answering "Yes;" 152 (94.4%) answering

"No;" and 3 (1.9%) answering "I do not know." 162 participants answered whether or not they

had been tested for ASD, with 11 (6.8%) answering "Yes;" 140 (86.4%) answering "No;" and 11

(6.8%) answering "I do not know." The vast majority of participants have not been diagnosed

nor have they been tested for Autism, Asperger's, or any Autism Spectrum Disorder.

Table 8 –Diagnosis of ASD

Diagnosis of ASD			
Yes	No	Unsure	Total
6	152	3	161
3.7%	94.4%	1.9%	

Sensory Processing Checklist Symptoms

Participants were asked to check off items on a sensory processing checklist to indicate

which issues they experienced between the ages of 4-12. See Table 9 for these results.

In addition to checking items off of a sensory processing checklist, participants were also

asked to reflect on their most salient sensory processing issues as a child in a textbox format,

allowing for qualitative responses. I went through and coded these responses, placing them into

categories based on the six categories on the sensory processing checklist used for the

quantitative question, created by Yack, Aquilla, and Sutton (2015). The six categories of sensory

processing difficulty in Yack, Aquilla, and Sutton's (2015) checklist are: auditory, visual,

smell/taste, touch, activity level/emotional responses, proprioception, and vestibular. I coded

them broadly, as some participants listed symptoms from multiple categories, and others listed

items that could be placed in multiple categories.

I used my own judgment to place items as broadly as possible, allowing items to fall into

multiple categories. This question had a response rate of 44.9%, with 51 participants (38.9%)

noting difficulties with touch, 40 (30.5%) citing auditory difficulties, 22 (16.8%) reflecting on

difficulties relating to smell/taste, 16 (12.2%) stating that they struggled with activity

level/emotional response difficulties, 8 (6.1%) citing visual difficulties, 7 (5.3%) citing

Table 9: Sensory Processing Symptom Checklist

Sensory Processing Symptom Checklist	No. of Participants (%)
Resisted changes in head position	11 (3.8%)
Appeared fearful of playground equipment or carnival rides	77 (26.4%)
Avoided balancing activities	27 (9.2%)
Were oblivious to risks of heights or moving equipment	20 (8.2%)
Over-reacted to unexpected touch or avoided light touch	60 (20.5%)
Disliked teeth brushing, hair washing/brushing, face wiping	99 (33.9%)
Appeared irritated or avoided certain food or clothing textures	108 (37.0%)
Disliked or avoided messy play or foods	48 (16.4%)
Appeared irritated when someone was in close proximity	64 (21.9%)
Insisted on rubbing or feeling objects	69 (23.6%)
Frequently placed mouth on objects	38 (13.0%)
Had difficulty manipulating small objects	9 (3.1%)
Sought pressure input through deep hugs, squeezing objects, hiding under pillows	57 (19.5%)
Enjoyed rough and tumble play	52 (17.8%)
Relaxed following massage or deep pressure	50 (17.1%)
Exerted too much or too little pressure when handling objects	21 (7.2%)
Appeared clumsy, bumped into people or objects	75 (25.7%)
Appeared uncomfortable (squinted, turned away) in strong sunlight or artificial lighting	82 (28.1%)
Had difficulty scanning the environment for desired object	26 (8.9%)
Appeared fascinated with flickering lights, flipping pages, bubbles, dripping water	38 (13.0%)
Stared at spinning objects, shadows, opening and closing doors	29 (9.9%)
Covered ears or became upset with loud or unexpected sounds	74 (25.3%)
Noticed sounds that others did not hear	72 (24.7%)
Appeared hard of hearing or missed certain sounds	45 (15.4%)
Disliked strong smells or tastes	71 (24.3%)
Crave strong smells or tastes	32 (11.0%)
Ate non-edibles	30 (10.3%)
Appeared restless and required frequent movement breaks	31 (10.6%)
Preferred quiet play	76 (26.0%)
Appeared anxious or fearful	91 (31.2%)
Had difficulty paying attention at school or home	73 (25.0%)
Required routine and had difficulty with transitions	40 (13.7%)
Other	6 (2.7%)

vestibular difficulties, 5 (3.8%) reporting difficulties with proprioception, 8 (6.1%) citing either no sensory difficulties, that they were unsure, or that sensory difficulties occurred outside of the age range specified (4-12 years old), and 1 (0.8%) citing having a sensory difficulty that I could not comfortably place in any category. See Table 10 below for the details of the qualitative results.

Table 10: Sensory Processing Symptoms – Qualitative Responses

Sensory Processing Symptoms (Qualitative)									
Touch	Auditory	Smell/Taste	Activity Level/ Emotional Responsiveness	Visual	Vestibular	Proprioception	None/ Unsure	Other	Total
51	40	22	16	8	7	5	8	1	131
38.9%	30.5%	16.8%	12.2%	6.1%	5.3%	3.8%	6.1%	0.8%	

Here is a sampling of participant's narratives describing their most salient sensory processing difficulties:

> "I chewed on everything. My nails/fingers, hair, erasers, Barbie feet, pens, rubber bands, shirt collars, leather gloves, etc..."

> "I struggled with personal space. I didn't like physical contact, even with family members. No history of any kind of abuse."

> "Could not sit still long enough to learn to read a book and fell behind in class as a result"

> "Very isolated, confused. Felt crazy because nobody else got angry at sounds"

> "Texture and smell were big for me. Certain fabrics like velvet made me recoil. Seams in socks and tights irritated me so much I would cry. My mom would have to pull the seams over my feet when I put shoes on. I needed to smell everything first before I decided what I thought about it (I still do this)"

> "I used to scream when having my hair washed because I didn't like the feeling of the water on my head"

Several participants also commented that their sensory sensitivities continue to persist into adulthood.

Invalidating Childhood Relationships

Caregivers. The survey asked participants to reflect on their relationships with their parents/caregivers, with a variety of questions designed from and developed based on the Invalidating Childhood Experiences Scale (ICES) (Mountford et al., 2007). Participants were asked to rate their responses on a Likert scale, with 1 indicating "never" and 5 indicating "all the time," typically with 1 meaning the environment was validating and 5 meaning that the environment was invalidating. Several items were reverse coded and asked such that "never" would indicate an invalidating environment, and "all the time" would indicate a validating environment. This question had a response rate of 63.7%. See Table 11.

Participants were also asked to reflect on how their parents/caregivers responded to their sensory needs throughout their childhood in the form of an open-ended narrative. I went through and coded these responses using my own judgment based on participant word choice, dividing them up into a variety of categories of participant experience of parent/caregiver responses. These categories include: validating/supportive, invalidating/negative/unsupportive; and none/neutral/other. Responses sometimes fell into more than one category, noting that parents/caregivers were supportive in some circumstances and not in others, or were inconsistent in their support. These results were coded into multiple categories, including responses where participants indicated that one parent was supportive and another invalidating. The "none/neutral" category includes responses in which the participant indicated that parents responded neutrally (e.g. "I wouldn't say my parents were neglectful about it or anything, I only had one or two things that bothered me") or in which no sensory issues indicated (e.g. "I don't have anything memorable"), as well as responses that focused on parenting style rather than sensory need (e.g. "I don't think the term "sensory needs" occurred to them in their parenting

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*Table 11: Invalidating Environment – Parents/Caregivers   ** = Reverse coded item*

Statement	All the time	Often	Sometimes	Infrequently	Never	N/A
Parent/Caregiver Invalidating Environment Likert Scale Results						
My caregiver usually understood my feelings and helped me manage them**	8.60%	24.70%	20.40%	33.90%	10.20%	5.40%
My caregiver encouraged me to believe that I was imagining things	4.30%	11.30%	15.10%	26.30%	37.60%	5.40%
When I felt uncomfortable or upset, my caregiver usually ignored this	8.10%	12.40%	24.20%	32.30%	22.00%	1.10%
My caregiver indicated that they thought I was being difficult in regards to my sensory needs	9.10%	15.10%	19.90%	16.70%	32.80%	6.50%
If I felt uncomfortable, my caregiver would say things like "you're fine, no one else has a hard time with this"	12.40%	17.30%	21.10%	25.40%	21.60%	2.20%
When I was upset, my caregiver would ask what was wrong so they could try to help me**	18.50%	32.10%	22.80%	17.90%	7.60%	1.10%
If I said I couldn't do something, my caregiver would say things like "you're being difficult on purpose"	9.70%	16.70%	15.10%	25.80%	30.10%	2.70%
My caregivers encouraged me to hide or control my emotions, or to "behave like a grownup"	22.70%	18.40%	21.60%	20.00%	14.60%	2.70%
I was encouraged to "suck it up" when I became upset	19.40%	19.40%	18.80%	23.10%	17.20%	2.20%
I was labeled a "trouble maker" at home	8.60%	8.10%	15.10%	18.80%	47.30%	2.20%
My caregiver helped me by teaching me ways to be comfortable even when I was experiencing challenges**	5.40%	16.80%	25.90%	29.70%	20.00%	2.20%

approach), and those who misunderstood the category of "caregiver" as all adults (e.g. "These response reflect the average of my time with caregivers. Teachers, other mentors and parents were all slightly different"). This question had a response rate of 35.6%, with 39 (37.5%) noting

a validating/supportive stance; 64 (61.5%) indicated an invalidating/negative/unsupportive

response, and 14 (13.4%) who fell into the category of none/neutral/other. See Table 13.

Table 12: Invalidating Environment – Qualitative, Parents/Caregivers

Parent Invalidating Environment Narratives			
Validating/ Supportive	Invalidating/ Negative/ Unsupportive	None/Neutral/ Other	Total
39	64	14	104
37.5%	61.5%	13.5%	

Here is a sampling of the unsupportive or invalidating experiences participants

remembered from their childhoods:

Positive:

"Very supportive but didn't coddle me - helped me to understand why I was responding, reasons to respond differently"

"I had a supportive caregiver who responded to my needs as they arose"

"My parents are both clinical psychologists and were generally very attentive to our needs while teaching us limits. I was comforted in the face of difficulty or upset, and responses to my fear were calm and receptive."

Negative:

"My parents were believers in 'tough love'... Emotions were not nurtured, sadness was brushed aside, too much enthusiasm was told to calm down"

"Didn't try and help too much on a day to day basis, instead they just sent me to therapy and hoped it would fix me"

"I was constantly told that I 'just wasn't trying hard enough'"

"My caregivers were very dismissive of my feelings of discomfort and an attempt to convince me that I was simply overreacting or attempting to draw attention to myself. I began to keep any mentions of discomfort to myself to avoid conflict"

Teachers. The survey asked participants to reflect on their childhood experiences with teachers in regards to how validating their school environments were, using similar methods to those for caregivers. This question had a response rate of 57.2%. See Table 13 for these results.

Participants were also asked to reflect on how their teachers responded to their sensory needs throughout their time in school, and write about these reflections. I went through and coded these responses using my own judgment based on participant word choice, dividing them up into a variety of categories of participant experience of their teachers. These categories include: validating/supportive, invalidating/negative/unsupportive; and none/neutral/other. This question had a response rate of 27.4%, with 32 (40.0%) reporting that their teachers were validating/ supportive, 38 (47.5%) stating that they felt their teachers were invalidating/negative/ unsupportive, and 25 (31.3%) stating that their teachers had a response in the category of none/neutral/other.

The following are a sampling of participant's narrative descriptions about teachers:

Positive:

> "Attended gifted school/Montessori and so was allowed to take frequent quiet-times and mostly dictate my own schedule/breaks as needed"

> "In preschool, teachers responded attentively to sensory needs providing stimulation like brushing, lying down in a dark place and squeezing stress objects. This was very salient to me and I still remember it strongly"

Negative:

> "Some were sensitive and knowledgeable to mental illness, empathetic. Others couldn't have cared less and were of the "suck it up" mentality"

> "Teachers did not often pay much attention to me because I was always very quiet"

> "They told me that I was lying when I've told them the truth"

> "Constantly sent to the "office"; detention. Said I had learning disabilities and was a trouble maker"

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Table 13: Invalidating Environment – Teachers   *** = Reverse coded item*

Teacher Invalidating Environment Likert Scale						
Statement	All the time	Often	Sometimes	Infrequently	Never	N/A
My teachers made a point of trying to understand my feelings and help me manage them**	1.80%	11.40%	37.70%	24.00%	16.80%	8.40%
My teachers encouraged me to believe that I was imagining things	2.40%	4.80%	12.00%	27.50%	41.30%	12.00%
My teachers helped me by teaching me ways to be comfortable even when I was experiencing challenges**	1.80%	10.80%	33.50%	21.00%	24.00%	9.00%
My teachers indicated that they thought I was being difficult in regards to my sensory needs	4.20%	9.00%	18.00%	23.40%	31.70%	13.80%
If I said I couldn't do something, my teachers said things like "you're being difficult on purpose"	2.40%	9.00%	14.40%	24.00%	41.90%	8.40%
I was labeled a "trouble maker" at school	7.20%	2.40%	13.20%	17.40%	54.50%	5.40%

Table 14: Invalidating Environment – Qualitative, Teachers

Teacher Invalidating Environment Narratives			
Validating/ Supportive	Invalidating/ Negative/ Unsupportive	None/Neutral/ Other	Total
32	38	25	80
40.0%	47.5%	31.3%	

     Peers. The survey asked participants to reflect on their childhood experiences with peers

in regards to how validating their environments with friends and same or similar-age children

were, using similar methods to those for parents/caregivers and teachers. This question had

varying response rates for each question; 54.8%; 54.1%; and 54.5% respectively. See Table 15

for these results.

Participants were also asked to reflect on how their peers responded to their sensory

needs throughout their time in school, writing qualitative responses. I went through and coded

these responses using my own judgment based on participant word choice, dividing them up into

a variety of categories of participant experience of their peers. These categories were also

validating/supportive, invalidating/negative/unsupportive; and none/neutral/other. This question

had a response rate of 21.6%, with 12 (19.0%) reporting that their peers fell into the category of

validating/supportive, 35 (55.6%) stating that they felt their peers were invalidating/negative/

unsupportive, and 19 (30.2%) falling in the category of none/neutral/other. See Table 16.

Table 15: Invalidating Environment – Peers   *** = Reverse coded item*

Peer Invalidating Environment Likert Scale Results						
Statement	All the time	Often	Sometimes	Infrequently	Never	N/A
My peers usually understood my feelings and adjusted our play to help me feel more comfortable**	1.30%	10.60%	36.30%	23.80%	15.60%	12.50%
My peers often said that they thought I was "just trying to get out of doing things" when I expressed my sensory needs	3.80%	14.60%	22.80%	21.50%	25.30%	12.00%
My peers teased or made fun of me when I was uncomfortable with something	10.10%	22.60%	32.70%	13.20%	13.80%	7.50%

Table 16 - Invalidating Environment (Qualitative, Peers)

Peer Invalidating Environment Narratives			
Validating/ Supportive	Invalidating/ Negative/ Unsupportive	None/Neutral/ Other	Total
12	35	19	63
19.0%	55.6%	30.2%	

Likewise, participants listed a range of experiences in terms of how their peers responded. The following is a sampling of experiences shared in regards to peer interactions in childhood:

Negative:

> "My sensory responses were either ignored by friends or ridiculed by others, they were a large source of bullying and social awkwardness"

> "If my peers found out I disliked a certain sound or movement they made, they'd continue to do it until I was in tears and excused from the classroom"

Positive:

> "I had close friends who were similar to me. I felt understood by them"

> "My friends teased me, but it was almost always in a light hearted and not mean spirited manner. All of my friends were a little strange in their own ways. We teased each other, but we also protected each other from the outside world"

Overall Correlations

The first statistical analysis examined if there was a correlation between the number of sensory processing items checked off and the client's experience of an invalidating environment. Pearson correlation tests were run to examine this correlation within the subscales of parents/caregivers, teachers, and peers. The Pearson correlation determined that there was a significant, positive, moderate correlation between number of sensory processing items checked off and the parent/caregiver invalidating environment subscale ($r = .531$, $p = .000$). Likewise, a Pearson correlation test determined that there was a significant, positive, moderate correlation between number of sensory processing items checked off and the teacher invalidating environment subscale ($r = .445$, $p = .000$). The Pearson correlation test found a significant, weak, positive correlation between number of sensory processing items checked off and the peer invalidating environment subscale ($r = .400$, $p = .000$).

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A Pearson correlation test was also run to examine the correlation between the number of sensory processing items checked off by overall invalidating environment, taking into account all three relationships (parents/caregivers, teachers, and peers). This test determined that there was a significant, positive, moderate correlation between the number of sensory processing items checked off and overall invalidating environment (r =.578, p=.000). These result indicates that the more sensory processing symptoms a participant had, the more likely that person was to also report an invalidating childhood environment across all three levels of relationship: parents/caregivers, teachers, and peers.

T-tests were run examining if there is difference in the invalidating experiences (means of the invalidating environment subscale results of parents/caregivers, teachers, and peers) of those with and without a mental health diagnosis and across the board there were statistically significant differences between these two groups. These t-tests demonstrated that the mean number on the parent/caregiver invalidating environment subscale was higher for those with a mental health diagnosis (m = 2.86) than those without (m = 2.34) (t (158) = 3.139, p = .002, two-tailed). Likewise, the mean number on the teacher invalidating environment subscale was higher for those with a mental health diagnosis (m = 2.37) than those without (m = 2.03) (t (148) = 2.002, p = .047, two-tailed). Similarly, the mean number on the peer invalidating environment subscale was higher for those with a mental health diagnosis (m = 2.91) than those without (m = 2.25) (t (143) = 3.118, p = .002, two-tailed).

A t-test was also run to determine the overall invalidating environment, taking into account all three of the invalidating environment subscales (parents/caregivers, teachers, and peers). This t-test also found a statistically significant difference in the overall mean of those with a mental health diagnosis (m = 2.75) and those without (m = 2.24) (t(158)=3.668, p=.000,

two-tailed). These results indicate that participants who reported a higher degree of invalidating childhood environments were significantly more likely to have a mental health diagnosis.

T-tests determined whether or not there was a difference between the mean number of sensory processing difficulties for those who sought counseling and/or have had a mental health diagnosis and those who have not. Two t-tests were run, one for individuals who sought counseling and one for individuals with a mental health diagnosis. A t-test determined that there was no significant difference between the mean number of sensory processing items checked off for those who had sought counseling and those who had not. The second t-test, however, determined that there was a statistically significant difference between those with a mental health diagnosis and those without (t(166)=3.108, p=.002, two-tailed). Those with a mental health diagnosis had a higher mean number of sensory processing difficulties (m = 8.94) than those without a mental health diagnosis (m = 6.18). These results indicate that there may be an association between sensory processing difficulties in childhood and the development of mental illness in adulthood. Table 17 outlines the overall correlations.

In the next and final chapter, I will discuss the implications of these findings in detail, as well as how these findings impact at the individual, clinical, and societal levels.

Table 17: Overall Results and Correlations

Overall Correlations					
Question	Variables	Test Type	Sample Size (n)	t or r value	p value
Do participants with a higher number of sensory processing symptoms have a greater likelihood of developing mental illness in adulthood?	MNTLHLTH;	T-test	n=168	t=3.108	p=.002*
	Number of sensory processing symptoms checked				
	COUNSEL;	T-test	n=191	t=1.745	p=.083
	Number of sensory processing symptoms checked				
Is there a correlation between the number of sensory processing symptoms in childhood and how invalidating the childhood environment was?	Parent subscale; Number of sensory processing symptoms checked	Pearson Correlation	n=158	r=.531	p=.000*
	Teacher subscale; Number of sensory processing symptoms checked	Pearson Correlation	n=148	r=.445	p=.000*
	Peer subscale; Number of sensory processing symptoms checked	Pearson Correlation	n=143	r=.400	p=.000*
	Total combined parent, teacher, peer subscales; Number of sensory processing symptoms checked	Pearson Correlation	n=158	r=.578	p=.000*
Do participants with a higher self-reported invalidating childhood environment have a higher likelihood of developing mental health issues in adulthood?	Parent subscale; MNTLHLTH	T-Test	n=158	t=3.139	p=.002*
	Teacher subscale; MNTLHLTH	T-Test	n=148	t=2.002	p=.047*
	Peer subscale; MNTLHLTH	T-Test	n=143	t=3.118	p=.002*
	Total combined parent, teacher, peer subscales; MNTLHLTH	T-Test	n=158	t=3.668	p=.000*

CHAPTER 5

Discussion

This study aimed to explore whether or not there appears to be an association between sensory processing difficulties in childhood, invalidating childhood environments, and the development of mental illness in adulthood. In this chapter, I discuss the findings listed in the previous chapter, how they agree with and/or contradict the current literature, study limitations, implications for the field of clinical social work, and directions for future research.

Discussion of Qualitative Findings

Sensory Processing Difficulties. The narrative responses participants provided gave a window into some of their most salient sensory processing difficulties. What is clear from participant's descriptions is that sensory processing difficulties shaped how participants experienced their childhoods. One example, demonstrates the multiple layers at which sensory sensitivities can cause difficulties:

> "Itchy clothing like wool or tags was unbearable when it touched my skin. I was ALWAYS cold, with blue hands and feet, unless it was summer and over 75 degrees. I refused to eat a lot of things and my parents would make me sit at the table for hours until I finished my peas or whatever disgusting food they were trying to make me eat. I never, ever ate what they were trying to force me to eat and I still don't eat those things. Finally they would just send me to bed. I was (am) a light sleeper and completely quit taking naps when I was 4 months old. I don't remember exactly what caused me so much stress but I would often end up in my closet (there was no light in there) laying on blankets in the dark."

This narrative describes sensory difficulties in terms of touch, smell/taste, and activity levels/emotional reactivity. From this participant's description, it appears as though the sensory

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sensitivities and parental response caused a great deal of stress. The findings of this study indicate that when sensory processing difficulties are present it impacts childhood in a variety of areas, and that it can cause children excess stress in attempting to manage their sensory symptoms. This is consistent with the current body of literature, which states that sensory processing difficulties impact how children experience the world. For example, as discussed in the literature review, Walbam (2013) discusses hypo-sensitive children and how "they may present as withdrawn or uninterested because they lack the neural activation needed to sustain focused attention" (p. 63). Alternatively, hyper-sensitive children "are bombarded with sensory messages. They may appear hyperactive or distractible" (Walbam, 2013, p. 63). It is easy to imagine how hypo- and hyper-sensitive children would find it difficult to function according to our socially-derived standards of living given how their sensory difficulties impact them. As discussed in the literature review, Koenig and Rodney's (2010) review of the literature speaks to similar difficulties, evaluating studies that look at play, sleep, and education/work. Their review finds that sensory processing issues impact children on all levels, contributing to "decreased quantity and quality of play," a lack of restful sleep, and children with SPD were less likely to participate in extracurricular activities (p. 432-6).

Participants in this study also cited difficulties meeting prescribed expectations in each of these areas (play, sleep, and education/work), noting that discomfort with sensory stimuli impacted their emotional stability (e.g. becoming angry over chewing sounds; being particularly afraid of loud sounds; having difficulty reinforcing personal boundaries with others due to discomfort with being hugged or touched; etc.). These types of emotional difficulties in children with SPD are well documented throughout the literature review (Brindle et al., 2015). One

participant discussed their emotional experience and understanding of their sensory differences, stating that they felt:

"Very isolated, confused. Felt crazy because nobody else got angry at sounds"

This lack of normalization around sensory difficulties is reflected in the literature, and further research indicates that these emotional and psychological difficulties can persist into adulthood, as several study participants indicated. For example, one study by Engel-Yeger and Dunn (2011) states that there may well be a link between sensory processing difficulties with both hypo- and hyper-sensitive individuals and the development of anxiety in adulthood. Engel-Yeger and Dunn (2011) also note that: "The negative impacts of extreme sensory processing patterns and anxiety expressed in unbalanced physiological regulation, and on behavior, might have a devastating influence on quality of life" (p. 211). In the example above, the feelings of being "crazy" for having what are considered abnormal emotional responses to sound were clearly very distressing for this participant.

Of course it is important to distinguish, as Brindle et al. (2015) do, that while "there is a relationship between SPS [Sensory Processing Sensitivities] and negative psychological symptoms, it is important to note that these symptoms are not a direct product of processing sensitivities" (p. 215). In other words, having difficulties with sensory processing does not in and of itself create psychological issues or mental health diagnoses. I argue that, rather, it is how these sensory differences are treated in the context of interpersonal relationships that contributes to negative mental health outcomes. Brindle et al. (2015) go on to state that the ability to regulate emotions is of the utmost importance in determining whether or not sensory processing difficulties will contribute to an outcome of psychological distress and mental health difficulties.

Invalidating Environments. The findings in this study support the current research, that sensory processing difficulties impact children across parental, academic, and peer relationships. Other research has explored the link between lack of parental attunement with a child and difficulties in psychological outcomes in later life, however few studies examine this through a lens of sensory processing difficulties. In terms of concrete parenting and attunement to a child's needs, one study observed how parental play preferences influence the ways in which a child plays. In this study, Welters-Davis and Lawson (2011) found that: "It is possible that children may prefer activities that offer more stimuli, but they are not exposed to more stimulating activities due to their parents' preferences" (p. 117). When parents are responsible for choosing and guiding play activities, it seems likely that child's needs become secondary to parental preference. Parents placing their own needs before their child's may be a contributing factor in having an invalidating environment as well. Many participants discussed following through with activities that they found difficult to tolerate in order to meet their parent's needs (e.g. eating foods they hated; wearing uncomfortable clothing for holidays, etc.). To a certain extent these experiences are part of a normative childhood, regardless of sensory processing capability. For children with SPD or particular sensory sensitivities, these experiences would be particularly abhorrent and a lack of parental attunement, potentially devastating.

Participants in this study described their own experiences with having parents invalidating their sensory processing experiences, including ignoring, minimizing, and even mocking sensory difficulties. Shenk and Fruzzetti (2014) discuss how adolescents fair in validating and invalidating environments. They state: "A validating behavior occurs when a child or adolescent expresses his or her private experience to a parent and this expression is met with understanding, legitimacy, and acceptance of this experience" (p. 44). Likewise, participants in

this study who had positive childhood experiences with caregivers referenced feeling

"understood" or "supported" by their parents. The following narratives from participants

demonstrate the themes prevalent throughout participant's negative experiences with

parents/caregivers:

> "My caregivers were very dismissive of my feelings of discomfort and an attempt to convince me that I was simply overreacting or attempting to draw attention to myself. I began to keep any mentions of discomfort to myself to avoid conflict"

> "They didn't react well to things so I feel like I just learned very early on not to say anything. For example, I had vision issues starting in the second grade but my asking to see an eye Dr. was seen as attention seeking so I never brought it up again for years"

Those who experienced invalidation noted, like Shenk and Fruzzetti (2014) posit, that "Such a

response [invalidation] conveys to a child or adolescent that his or her emotional experience in a

given situation is incorrect and attributes that experience to socially unacceptable or undesirable

standards" (p. 44). Invalidating themes of participants being told they were "wrong" to respond

to sensory stimuli in the way that they did were prevalent throughout the qualitative responses, as

well as those that indicated they were seeking attention or special treatment rather than trying to

convey genuine discomfort.

Going hand-in-hand with an invalidating environment is difficulties with attachment style

in adulthood. There is compelling evidence that points to attachment difficulties and sensory

processing disorder. As discussed in the literature review, Jerome and Liss (2005) made some

hypotheses about how sensory processing difficulties may be indicative of a child's eventual

attachment style (e.g. those with sensory sensitivities may having avoidant attachment styles,

while those who are hypo-sensitive may require more input in a relationship as well, having

preoccupied attachment styles) (p. 1343). As the body of research indicates that parental

attunement within the first year of life greatly predicts attachment outcomes (Bowlby, 1969, as

cited in Meredith, Bailey, Strong, & Rappel, 2016), it stands to reason that parents may potentially have influence over how a child develops and copes with sensory processing difficulties. With a greater understanding of sensory processing difficulties, parents may be able to ameliorate how much sensory difficulties impact a child's life, as "Sensory processing style may be one temperamental component of attachment style" (Jerome & Liss, 2005, p. 1343). A recent study by Meredith, Bailey, Strong, and Rappel (2016) also examined sensory processing difficulties and adult attachment style. In line with previous research, they discovered that "attachment anxiety was related to sensory sensitivity" (prior to controlling for stress) (p. 6). They also found, however evidence that contradicted Jerome and Liss' (2005) hypothesis, noting that avoidant attachment style was linked to sensory sensitivity rather than sensory avoidance. While this evidence contradicts some previous research, it continues to emphasize that there is a connection between sensory sensitivity and attachment style, regardless of how this association manifests itself.

While participants in this study were not asked to identify their attachment style nor assessed in terms of attachment style, it was apparent from the qualitative results that participants felt misunderstood and invalidated by their parents and that there was a lack of attunement in regards to their sensory difficulties. This study asked participants to discuss their sensory processing difficulties and how their parents responded to them. The qualitative findings indicate that, overall, children found that their parents/caregivers were unsupportive or invalidating towards them in regards to sensory processing difficulties (68.3% of unsupportive/negative experiences to 43.3% positive or neutral experiences).

This study also looked at other important childhood relationships including those with teachers and peers. The findings of this study agree with the current research, indicating that

other significant childhood relationships impact children's emotional wellbeing. Participants in this study had a variety of both positive and negative experiences with these extrafamilial relationships, including experiences of being validated, supported, and having teachers and peers demonstrate flexibility in terms of activities, as well as experiences of being ridiculed, bullied, and excluded by friends and peers. The following examples demonstrate the positive experiences participants had with teachers:

> "In preschool, teachers responded attentively to sensory needs providing stimulation like brushing, lying down in a dark place and squeezing stress objects. This was very salient to me and I still remember it strongly"

> "I was lucky to have amazing teachers who made accommodations for my needs and taught me coping strategies"

In agreement with these findings, other studies indicate that these student-teacher or mentoring relationships can have an ameliorating impact on children if the parental relationships are insufficient. Simões and Alarcão discuss the role of mentors, noting: "[Mentoring program] growth relies on the premise that young people who experienced adversities in their lives may find in mentoring an opportunity to readjust their internal working models and compensate for losses in previous relationships with adults" (p. 114). They go on to discuss how the quality of the mentor relationship is the largest indicator of whether or not the relationship will yield positive outcomes for the child. Likewise, it stands to reason that these relationships can negatively impact psychological health and childhood development. Throughout this study, there were participant narratives that demonstrate the negative impact when teachers and peers are not attuned with children with sensory processing difficulties.

> "Was often teased/bullied or became a bully, depending on the schoolyard dynamic that year (moved/changed schools frequently). Can recall a number of times that I was alienated or mocked because I was anxious about an activity/setting"

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"There was no label for my problems. My peers just thought I was being difficult or weird"

"Constantly sent to the "office"; detention. Said I had learning disabilities and was a trouble maker"

These relationships with teachers and peers are clearly important for child development, however, as the findings of this study demonstrate, teachers and peers are often not attuned to sensory processing difficulties. The literature discusses SPD in a school setting and how teachers and other school professionals respond to sensory difficulties, citing many of the same issues that participants in this study note. From the literature review, Maxam and Henderson (2013) speak to a case study of how teachers address invisible disabilities, citing the complicated interplay of standardized testing, public funding, teacher resources, and student needs. Maxam and Henderson (2013) ultimately state: "To promote inclusivity with regard to disabilities, there needs to be an atmosphere of understanding and respect for individual differences, ultimately celebrating the uniqueness or each individual" (p. 78). This view may be idealistic, however it does reflect the sentiment that participants shared, that they wished that their teachers were more understanding and sensitive to their sensory needs, while lauding those who demonstrated the patience and empathy they required. It also appears likely that small changes in a classroom setting could easily be made to better meet the needs of students. One study by Buckle, Franzsen and Bester (2011) examined how children with ADHD responded in a classroom context simply by giving them weighted vests to wear. The results indicated that children were able to stay seated longer and, significantly, that they were able to complete tasks more quickly. This study opens the door to more innovative sensory-based interventions in a school setting.

In terms of peer relationships, we see from this study participants remembering feeling different than their peers, being teased or bullied for these differences, and labeled as "sensitive,"

"dumb," and "misfits." Shtayermman (2009) discusses some of the qualities that individuals with ASD exhibit, that those with SPD may also exhibit, stating "people often use movement cues of others when forming impressions of others, and in individual's responses and perceptions to physical cues may also serve as a basis for the construction of stereotypes and for social interactions" (p. 300). The body cues that Shtayermman is referring to include things such as rocking as a form of soothing, but we can expand upon that idea to include other body-based behaviors that individuals with SPD may exhibit, including those aimed at soothing vestibular or proprioceptor sensory difficulties. Shtayermman also discusses the stigma associated with exhibiting these types of bodily displays, and that stigma often results in teasing, bullying, or excluding behaviors from other children.

Cosbey, Johnston, Dunn, and Bauman (2012) discuss how children whose development differs from the norm, such as children with SPD, struggle with meeting play expectations. They state: "By 6 to 12 years of age, children are expected to cooperate with others, demonstrate empathy, and have self-control and flexibility during their play activities. However, children with disabilities demonstrate a slower rate of developmental changes in play…further limiting the children's access to play opportunities" (p. 39-40). A theme that was noticeable throughout this study was people feeling left out or otherwise excluded from their peers and the literature supports that children with SPD struggle in social settings. Cosbey et al. (2012) note: "children with SPD demonstrated more frequent conflict than their peers, which is not surprising given that children with SPD often have difficulty resolving conflict appropriately" (p. 44). Resolving conflict is an essential skill in terms of developing successful interpersonal relationships (Ames & Murray, 1982 as cited in Laursen & Hafen, 2010, p. 860). Laursen and Hafen (2010) note: "Conflict with peers is thought to be especially critical to cognitive and social cognitive

development" (p. 860). It stands to reason that if children with SPD struggle in the context of conflict, they would be less likely to have the opportunity to develop these social cognitive skills that are inherently important in developing fulfilling relationships.

It is important to recognize that many participants also reflected on how their peers were kind, sensitive, or responded neutrally to their sensory needs. The relative diversity in terms of interpersonal experiences from participants with sensory sensitivities demonstrates that, though socially prescribed, there is not an innate social script for how we respond to difference in general and sensory processing differences in particular. A key component to this work would be helping children develop empathy and have them understand that others may see and interpret the world differently. Likewise, there is literature describing how to foster this level empathy and kindness in children, much of it focusing on how "For children, empathy is an energizing change agent for the 'boosting power' to increase prosocial behavior" (Masterson & Kersey, 2013, p. 212). Future research and clinical work could continue to look at developing a curriculum for providing psychoeducation to both teachers and children about sensory processing differences and sensitivities and how to respond in an empathic way.

Beyond interpersonal considerations, there is also evidence that the types of play children with SPD prefer differ from those with normal sensory processing, particularly in terms of which toys they choose to play with and in terms of how often they change play, how they feel about adding additional toys, etc. (Lawson & Dunn, 2008). This has implications in terms of the types of play that feel comfortable and palatable to children with SPD. As Ismael, Lawson, and Cox (2015) note: "it is important to consider children's sensory preferences when offering play, leisure, and educational activities" (p. 317). Participants reflected being told to "suck it up" or being told they were "too sensitive" when they had an adverse reaction to the types of activities

or events we routinely expect children to tolerate or enjoy. In general, however, Ismael et al.

(2015) found that, on the whole, children with sensory processing difficulties enjoyed the same

activities, albeit they may perform these activities differently (e.g. light shading versus pressing

down hard with writing utensils) (p. 321). This indicates that perhaps the difficulty with children

not feeling as though their sensory sensitivity is accepted lies in how prescribed and specific we

are about the ways that it is acceptable to engage in activities. For example, if a child needs to

doodle or color in order to pay attention during school it is assumed that they are not paying

attention and this behavior is deemed unacceptable. It seems likely that society having low

tolerance for different ways of interacting with the world could be part of the equation in terms

of how children feel invalidated in various environments, such as in school and with peers

socially.

   Mental Health Diagnosis. An unexpected note was that participants felt as though

receiving a mental health diagnosis had a deleterious effect on their mental health. This idea that

mental health diagnosis impacts clients is well documented in the literature. One study by

Shtayermman (2009) examines how adolescents feel about themselves following a diagnosis of

Asperger's Syndrome. Asperger's is now classified within the DSM-V as being under the

umbrella of ASD, and people with this diagnosis may exhibit some traits of SPD or other sensory

processing difficulties. Shtayermman (2009) explores the stigma behind diagnosis, stating:

"Stigmatized persons can be defined as persons who possess a quality that others perceive as

negative, unfavorable, or in some way unacceptable" (p. 299). It is undeniable that receiving a

mental health diagnosis comes along with a great deal of stigma. A study by Milton and Mullan

(2014) notes that this stigma comes at all levels, including internalized stigma. Milton and

Mullan (2014) state: "some individuals spoke of a process of self stigmatization, as they

themselves may hold misconceptions about mental health which could impact on their own feelings of self-worth" (p. 462). This internalized sense of shame around receiving a mental health diagnosis is particularly problematic as in order to receive mental health treatment through many healthcare systems you need a diagnosis. Another study by Sayre (2000) confirms the internalized stigma experienced by clients receiving treatment from an inpatient facility, noting that some of their participants "saw their situation as a response to current stressful events, which they defined as a temporary period of danger and/or trouble" (p. 77). While some may find diagnosis helpful in terms of conceptualizing their mental illness, it appears as though many do not find this to be the case and rather see it as stigmatizing and decreasing self-worth.

Discussion of Quantitative Findings and Correlations

  Sensory Processing Symptoms and Mental Health Diagnosis. The most profound results of this study come from the statistically significant correlations that were found. There was an association between the number of sensory processing difficulties in childhood and the mental health outcomes in adulthood. In other words, participants with a mental health diagnosis had a higher mean number of sensory processing difficulties in childhood (t(158)=3.668, p=.000, two-tailed). This indicates that sensory processing difficulties in childhood move beyond creating difficulties in the biological realm and contribute to psychological difficulties. This is supported by much the research presented in the literature review, particularly the work of Brindle et al. (2015). Brindle et al. (2015) explored the link between sensory sensitivity and emotional difficulties, finding "that experiencing sensitivity to both internal and external stimuli leads to a level of learnt helplessness regarding repeatedly and unavoidably experiencing negative internal states" (p. 219). Participant's narrative experiences of their sensory processing

difficulties further elucidated this point, as they described the psychological implications of

living with sensory processing difficulties in childhood.

> "I get unnaturally angry and irrational around sounds (or certain movements) that annoy
> me. I can hear things people can't and I can't focus on anything but the sound that is
> bothering me, no matter how hard I try/tried."

> "Whistling and other oral noises (chewing, clicking, certain singing) caused me to feel
> extremely frustrated and sometimes provoked outbursts."

> "Extreme aversion to sounds such as chewing or breathing. Kept me awake all night."

Participants in this study indicated that they experienced adverse psychological consequences as

a result of their sensory processing issues, including an inability to use emotion regulation skills

as well as having adults, peers, and themselves invalidating their experiences of sensory

underwhelm or overload.

Invalidating Childhood Environments and Mental Health Diagnoses. Another

significant correlation was that the higher a participant rated their childhood experiences as

invalidating, the more likely they were to have received a mental health diagnosis (t(158)=3.668,

p=.000). The association between invalidating childhood environments and adverse mental

health outcomes is well documented in previous research. As Gentzler, Contreras-Grauc, Kerns,

& Weimer (2005) state: "findings showing that unsupportive parental reactions, such as punitive,

minimization, or distress reactions, are associated with problematic coping by children" (p. 592).

The results of this study indicate that invalidating childhood environments are correlated with

adverse mental health outcomes beyond just BPD, as it is traditionally used.

The term invalidating environment has been used most prolifically by Linehan (1993) as

part of her biosocial theory of how BPD develops. The biosocial theory points to the unique

combination of an individual who is emotionally reactive biologically and is placed in an

environment where emotional reactivity is deemed an inappropriate response, that individual is

at a risk of developing BPD. Since then, the concept of the invalidating environment has been applied to different mental health diagnoses beyond BPD, such as eating disorders (Mountford et al., 2007; Haslam et al., 2008; Ford, Gillian, Waller, Glenn, & Mountford, 2011). In light of the results of this study, I would expand upon the biosocial theory, adding that in addition to a biological predisposition to emotional reactivity is potentially a biological sensitivity to sensory stimuli. Likewise, perhaps the emotional reactivity is, at least in part, a reaction to sensory stimuli. Many study participants described emotional reactions as being linked with their sensory concerns. This study indicates that a new biosocial theory that also incorporates Ayers' (1986) sensory integration theory holds weight, however much more research is needed to validate this claim.

Sensory Processing Symptoms and Invalidating Childhood Environments. In addition to the association found between sensory processing difficulties and mental health outcomes, there was also a statistically significant positive correlation between sensory processing difficulties and invalidating childhood environments (r=.578, p=.000). This indicates that children with more sensory processing difficulties experience more invalidation in their parent/caregiver, teacher, and peer relationships. This finding is similar to what the research shows, as discussed in the literature review. Rass (2003) wrote a particularly salient piece, which focused on self-esteem in children with sensory integration issues. Rass (2003) notes: "The child is then labelled as suffering from 'anxiety'; however such a label only stresses the emotional aspect of the problem and the cause of the anxiety and physical insecurity goes unnoticed" (p. 290-1). The labelling of sensory-motor issues as emotional issues is inherently invalidating to the child's experience and can only be corrected, as Rass (2003) posits, "Once the parents are able to create a therapeutic milieu, they, in turn, can inform other caretakers about the proper response to

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these symptomatic children" (p. 306). Parents/primary caregivers are the most fundamental

support that children with sensory sensitivities need in order to navigate the outside world – a

way of responding to their children which many participants in this study felt their parents

lacked.

The study by Shenk and Fruzzetti (2014) further elucidates this point, noting that "A

validating behaviour does not directly seek to change or alter a child's emotional experience;

instead, it seeks to highlight the emotional experience in order to facilitate an individual's

acceptance and experiencing of the emotion" (p. 44). Participants in this study who reported

higher numbers of sensory processing symptoms in childhood indicated that their childhood

environments did not seek to understand their emotional responses, only to change them. This

kind of invalidating environment has been known to have deleterious effects on mental health as

a child matures (Linehan, 1993).

Characteristics of Participants

The sample was collected via convenience and snowball sampling methods, with 360

participants beginning the survey, and 292 qualifying as participants (n=292). The criteria for

participating in this study was to be an adult over the age of 18 and to have the ability to

complete an online, English language based survey. In spite of the broad inclusion criteria, the

participant demographics appeared to lack diversity across all areas measured (age, gender, race,

and socioeconomic status). This lack of diversity is prevalent throughout much academic

literature, and I discuss potential reasons for having such a homogenous sample in each

demographic section below. It is, however, imperative to recognize and highlight the importance

of a diverse sample in mental healthcare research. As Jeste, Twamley, Cardenas, Lebowitz, and

Reynolds III (2009) state:

> Members of racial and ethnic minority groups face disparities in both access to and quality of health care. These disparities carry over to mental health care, and members of minority groups who have mental illnesses face even greater disparities in routine, preventative, or emergency medical care. A diverse workforce is desirable for every type of research…Translational research is needed to move treatments and preventive interventions not only from bench to bedside, but also from bedside to community (p. S31).

The homogenous sample for this research project is indicative of the greater systemic inequities that contribute to a lack of accessible mental healthcare services for individuals from marginalized groups, as I discuss below. While this research is promising, this is a limiting factor in terms of what conclusions can be drawn, as this sample has limited cross-population generalizability (Engel & Schutt, 2013, p. 14).

Age. The majority of participants (55.3%) in this study were between the ages of 25-34, with an additional 29.2% between the ages of 18-24. There could have been many reasons for the sample to be skewed towards a younger audience, in spite of the broad inclusion criteria. As the collection methods involved convenience and snowball sampling, I used my own social networks and social media accounts as a means of collecting data. Given that the majority of individuals in my networks are between the ages of 25-34, a younger sample makes sense. Likewise, I recruited participants from the website Reddit. A relatively recent survey indicates that the majority of Reddit users are between the ages of 18-29 (Pew Research Center, 2013). In general, younger people are more likely to respond to surveys on the Internet as "People…age 65 and older are underrepresented among internet users" (Pew Research Center, 2011). Given that Reddit and my own social networks were my primary sources of data collection, a younger sample naturally follows.

Gender. This study also had limited diversity in terms of gender, with an overwhelming 78.3% of the participants identifying as female. Only 13.7% identified as male, and 8.1%

identified as transgender, genderqueer, or as another gender identity. Understanding the lack of diversity in this study in terms of gender is more complicated than understanding the lack of a variety of ages. While my social network is primarily people who identify as female, these percentages do not reflect my social media network. Additionally, Reddit users are primarily male, so this does not accurately reflect my other data source (PEW Research Center, 2013). There are, however, ways of understanding this beyond just chance. There is evidence to suggest that men experience a greater degree of stigma in terms of discussing mental health issues and concerns. As Wendt and Shafer (2015) state: "Men are typically socialized into a masculine gender role, which requires men to conform to a socially constructed masculine ideal that values independence, emotional silence, self-reliance, and the rejection of personal weakness. These norms conflict with the idea of getting professional help for one's problems" (p. e21). This study goes on to cite that men are "more likely to stigmatize mental health problems [compared to women]" (Wendt & Shafer, 2015, p. e25). Given the higher degree of stigma, it stands to reason that people who identify as male might be both less likely to occupy spaces for folks with mental illness (e.g. the SubReddit forums where the survey was posted) and might be less inclined to participate in a survey where many of the questions focused on mental illness and participants were asked to self-disclose having a mental health history.

Race. The vast majority of participants in this study identified as white (90.1%). Similar to reasons for a lack of range among other participant demographics, my social network is primarily white. This overwhelming percentage, however, does not account for the ways I collected data. There could be several circumstances that contribute to the lack of racial diversity within this study. Similar to considerations of gender, studies indicate that people of color are less likely to access mental health services, and, it would follow, have a mental health diagnosis.

As Smith and Trimble (2016) state: "Studies in recent years demonstrated greater racial inequities in mental health service utilization than studies conducted in previous decades" (p. 80). Since the SubReddits I recruited from specifically cater to individuals with a mental health diagnosis, it would make sense that there would be fewer people of color in those groups if they are less likely to seek the mental health treatment that would result in receiving a mental health diagnosis. Smith and Trimble (2016) go on to discuss the reasons for the lack of seeking mental health services among people of color, citing reasons including a lack of feeling that mental health treatment will be effective, differing definitions of reasons to seek mental health treatment, and lacking monetary means to access mental health services (p. 68). The authors also address the systemic racism that lends itself towards a lack of access to mental health services by people of color, noting: "Systematic differences in the rates or the severity of mental illness across race may occur but seem unlikely explanations for underutilization of mental health services by people of color" (Smith & Trimble, 2016, p. 92). It is not a lack of a need for mental health treatment but rather a lapse in the system not being designed to meet the needs of people of color.

In addition to being less likely to access the system, children of color are more likely than their white counterparts to be disciplined and labeled with behavioral difficulties in a school setting, rather than being understood through a more holistic lens of their struggles, which could include sensory processing difficulties. The fact that Black children in particular are more likely to be disciplined than White children is clear. One study by Okonofua and Eberhardt (2015) discusses how stereotypes about Black children contribute to how teachers treat children in the classroom. As Okonofua and Eberhardt (2015) state: "Research shows that teachers commonly perceive Black students to have more negative demeanors, to have a longer history of

misbehavior, and to earn lower grades than White students do" (p. 618). Given the consistent pathologizing of Black behavior, it could follow that Black participants may be less likely to take an interest in a study focused on sensory processing difficulties, as they are more likely to be identified as having behavioral problems understood in a stigmatizing way rather than being labeled from a more compassionate stance of struggling with biologically based sensory processing difficulties.

Socioeconomic Status. Approximately one third of participants in this study (30.6%) identified as being in the income bracket of less than $20,000. This is lower than the national average according to the 2014 U.S. Census report, which cites that the average household income is $32,047 for nonfamily households. However, 17.5% reported earning within that bracket ($20,000-$40,000 annually), and 18.1% identified in the next bracket up ($40,000-$60,000 annually). These numbers are similar to the U.S. census national average, and I believe that my social network influenced this number the most, as many individuals in my social network are students or new professionals who make less money than those who have been working for an extended period of time (Income and Poverty in the United States, 2014).

Overall Implications of Sample Characteristics. While the lack of a diverse population is notable within this study, I also consider that this could be related to whom the content of this study speaks to. As this was a lengthy survey, individuals without sensory processing difficulties and those without mental health issues may have been unmotivated to participate. Perhaps the sample also reflects the types of people who are more likely to be recognized as having sensory difficulties rather than simply behavioral issues or "trouble makers" (e.g. white people) as well as those who are more likely to seek mental health treatment and be diagnosed with mental

illness (e.g. women) (Okonofua & Eberhardt, 2015; Wendt & Shafer, 2015), in addition to the limitations of using convenience and snowball sampling with an online survey.

Study Limitations

There are several weaknesses inherent in the methodology and outcomes of this study. First, the sample lacked diversity in the areas of gender, age, race, and socioeconomic status. In order to make broad claims about the human experience in any capacity, having diversity within a sample is of the utmost importance (Engel & Schutt, 2013, p. 114). Likewise, through using an online survey I inevitably did not survey a representative sample of the population for many reasons, including the fact that it is a computer-based survey that is in English and not all populations have access to a computer and speak English. In addition, because I am using non-probability sampling methods, the groups that I have access to do not represent the larger population, and the results from this convenience sample are not generalizable. As Engel and Schutt (2013) state: "What makes availability sampling haphazard is precisely that a great many things other than chance can affect the selection of cases" (p. 124). Further research employing probability sampling methods will be needed to confirm that any results from this study are generalizable to a larger population.

In addition, I did not ask participants about level of schooling completed in spite of asking about their experiences with teachers in a school setting. As Driscoll, Wang, Masburn and Pianta (2011) state: "Relationships between teachers and children that are characterized by warmth, closeness, and a lack of conflict promote children's opportunities to learn within classrooms and their subsequent adaptation to and success in the school environment" (p. 594). Looking at how long participants stayed in school is relevant in terms of whether they

experienced school as an invalidating environment and how their teachers responded to them in a school setting.

One further limitation in this study is that I asked adults to reflect on their experiences as children, and memory is an imperfect recording of childhood events. As Liss et al. (2005) state: "all investigations about sensory processing, including the present investigation, have utilized self report measures"(p. 1438). Self-report is an imperfect measure; however, there is no other way to gain insight into the childhood sensory experiences of participants who are now adults, especially as SPD is not a current DSM-V diagnosis.

An additional limitation of this study is that individuals who endorse symptoms of SPD could meet the criteria for ASD, negating my claim that SPD should be considered a stand-alone diagnosis separate from ASD. While I will ask participants to indicate whether or not they have ever been diagnosed with Asperger's Syndrome or ASD, as well as if they have ever undergone testing to determine if they have ASD, it is possible that individuals who have undiagnosed ASD did participate in this survey. This would skew the results and potentially make SPD seem more prevalent, when in reality for those particular individuals their sensory processing struggles would fall under the umbrella of an ASD diagnosis. In addition, there is a significant link between ASD diagnosis and co-occurring mental illness in adulthood. As Salazar, Baird, Chandler, Tseng, O'Sullivan, Howlin, Pickles, and Simonoff (2015) state, "there is substantial literature in older children, adolescents and adults describing the prevalence and correlates of co-occurring psychiatric disorders in ASD" (p. 2284). Given this already established link, it will be challenging to determine a similar link involving SPD without thoroughly ruling out an underlying ASD diagnosis to explain sensory symptoms. The ability to rule out ASD is compromised by using a self-report, anonymous survey.

Implications for Social Work

      Social Work Practice. All social workers should have an understanding of SPD and how to work with individuals who are struggling with sensory stimuli (Walbam, 2013). This is particularly true in the context of working with children and families. The results of this study indicate a higher level of interfamilial conflict where a child struggles with sensory processing difficulties. Recognizing and addressing sensory processing difficulties, providing psychoeducation to parents whose children are hypo- or hyper-sensitive, and working in an interdisciplinary setting with occupational therapy is the most comprehensive way to treat families. As Walbam (2013) states: "though psychotherapy does not treat the underlying cause, it can help a child cope with the resulting behaviors and emotions of SPD" (p. 67). Social workers may take a backseat to occupational therapists in the treatment of SPD itself, but they are essential to successful family healing and in creating a holding environment for those with SPD and their loved ones.

      Clinician Training. Current clinical training posits the importance of social workers understanding biologically based difficulties such as SPD through the biopsychosocial model of assessment and treatment. There is a great deal of research on the importance of incorporating biology into training along with the psychological and social/societal implications that we tend to focus on, given how these three aspects of human life are inherently intersectional. In addition to general biology, specific training about SPD will be essential for all clinicians both in terms of understanding their client's sensory development, but also in order to assess for potential treatments that may involve sensory interventions (Walbam, 2013).

      In training clinicians about these biological aspects of human functioning, training about SPD should also occur through a lens that incorporates ableism. Understanding the challenges

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that individuals with SPD face as the result of living with an invisible disability will help

clinicians identify, case manage, and treat individuals struggling with SPD. As Ismael et al.

(2015) state: Sensory processing patterns are reflections of what people are; these patterns are

not a pathology that needs fixing" (p. 317). This phenomenological understanding of SPD is

imperative to training clinicians with the same levels of empathy and compassion that social

workers need in order to work with vulnerable populations such as this one.

Policy. In addition to the clinical and training implications, there are also policy

implications that follow from this study. The largest consideration is about how mental health

treatment is funded. Currently in the U.S. in order for a mental health issue to be covered by

insurance there often must be a diagnosis attached to the individual receiving treatment. As SPD

is not currently a diagnosis within the DSM-V there are two different ways to address this issue.

The first would be to include SPD in the DSM-V. As discussed in the literature review, there is a

great deal of evidence that there are many benefits to understanding SPD as a unique diagnostic

category. It was previously noted that diagnostic manuals other than the DSM-V use SPD as a

distinct diagnostic category (Anazlone et al., 2007). In addition, studies by Chang et al. (2014)

and Owen et al. (2013) indicate that the part of the brain that processes sensory integration is

distinctly separate than the parts of the brain that appear different as a result of ASD or ADHD.

Including SPD as its own diagnosis would create space within the system for the highest

standards of treatment to occur.

A second solution, and one that would require a more radical overhaul of the current

system would be to abolish the current system, allowing individuals to receive mental healthcare

without an attached diagnosis. As stated in a 2013 report by the World Health Organization

(WHO) about barriers to mental health treatment: "Self-stigma and label avoidance can be

related to the desire to handle the problem by oneself" (p. 1312). Receiving a mental health diagnosis is a deterrent from seeking necessary treatment. These adjustments to the DSM-V or to our healthcare systems would also need to include occupational therapists to be covered by all insurance plans. Walbam (2013) discusses best practices for working with children with SPD, stating: "A referral to an occupational therapist should be made if a social worker suspects that a child's behaviors may be result of SPD." (p. 67). Occupational therapists are essential partners in the treatment of SPD and insurance policies need to reflect this.

Another policy area that this study highlights is a lack of funding for psychoeducation, particularly in the public school systems. Public Schools need to have more funding focused on student wellness and treating mental health issues. As Vanderbleek (2004) states: "school-based mental health services are fragmented, marginalized, and underutilized" (p. 211). The current focus appears to be on prescribed or standardized ways of learning that do not fit the needs of all children, particularly children with SPD. As Maxam and Henderson (2013) state within their case study: "Mr. Lopez [the school administrator] was told – in no uncertain terms – that his sole priority at this point was to raise grades and improve SAT scores or they would risk losing more state and federal funding" (p. 75). Maxam and Henderson's (2013) case study looked at a school administrator putting more time, effort, and resources into addressing invisible disabilities similar to SPD. The school system made it clear that this is not a priority. Given the importance of teachers in child development, more funding and attention need to be directed towards programs such as the one that Maxam and Henderson (2013) report on. This could have an unprecedented impact on the educational experiences of all children, particularly those with SPD.

Future Directions

The results of this study demonstrate the need for further research on how sensory processing difficulties in childhood impact childhood relationships and mental health outcomes in adulthood. This is a pilot study, and it will initially be important to replicate the study using a larger and more diverse sample to confirm these results as well as to determine if these findings hold true across the population or if certain populations are more adversely impacted by sensory processing difficulties. When replicating this study, it would be important to do more advanced statistical analysis, looking at whether the combination of sensory processing difficulties and invalidating childhood environment lead to the greatest possibility of developing a mental health diagnosis.

A longitudinal study would be important in terms of understanding how sensory processing difficulties evolve across a lifetime. Identifying children with sensory processing difficulties and looking at their relationships with parents/caregivers, teachers, and peers. This would both eliminate the need for retrospective self-report and it would give researchers the opportunity to engage in randomized control trials with various sensory or attachment-based interventions to determine if there are positive outcomes in regards to the development of mental health diagnoses in adulthood.

Another interesting direction would be to look at the types of labels that children with sensory processing difficulties are given, and how these labels impact their mental health outcomes. For example, if children with similar sensory issues are labeled as having ADHD, ASD, emotional reactivity, or simply as "problem children," how do these labels affect a child's sense of self, the levels of validation/invalidation in various childhood environments, and the eventual mental health outcomes in adulthood? While there is some promising research that

examines this, more questions of language need to be examined through the lens of sensory processing difficulties and a child's understanding of self and their self-worth.

Conclusion

Up until recently, sensory processing has been a neglected area of study, particularly from holistic perspectives that differ than those rooted in the biological implications of sensory processing difficulties. As social workers, we are aware that biological implications do not exist in a vacuum and we recognize the need for inquiry into how biology intersects with social and psychological factors. This study indicates that in the case of sensory processing difficulties, there is far more at play than simply a biologically based difficulty. The participants in this study indicated that they experienced psychological pain and relational difficulties as a result of struggling with sensory processing issues, and the statistical results suggest that those individuals were significantly more likely to receive a mental health diagnosis in adulthood. Until sensory processing difficulties are better understood and the public is better educated on the issues they create, sensory processing will continue to be an invisible struggle, often labeled as a behavioral concern rather than as a unique and valuable way of seeing, hearing, touching, and interacting with the world around us.

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Appendix A: Smith College Human Subjects Review Committee Approval Letters

![Smith College logo]

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

January 27, 2016

Emma Ross

Dear Emma,

You did a very nice job on your revisions. 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.

Congratulations and our best wishes on your interesting study.

Sincerely,

Elaine Kersten, Ed.D.
Co-Chair, Human Subjects Review Committee

CC: Rob Eschmann, Research Advisor

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

February 10, 2016

Emma Ross

Dear Emma,

I have reviewed your amendments and they look fine. The amendments to your study are therefore approved. Thank you and best of luck with your project.

Sincerely,

Elaine Kersten, Ed.D.
Co-Chair, Human Subjects Review Committee

CC: Rob Eschmann, Research Advisor

Appendix B: Informed Consent

Smith College
2015-2016
Consent to Participate in a Research Study
Smith College School for Social Work ● Northampton, MA
……………………………………………………………………………….
Title of Study: Is Sensory Processing Disorder in Childhood a Predictor for a Diagnosis of Emotional or

Psychological Problems in Adulthood?

Investigator(s): Emma Ross, MSW Candidate, xxx-xxx-xxxx

……………………………………………………………………………….

Introduction
- You are being asked to be in a research study about your sensory processing experiences as a child and your early relationships with your parents/caregivers, teachers, and peers. You sometimes use attachment only and sometimes invalidating environments throughout your proposal, be consistent that you are looking beyond the family into broader invalidating environments.
- You can participate in my study if you are at least 18 years of age, can participate in an English language computer-based survey, and have an interest in this topic. This doesn't say they have to have sensory processing difficulties, so how do you know who is relevant? This is inclusive of all adults.
- We ask that you read this form and ask any questions that you may have before agreeing to be in the study.

Purpose of Study
- The purpose of the study is to gain an understanding of whether sensory processing challenges in childhood are associated with difficulties in relationships with parents/caregivers, teachers, and/or peers, and whether there is an association with emotional or psychological distress in adulthood.Change causal language to correlational
- This study is being conducted as a research requirement for my master's degree in social work.
- Ultimately, this research may be published or presented at professional conferences.

Description of the Study Procedures
- If you agree to be in this study, you will be asked to complete an online survey asking you questions about your childhood experiences with sensory processing. In addition, you will be asked personal information including if you have ever sought counseling for emotional or psychological distress. You will also have the opportunity to write about your experiences if you choose.

Risks/Discomforts of Being in this Study
- There are no reasonable foreseeable (or expected) risks, however if you experience discomfort as the result of participating in this study, please contact the Crisis Call Center via phone (1800-273-8255) or text (Text "ANSWER" to 839863). If you would like to meet with someone in person, you can contact the American Psychological Association to find a psychologist at: http://locator.apa.org or a clinical social worker through your local chapter of the U.S. National Association for Social Workers (NASW) or clinical social work chapters in the state or province where you live.

Benefits of Being in the Study
- The benefits of participation might include gaining insight into childhood experiences and relationships and how they may be influenced by sensory processing factors, and having an opportunity to share your thoughts about such issues that may be important to you.
- The benefits to social work/society are: determining a connection between sensory processing difficulties and emotional distress could contribute to new preventative measures both for individuals and families with children managing sensory processing challenges. In addition, this study could provide evidence for sensory processing disorder as its own diagnosis or as a component of other diagnoses, which could help people gain access to preventative resources such as occupational or other therapists.

Confidentiality

- This study is anonymous. We will not be collecting or retaining any information about your identity.

Payments/gift
- I am unable to offer any financial payment for your participation.

Right to Refuse or Withdraw
- The decision to participate in this study is entirely up to you. You may refuse to take part in the study *at any time* until you submit your survey. Choosing to exit the survey will not affect your relationship with the researchers of this study or Smith College. Your decision to refuse will not result in any loss of benefits (including access to services) to which you are otherwise entitled. You have the right not to answer any single question, as well as to withdraw completely up until you submit your survey. As the results of the survey are anonymous, once you submit your survey I will have no way of identifying which survey is yours and therefore no way of removing your responses. New language about their responses may still be counted if they don't finish the survey?

Right to Ask Questions and Report Concerns
- You have the right to ask questions about this research study and to have those questions answered by me before, during or after the research. If you have any further questions about the study, at any time feel free to contact me, Emma Ross at eross@smith.edu or by telephone at xxx-xxx-xxxx. If you have any other concerns about your rights as a research participant, or if you have any problems as a result of your participation, you may contact the Chair of the Smith College School for Social Work Human Subjects Committee at (413) 585-7974.

Consent
By checking the boxes below, you indicate that you have decided to volunteer as a research participant for this study, and that you have read and understood the information provided above.

Appendix C: Survey Questions

1. **I am 18 years of age of older**
   Yes   No

2. **I am able to participate in an English language survey**
   Yes   No

Informed Consent – See Appendix B

3. **I have read the above information and consent to participate in this survey**
   Yes   No

4. **Between the ages of 4 and 12, did you experience (check all that apply):**

   Resisted changes in head position
   Appeared fearful for playground equipment or carnival rides
   Avoided balancing activities
   Were oblivious to risks of heights or moving equipment
   Over-reacted to unexpected touch or avoided light touch
   Disliked teeth brushing, hair washing/brushing, face wiping
   Appeared irritated or avoided certain food or clothing textures
   Disliked or avoided messy play or foods
   Appeared irritated when someone was in close proximity
   Insisted on rubbing or feeling objects
   Frequently placed mouth on objects
   Had difficulty manipulating small objects
   Sought pressure input through deep hugs, squeezing objects, hiding under pillows
   Enjoyed rough and tumble play
   Relaxed following massage or deep pressure
   Exerted too much or too little pressure when handling object
   Appeared clumsy, bumped into people or objects
   Appeared uncomfortable (squinted, turned away) in strong sunlight or artificial lighting
   Had difficulty scanning the environment for desired object
   Appeared fascinated with flickering lights, flipping pages, bubbles, dripping water
   Stared at spinning objects, shadows, opening and closing doors
   Covered ears or became upset with loud or unexpected sounds
   Noticed sounds that others did not hear
   Appeared hard of hearing or missed certain sounds
   Disliked strong smells or tastes
   Craved strong smells or tastes
   Ate non-edibles
   Appeared restless and required frequent movement breaks
   Preferred quiet play
   Appeared anxious or fearful
   Had difficulty paying attention at school or home

Required routine and had difficulty with transitions
Other (please specify)

5. **Please Reflect on and describe your most salient sensory processing issues as a child**

6. **Have you ever, either as a child, adolescent, or adult, sought professional help for psychological or emotional distress?**
      Yes   No

7. **If yes, did you receive a mental health diagnosis?**
      Yes   No   N/A

8. **If yes, what was the diagnosis?**

9. **Please answer the following questions related to how your parent or caregiver responded to your sensory needs:**

My caregiver usually understood my feelings and helped me manage them
Never   Infrequently   Sometimes   Often   All the Time   N/A

My caregiver encouraged me to believe that I was imagining things
Never   Infrequently   Sometimes   Often   All the Time   N/A

When I felt uncomfortable of upset, my caregiver usually ignored this
Never   Infrequently   Sometimes   Often   All the Time   N/A

My caregiver indicated that they thought I was being difficult in regards to my sensory needs
Never   Infrequently   Sometimes   Often   All the Time   N/A

If I felt uncomfortable, my caregiver would say things like "you're fine, no one else has a hard time with this"
Never   Infrequently   Sometimes   Often   All the Time   N/A

When I was upset, my caregiver would ask what was wrong so they could try to help me
Never   Infrequently   Sometimes   Often   All the Time   N/A

If I said I couldn't do something, my caregiver would say things like "you're being difficult on purpose"
Never   Infrequently   Sometimes   Often   All the Time   N/A

My caregivers encouraged me to hide or control my emotions, or to "behave like a grownup"
Never   Infrequently   Sometimes   Often   All the Time   N/A

I was encouraged to "suck it up" when I became upset
Never   Infrequently   Sometimes   Often   All the Time   N/A

I was labeled a "troublemaker" at home
Never   Infrequently   Sometimes   Often   All the Time   N/A

My caregiver helped me my teaching me ways to be comfortable even when I was experiencing challenges
Never   Infrequently   Sometimes   Often   All the Time   N/A

10. **Please reflect on how your parents/caregivers responded to your sensory needs throughout your childhood**

11. **Please answer the following questions related to how your teachers or educators responded to your sensory needs**

My teachers made a point of trying to understand my feelings and help me manage them
Never   Infrequently   Sometimes   Often   All the Time   N/A

My teachers encouraged me to believe that I was imagining things
Never   Infrequently   Sometimes   Often   All the Time   N/A

My teachers helped me by teaching me ways to be comfortable even when I was experiencing challenges
Never   Infrequently   Sometimes   Often   All the Time   N/A

My teachers indicated that they thought I was being difficult in response to my sensory needs
Never   Infrequently   Sometimes   Often   All the Time   N/A

If I said I couldn't do something, my teachers said things like "you're being difficult on purpose
Never   Infrequently   Sometimes   Often   All the Time   N/A

I was labeled a "troublemaker" at school
Never   Infrequently   Sometimes   Often   All the Time   N/A

12. **Please reflect on how your teachers responded to your sensory needs throughout your childhood**

13. **Please answer the following questions related to how your childhood friends or peers responded to your sensory needs**

My peers usually understood my feelings and adjusted our play to help me feel more comfortable
Never   Infrequently   Sometimes   Often   All the Time   N/A

My peers often said that they thought that I was "just trying to get out of doing things" when I expressed my sensory needs
Never   Infrequently   Sometimes   Often   All the Time   N/A

My peers teased or made fun of me when I was uncomfortable with something

Never   Infrequently   Sometimes   Often   All the Time   N/A

14. Please reflect on how your friends or peers responded to your sensory needs

15. Have you ever been *diagnosed* with Autism, including Asperger's, or any other Autism Spectrum Disorder?
    Yes   No   I do not know

16. Have you ever been tested for Autism, including Asperger's or any other Autism Spectrum Disorder?
    Yes   No   I do not know

17. What is your gender identity?
    Male
    Female
    Transgender
    Genderqueer
    Other (Please Specify)

18. What is your age?
    18-24
    25-34
    35-44
    45-54
    55-64
    65+

19. How do you identify your race/ethnicity (check all that apply)?
    White
    Hispanic or Latino
    Black
    Native or Aboriginal
    Asian or Pacific Islander
    South Asian or Indian
    Middle Eastern
    Other (please specify)

20. How do you identify your socioeconomic status (SES)?
    Less than $20,000
    $20,000 - $40,000
    $40,000 - $60,000
    $60,000 - $80,000
    $80,000 - $100,000
    Above $100,000
    Other (please specify)

Appendix D: Sensory Processing Checklist by Yack, Aquilla, & Sutton

SENSORY SCREENING - Does your child:

VESTIBULAR
q resist changes in head position
q appear fearful of playground equipment or carnival rides
q appear fearful of heights (slides, stair climbing)
q avoid balancing activities
q seek fast moving rides or activities
q oblivious to risks of heights or moving equipment
q frequently spin, jump, bounce, run

TOUCH
q over-react to unexpected touch or avoids light touch
q dislike teeth brushing, hair washing/brushing, face wiping
q appear irritated or avoids certain food or clothing textures
q dislike or avoid messy play or foods
q appear irritated when someone is in close proximity
q insist on rubbing or feeling objects
q frequently mouths objects
q have difficulty manipulating small objects

PROPRIOCEPTION
q seek pressure input through deep hugs, squeezing objects, hiding under pillows
q enjoy rough and tumble play
q relax following massage or deep pressure
q exert too much or too little pressure when handling object
q appear clumsy, bump in to people or objects

VISUAL
q appear uncomfortable (squints, turns away) in strong sunlight or artificial lighting
q have difficulty scanning the environment for desired object
q appear fascinated with flickering lights, flipping pages, bubbles, dripping water
q stares at spinning objects, shadows, opening and closing doors

AUDITORY
q appear distracted by noises
q covers ears or becomes upset with loud or unexpected sounds
q notice sounds that others do not hear
q appear hard of hearing or misses certain sounds
q seek out certain music or sounds

SMELL/TASTE
q dislike strong smells or tastes
q crave strong smells or tastes
q smear their stool
q eat non-edibles

ACTIVITY LEVEL AND EMOTIONAL RESPONSES
q appear restless and require frequent movement breaks
q prefer quiet play
q appear anxious or fearful
q have difficulty paying attention at school or home
q require routine and have difficulty with transitions

Ellen Yack and Associates

Appendix E: Invalidating Childhood Experiences Scale (ICES) by Mountford et al.

The following questions address your experiences of how your parents responded to your emotions when you were young. For each item, please choose the rating from 1 to 5 that most closely reflects your experience up to the age of 18years.

1 – Never
2 – Rarely
3 – Some of the time
4 – Most of the time
5 – All of the time

Because your parents may have been very different, please rate them separately. The left hand column is to rate your mother, and the right hand column is to rate your father.

Mother   Father

During my childhood
- My parents would become angry if I disagreed with them.
- When I was anxious, my parents ignored this.
- If I was happy, my parents would be sarcastic and say things like: "What are you smiling at?"
- If I was upset, my parents said things like: "I'll give you something to really cry about!"
- My parents made me feel OK if I told them I didn't understand something difficult the first time.
- If I was pleased because I had done well at school, my parents would say things like: "Don't get too confident".
- If I said I couldn't do something, my parents would say things like: "You're being difficult on purpose".
- My parents would understand and help me if I couldn't do something straight away.
- My parents used to say things like: "Talking about worries just makes them worse".
- If I couldn't do something however hard I tried, my parents told me I was lazy.
- My parents would explode with anger if I made decisions without asking them first.
- When I was miserable, my parents asked me what was upsetting me, so that they could help me.
- If I couldn't solve a problem, my parents would say things like: "Don't be so stupid — even an idiot could do that!"
- When I talked about my plans for the future, my parents listened to me and encouraged me.

Finally, we would like to know how you saw your whole family when you were younger. Please read the following descriptions and rate how closely each one matches your experience of growing up in your family (up to 18 years).

1 – not like my family
2 – a little bit like my family
3 – like my family some of the time
4 – like my family most of the time

5 – like my family all of the time

Family types Rating (1–5)
1. During my childhood, my parents were often not available, and I got little time or attention. I was often left to fend for myself or go round to friends/relatives. My parents often got angry if I asked for things. One or both of my parents may have had substance misuse difficulties, mental health problems or financial problems. (Chaotic)
2. During my childhood, I felt listened to and cared for. My parents were interested in my thoughts and ideas and encouraged me to make my own decisions and choices. If things were difficult for me, they supported me and tried to comfort me. (Validating)
3. During my childhood, everything in my family was perfect on the surface. However, my parents couldn't stand it if I showed I was upset, scared or angry. They expected me to put hide my feelings and get on with it. (Perfect)
4. During my childhood, it was important to be able to control your emotions and focus on achievement and success. "Behaving like a grown-up" was desirable. (Typical)

Thank you very much for answering these questions.

Appendix F: Sampling of Participant Narrative Responses

Salient Sensory Processing Symptoms

"Didn't like people near my hair. I also didn't like loud children - found the sounds of other children playing and laughing abrasive"

"I chewed on everything. My nails/fingers, hair, erasers, Barbie feet, pens, rubber bands, shirt collars, leather gloves, etc..."

"Loud noises drove me nuts and hurt my head way more than it should have"

"The sound of people chewing drove me absolutely crazy to the point of anger or having to leave the room"

"I struggled with personal space. I didn't like physical contact, even with family members. No history of any kind of abuse."

"Itchy clothing like wool or tags was unbearable when it touched my skin. I was ALWAYS cold, with blue hands and feet, unless it was summer and over 75 degrees. I refused to eat a lot of things and my parents would make me sit at the table for hours until I finished my peas or whatever disgusting food they were trying to make me eat. I never, ever ate what they were trying to force me to eat and I still don't eat those things. Finally they would just send me to bed. I was (am) a light sleeper and completely quit taking naps when I was 4 months old. I don't remember exactly what caused me so much stress but I would often end up in my closet (there was no light in there) laying on blankets in the dark."

"I remember being in a summer camp. We were on a nature walk and had to walk on a log over a shallow mud hole. I did not want to do it. I was sure I would fall. The camp counselors made me do it. I fell in and got very muddy and had to be walked back to camp. I was vindicated but also very embarrassed. The camp counselors were very annoyed"

"…My mom says I always had problems with transitions and she's probably right, but I don't quite interpret it that way"

"A particularly salient memory was being thoroughly traumatized by fire drills in pre-school. The concept of fire was terrifying to me along with the extremely loud alarm and (simulated) panic to get out. The teachers at my school were concerned enough that they asked my mom to come in so they could talk about it"

"Sense of sound. It started around 6 or 7, but I get unnaturally angry and irrational around sounds (or certain movements) that annoy me. I can hear things people can't and I can't focus on anything but the sound that is bothering me, no matter how hard I try/tried"

"Strongly disliked the "feeling" of "squeeky" snow under foot. I disliked this to the point that I would avoid walking on the snow if there was an alternative, or cleared, path. I still have this sensitivity, but it's not as strong"

"Could not sit still long enough to learn to read a book and fell behind in class as a result"

"Whistling and other oral noises (chewing, clicking, certain singing) caused me to feel extremely frustrated and sometimes provoked outbursts"

"Very isolated, confused. Felt crazy because nobody else got angry at sounds"

"Texture and smell were big for me. Certain fabrics like velvet made me recoil. Seams in socks and tights irritated me so much I would cry. My mom would have to pull the seams over my feet when I put shoes on. I needed to smell everything first before I decided what I thought about it (I still do this)"

"Food textures were the most difficult for me. I also had no concept of where my body was in space and actually broke my arm and gave myself multiple concussions falling off of or running into things (couch, table, playground equipment, etc.)"

"Loud environments would make me extremely uncomfortable. Rough housing made me very upset to the point of crying"

"Was very bothered by feet moving, certain people "clicking" hard candies, gum chewing, certain people eating food loudly, and the sight of fingers moving slightly on the steering wheel, to the extent I would always carry music to cancel out sound an would have to leave the room or obstruct bothersome sights with a pillow"

"I used to scream when having my hair washed because I didn't like the feeling of the water on my head"

Parental/Caregiver Relationships

"My parents were believers in 'tough love'... Emotions were not nurtured, sadness was brushed aside, too much enthusiasm was told to calm down"

"I was the oldest of 4 and was often told to be a big girl rather than process my emotions or feelings"

"Mostly my parents thought I had "quirks" because I had a high-IQ. They just ignored some of my weird things but things like not eating and always being cold they got really irritated with"

"Didn't try and help too much on a day to day basis, instead they just sent me to therapy and hoped it would fix me"

"I was constantly told that I 'just wasn't trying hard enough'"

"With punishment. sent to room. got angry"

"They didn't respond. I had to just go along as if everything was normal"

"My parents reprimanded me for feeling irritated or overly scared by noises that were aversive to me"

"My caregivers were very dismissive of my feelings of discomfort and an attempt to convince me that I was simply overreacting or attempting to draw attention to myself. I began to keep any mentions of discomfort to myself to avoid conflict"

"They didn't react well to things so I feel like I just learned very early on not to say anything. For example, I had vision issues starting in the second grade but my asking to see an eye Dr. was seen as attention seeking so I never brought it up again for years"

"My mom was okay, and tried pretty hard, but my dad frequently told me I was imagining things, that I was making things up, or that I was trying to be 'special'"

"Mostly ignoring it, saying 'get over it, calm down for fuck sake' etc."

"Dad didn't understand and mom acted like I was being a big baby"

"I was mostly neglected and shamed"

"My parents often dismissed my challenging sensory needs. They often ignored me alone until I calmed down, made me do things that really upset and scared me, or made me make compromises such as, 'You have to wear those uncomfortable, tight fitting dress clothes until after Christmas dinner, then you can bring more comfortable clothes to change into after dinner.'"

"It was a running family joke and my caregiver certainly made light of it. Sometimes I didn't mind, but sometimes I felt like my family was laughing at my expense and not respecting that I had different boundaries and needs"

Teacher Relationships

"I was seen to be a 'chatty Cathy' and was frequently disciplined whereas I has no idea what I was doing wrong"

"Attended gifted school/Montessori and so was allowed to take frequent quiet-times and mostly dictate my own schedule/breaks as needed"

"My teachers were unaware that I had any needs. In the 80s and 90s I think that type of discussion was pretty uncommon"

"Some were sensitive and knowledgeable to mental illness, empathetic. Others couldn't have cared less and were of the "suck it up" mentality"

"Teachers did not often pay much attention to me because I was always very quiet"

"They told me that I was lying when I've told them the truth"

"I was a perfectionist, and highly functional at school. Doodling helped me pay attention, and because I was quite active in class, I think my teacher's let me get away with it. I did struggle in math, and would seek extra help after school. Visual and graphic aids were immensely helpful to me, and most of my teachers -- seeing that I was taking extra effort to understand -- would attempt to explain a concept that way"

"My teachers never said anything about my sensory needs other than believing that I had attention span issues and telling me to stop mouthing objects. Explicit discussion of sensory related behaviors never occurred during my education"

"Constantly sent to the "office"; detention. Said I had learning disabilities and was a trouble maker"

"They didn't know what else to do rather than just excuse me from certain situations. Some would allow me to bring headphones to class, but others didn't believe I had any problem that the other kids didn't have"

"In preschool, teachers responded attentively to sensory needs providing stimulation like brushing, lying down in a dark place and squeezing stress objects. This was very salient to me and I still remember it strongly"

"I hid my troubles at school. Hid in the bathroom etc."

"My teachers recognized that I was a particularly sensitive child and sometimes tried their best to deal with that fact"

"Having gone to a pretty strict Catholic school, sometimes children's feelings weren't priority #1 for the teachers (read: sometimes nuns) running classes"

"My first grade teacher was fantastic but the rest kind of endured me. I had full-on meltdowns whenever the fire alarm went off and they didn't know how to handle it. I got better as I got older, but the anxiety never fully went away, and I was very avoidant"

"My teachers pretty much expected me to do the regulating myself. I don't ever remember talking about how to regulate emotions. They would be good about understanding emotions though"

"I was lucky to have amazing teachers who made accommodations for my needs and

taught me coping strategies"

"From the second grade on I was in a self-contained gifted/talented classroom with very specialized instruction"

"I think I hid it pretty well at school. I loved learning and being a student and found that my physical boundaries were better respected at school than they were at home"

"I was a bit hyperactive and I think I tried my teachers' patience, so they rarely comforted me or tried to help"

Peer Relationships

"They just said 'oh' and we used/ played something else"

"They didn't understand how I was unable to eat foods they loved. They couldn't understand that they didn't smell like food to me"

"I was a very overweight child and often any need to satisfy sensory needs was seen as manifesting the fact that I couldn't control myself"

"My peers are usually just curious why I can't do certain things. They tease but not to the point of bullying"

"Was often teased/bullied or became a bully, depending on the schoolyard dynamic that year (moved/changed schools frequently). Can recall a number of times that I was alienated or mocked because I was anxious about an activity/setting"

"There was no label for my problems. My peers just thought I was being difficult or weird"

"I would usually adapt to my friends' needs and wants, while neglecting my own"

"My peers were my older three brothers so they gave me a hard time any time I complained about noise or things that would be 'inconvenient'"

"Very helpful and understanding"

"I am a highly sensitive person, and over stimulation is exhausting for me. I live in New York where I am constantly stimulated. I have a lot of friends here, and often have to turn down social commitments because I need time to recuperate and be alone. Very few people understand this. In high school I used to blame this on my parents, in college on my workload, but now, I really have no other excuse than "I'm too tired" to which they respond "you just don't like us." I don't know how to explain the fatigue I feel every day from being so highly sensitive -- both reactive to experiences, and anxious about potential threats to my stability"

"My sensory responses were either ignored by friends or ridiculed by others, they were a large source of bullying and social awkwardness"

"If my peers found out I disliked a certain sound or movement they made, they'd continue to do it until I was in tears and excused from the classroom"

"Made fun of constantly. Picked on. Bullied"

"Generally more understanding, as there was more communication about being uncomfortable around peers"

"Increasingly supportive of each others discomforts the older we became"

"I was definitely picked on because they saw me as 'weird' and different"

"My friends were quite understanding of my needs but would still try to get me to push through them. My peers made it more difficult for me to feel comfortable in a school environment, as they felt the need to bully me"

"My good friends would tease in a loving way, and almost always made accommodations"

"None of my friends could fully relate to my difficulty to focus on things so they would push it off, and make me feel a little "dumb" sometimes during tests, homework, etc."

"I was a social misfit in school until 7th grade, I was a total outcast until I switched schools and started over. I was terrorized in gym class especially"

"My friends teased me, but it was almost always in a light hearted and not mean spirited manner. All of my friends were a little strange in their own ways. We teased each other, but we also protected each other from the outside world"

"My peers were assholes because I was an easy target. They loved seeing how I reacted to certain things"

"I tried to be tough around loud sounds if I was with friends. I never made my friends accommodate my sensory needs that I remember. I did get teased and bullied often for being "too sensitive" and "not being able to take a joke" and things"

"Early on, certain kids picked up that I am a sensitive person. I went to religious school where from grades 2-4 I was bullied by other immigrant children like me. When I went to a diverse public school class, this ended. I don't know that the bullies were picking up on sensory issues so much as trauma associated with immigration and other psychological things"

"My friends pulled and pushed my comfort zone day to day. They did what they wanted whether I liked it or not"

"I was teased for being bad at sports--competitive sports made me nervous and was uncomfortable"

"I had close friends who were similar to me. I felt understood by them"