SENSORY PROCESSING DISORDER: FAMILY PERSPECTIVES ON THE DISORDER AND THE ROLE OF COUNSELING

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ABSTRACT

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Sensory Processing Disorder (SPD) is defined as an "inability to use information received through the senses in order to function smoothly in daily life" (Kranowitz, 2005, p. 9). The purpose of this study was to examine the perspectives and experiences of families in the process of seeking treatment for their child's sensory processing disorder and the availability of family mental health support (defined as counseling). There is limited literature in the area of the mental health support for children living with SPD. A qualitative interview methodology was utilized in this study. The qualitative research data consisted of seven telephone interviews with parents of children living with SPD. These parents were either Parent Connection Hosts or Parent Connection group members from the Sensory Processing Foundations Parents' support groups for SPD parents. Comparative data analysis involved looking for similar and distinct themes in the participant's stories from which several main themes emerged. Findings indicated that counseling was not offered to most of the participants and that they had to independently seek out other necessary services for their children. In light of the experiences of the participants, implications for counselors are provided. It was concluded that counselors should endeavor to become a part of the collaboration process necessary to better provide mental health support to families with children living with SPD.

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DEDICATION

Deciding to do this study was a choice that affected my whole family. This study was something that I felt I had to do; something that was important for me to do. They understood and supported my endeavor.

This thesis is dedicated to my family. This was truly a family journey filled with sacrifice, endurance, and love.

Greg, my husband and the love of my life...You have held us together this year and I thank you for allowing me this opportunity. Thank you for being an editor extraordinaire, for continually seeing good in me that I did not know could develop, and for living a life of faith and service that displays a love for people to which I aspire. Thank you, I could not have done this without you.

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“All things can be done for the one who believes.”

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CHAPTER I

INTRODUCTION

As children struggle so too do their families. Sensory perception disorder also known as sensory processing disorder is prevalent in children; research shows that Sensory Processing Disorder affects 5% of children in the United States (Auer & Blumberg, 2006). Sensory Processing Disorder, hereafter referred to as SPD, has yet to be recognized formally in the Diagnostic and Statistical Manual of Mental Disorders (DSM). The Sensory Processing Foundation has currently presented an application for SPD to be entered as a separate diagnosis in the next publication of the Diagnostic and Statistical Manual which will be the DSM-V. It is significant to note that SPD has been included in the 2005, *Zero to Three: Diagnostic Classification of Mental Health in Developmental Disorders* in *Infancy and Early Childhood* as disorders of Regulation, a diagnostic category for infants and toddlers. Also the *Diagnostic Manual for Infancy and Early Childhood* (ICDL) is published by the Interdisciplinary Council on Developmental and Learning Disabilities and for the first time in 2007 included SPD as a Regulatory Sensory Processing Disorder. Inclusion in the DSM-V would open doors not only for research but would assist parents in their concern for their children's diagnosis and treatment opportunities. For some families the hurdles on the journey can include obtaining a diagnosis, teaming with the appropriate clinicians, and finding proper treatment.

I describe the family experience as a journey. As the families seek professional services in order to best care for their children this is a journey that is traveled together. The word journey in the Oxford American Dictionary is defined as the "act of going from one place to another" (Lindberg, 2009, p.705). This invokes a depiction of movement and adjustment. Journey is listed with similar words such as "expedition, pilgrimage, campaign, quest, voyage and trek" that give an indication of the enormity of the strength and inner reserve that the tasks of the journey might demand along the way (Lindberg, 2009, p.705).

Acquiring an understanding of the experiences and perspectives of families of children living with SPD would allow counselors to better facilitate honest hope and a true therapeutic relationship. It is my assumption that there is a gap in service to parents of children living with SPD. SPD is a disorder that can be difficult to decipher. Counselors need to be aware of this and begin to look for the tell-tale signs of SPD. They need to begin to listen well to parents who are traveling this journey with their children.

Sensory processing disorder is often misdiagnosed as learning disabilities (LD), speech/language problems, auditory or visual discrimination, Attention-Deficit Hyperactivity Disorder (ADHD), Oppositional Defiant Disorder (ODD), or other behavioral disorders. It can be easily misinterpreted not only by the medical community but by family and friends as well. According to Dr. Miller, founder of the SPD research program, to distinguish between SPD, ADHD, and other disabilities requires collaboration with occupational therapists to define the underlying neurological and physiological foundations of SPD (Kranowitz, 2005). SPD and ADHD differ in the children's responses to "unexpected sensations, such as light touches, loud noises, flickering lights, strong smells, and being tilted backward in a chair" (Kranowitz, p. 29).

Struggling through misdiagnoses, with consequent unnecessary treatment as well as the challenges of SPD can cause the journey to be more complicated. Kranowitz notes that these misinterpretations as well as difficulties of the disorder can have psychosocial implications for the child and the family.

As the family travels through the medical community they come in contact with health professionals whose main calling is to provide help and healing to different parts and functions of the body. These professionals, depending on the child's symptoms, could be pediatricians, nutritionists, physical therapists, occupational therapists, speech-language therapists, teachers, psychiatrists and counselors or some combination therein. One can already imagine that the family's journey just got longer, the path added more sharp turns, and thus the family grows wearier.

Hope

Families and researchers have hope for the children living with SPD. Finding the right clinicians can instill the family and the journey with hope. Researchers and therapists have found that a child with SPD, because their nervous system is still flexible responds well to intervention. This intervention can make a difference physically, academically, and emotionally (Kranowitz, 2005). Kranowitz explains that flexible implies plasticity, meaning their brain function is not fixed. The purpose of treatment is to help the child regain function. Kranowitz notes that better sensory processing leads to better adaptive behavior which can in turn lead to overall psychosocial improvement. It is my supposition that this work requires a team of clinicians, which includes counselors. I presume this not just because of the complexities of this persistent disorder and not just because we are dealing with the whole family. I presume this because I am hearing from families that they are hurting and have more than physical needs.

Occupational therapy is at this time the core treatment for SPD (Auer & Blumberg, 2006). It is assumed that most children will receive a referral to occupational therapy from their primary care physician or pediatrician. The focus of this paper is the experience of the family and their child and thus the services available for the family as they travel this journey with their child who is affected by SPD.

Authors Auer and Blumberg tell of the standard airline safety guideline when a journey is altered by an unexpected frightening event: put on your oxygen mask before putting one on your child, so that you do not pass out or become incapable of taking care of those which you are responsible.

These safety guidelines are lessons about tending to individual needs before one can take care of their child. Also bear in mind that this does include putting oxygen on the child once the caregiver's is in place. At first this may sound self-centered or foreign to a caregiver but in a time of great need this is of the utmost priority. The needs on this journey are long and parents may find it difficult trying to meet those needs. How better to do so than to avail oneself of mental health support to help navigate this journey of unknowns? There are new challenges, new depths, new costs, new grief, new heights, new strains, old communication patterns, old habits, old dreams and now a new family focus. Kranowitz suggests that family counseling can "help the child, parents, and siblings become a healthier unit" (2005, p. 225).

The Sensory Processing Disorder Foundation which is not only responsible for ongoing research, but also for connecting families affected by SPD, has a section on their website entitled "Emotional and Other Impacts" which states:

> "Children with Sensory Processing Disorder (SPD) often have problems with motor skills and other abilities needed for school success and childhood accomplishments. As a result, they often become socially isolated and suffer from low self-esteem and other social/emotional issues. These difficulties put children with SPD at high risk for many emotional, social, and educational problems, including the inability to make friends or be a part of a group, poor self-concept, academic failure, and being labeled clumsy, uncooperative, belligerent, disruptive, or 'out of control.' Anxiety, depression, aggression, or other behavior problems can follow. Parents may be blamed for their children's behavior by people who are unaware of the child's 'hidden handicap.' Effective treatment for SPD is available, but far too many children with sensory symptoms are misdiagnosed and not properly treated. Untreated SPD that persists into adulthood can affect an individual's ability to succeed in marriage, work, and social environments." (Sensory Processing Foundation, 2010).

Counseling can aid in issues of poor self-concept, anxiety, depression, aggression and social issues that may be present in adjusting to diagnosis and life with SPD. In addition there are family dynamics that are probable on a journey filled with turns, peaks, and valleys. Siblings of children with special needs often have additional responsibilities that can last a lifetime and some researchers have questioned whether these additional responsibilities are harmful. Some say they are at greater risk for anxiety, depression, poor self-concept, and cognitive problems (Kupper, 1993). Other issues to explore include relationships with siblings for the child living with SPD, extended family dynamics, teenage transitions and hopes, future plans such as college, and independence.

Purpose of Study

The purpose of this study is to examine the perspectives and experiences of families in the process of seeking treatment for their child's sensory processing disorder and the availability of family mental health support (defined as counseling).

Research Objectives:

- To examine the impact of a child living with SPD on the family system.
- To examine the needs of families with a child living with SPD.
- To understand how the needs of the families are being met. To find out what services are being used.

- To explore how to best support with counseling the family system of a child living with SPD.
- To investigate what services have been made available and if mental health support (counseling) was among them.
- To investigate the effect on families of a child's SPD being misjudged or misdiagnosed as a behavioral problem or other disorder.
- To examine the competing needs of families with a child living with SPD, including mental health.

The journey that the families with a child living with SPD are on has been one of professional and personal interest for me for a number of years. As a graduate student counselor it is my hope to expand the literature to include more data from families with a child living with SPD. Their stories need to be heard. As mental health professionals serve this population we need to listen well, work creatively, and be challenged to work collaboratively with other health care providers.

Research Question

Do families with a child living with SPD have mental health support or access while seeking other services? If so, who provides that support and what form does it take? If not, would they like mental health support?

Definition of Sensory Processing Disorder

Sensory Processing Disorder (SPD) is the "inability to use information received through the senses in order to function smoothly in daily life" (Kranowitz, 2005, p. 9). SPD is a complex disorder that can affect one or many of the senses and typically occurs in children during their developmental years. It may cause difficulty in one's emotional response, adaptive response, attention, or movement. As you can see in Figure 1, Sensory Processing Disorder has several patterns and each pattern has what are known as subtypes.

Understanding Sensory Processing Disorder

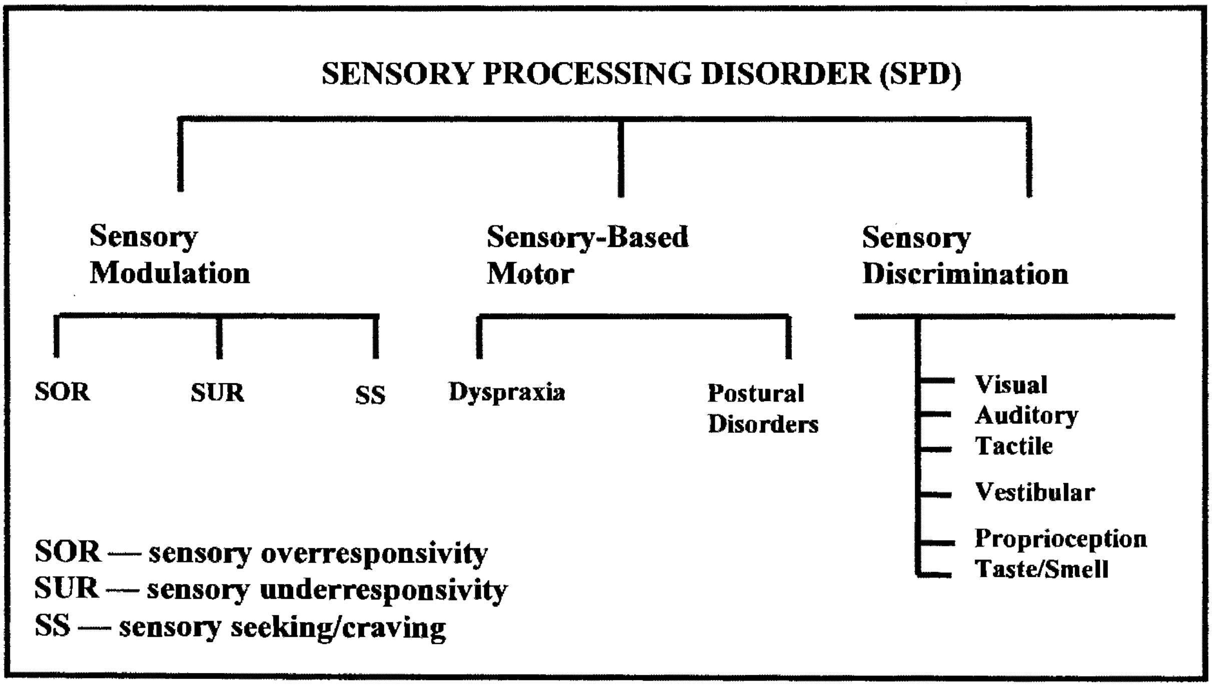

Figure 1. A Proposed New Nosology for Sensory Processing Disorder. Reprinted from "Concept Evolution in Sensory Integrations: A proposed Nosology for Diagnosis," by Miller, L. J., Anzalone, M.E., Lane, S. J., Cermak, S.A., & Otr, E. T., 2007, The American Journal of Occupational Therapy, Volume 61, Number 2, p. 137. Copyright 2007.

Sensory Modulation Disorder (SMD) pattern one of SPD has three subtypes. The first two subtypes are (1) Sensory Overresponsivity and (2) Sensory Underresponsivity. Subtype (1) Sensory Overresponsivity (SOR) "may occur in only one sensory system (e.g., tactile defensiveness) or multiple sensory systems (sensory defensiveness) and people with SOR tend to respond to sensation faster, with more intensity, or for a longer duration than those with typical sensory responsivity" (Miller, Anzalone, Lane, Cermak, & Otr, 2007, p. 136). According to Kranowitz (2005) Sensory Underresponsivity (SUR) Subtype (2), a "sensory disregarder," may miss signals other children catch easily because they do not differentiate them in time to move aside or they may not register "hot" or "sharp" as painful sensations and thus hurt themselves (p. 72). The third subtype of Sensory Modulation Disorder (3) Sensory seeking/craving (SS) often leads to unsafe behavior, including constant moving, "crashing and bashing," "bumping and jumping," impulsiveness, carelessness, restlessness, and "over expression of affection" (Miller et al., 2007, p. 137). This behavior may be misdiagnosed as other disorders if not properly ruled out. Children living with SPD are extreme in their quest for this sensory need compared to typically developing age appropriate and sensing peers. The sensory seeker is often labeled as an annoyance.

The Sensory-Based Motor Disorder (SBMD) pattern has two subtypes (1) Dyspraxia and (2) Postural Disorder as you can see in the center of Figure 1. Postural Disorder is an inability to command body stability to meet the everyday functioning needs of a child (Miller et al., 2007). When the "postural control is good, the child is able to execute functional behaviors such as reaching and resistance against gravity and when control is poor, they will slump in a standing or sitting position and then cannot easily move body and limbs" (p. 138). "Keeping up with her peers wear her out and getting into different positions, such as kneeling or stretching to her tiptoes, without tipping over may also be a challenge" (Kranowitz, 2005, p. 76).

SBMD pattern (2) Dyspraxia is an "impaired ability to imagine of, plan, or execute novel actions" (Miller et al., 2007, p.138). The child appears ill at ease and poorly coordinated in gross, fine, or oral – motor areas; they are unsure of where their body is in space and have trouble judging their distance from objects, people, or both (p. 138). They are often viewed as accident prone or opt out of activities that require coordination such as sports. People with dyspraxia are often inactive, preferring stationary activities such as watching TV, playing video games, or reading, which can "result in a tendency toward obesity" and children "often have low frustration tolerance" that "may be perceived as manipulative or controlling" (pp.138-139). Miller et al. also notes that "self-esteem may be poor because of dissatisfaction with abilities and repeated feelings of failure" (p.139).

The final pattern is Sensory Discrimination Disorder (SDD). People with SDD have difficulty distinguishing sensory stimuli. "They can perceive that stimuli are present and can regulate their response to stimuli but cannot tell precisely what or where the stimulus is" (p.138). According to Miller et al. people with SDD often require more time to process sensory stimuli leading to "slow performance" which may lead to "low self-confidence, attention-seeking behavior, and temper tantrums" (p. 138).

Summary

Chapter I explored the significance of the formal recognition of SPD by the DSM and reviewed the emotional impact of SPD which included issues of misdiagnosis, misinterpretation, and the high risk of social, emotional, and educational issues for a child living with SPD. The chapter noted occupational therapy as the primary current treatment for SPD. The purpose of the study and the research question were named and the chapter concluded by defining SPD and its patterns of Sensory Modulation Disorder, Sensory-Based Motor Disorder, and Sensory Discrimination Disorder.

CHAPTER II

LITERATURE REVIEW

The purpose of this study is to examine the perspectives and experiences of families in the process of seeking treatment for their child's sensory processing disorder and the availability of family mental health support (defined as counseling).

The literature revealed little in regard to counseling services and the mental health needs of families with children living with SPD. Kranowitz (2005) noted under the heading of social and emotional functioning that children living with SPD may be "inflexible, irrational, overly sensitive to change, stress, and hurt feelings, may be demanding, seek attention in negative ways, angry or panicky for no obvious reason" and that "low self-esteem is one of the most tell-tale symptoms of SPD" (p. 28). According to Kranowitz (2005) therapy may be appropriate if the child is experiencing depression, presenting conduct problems or self-esteem issues. "Family therapy is suggested to help the child's parents and siblings become a healthier unit, play therapy to promote the child's social-emotional development," and "behavioral therapy to help the child deal with problematical symptoms and behaviors" (p. 225). Parents have mentioned that "parents of children with a visible handicap get a lot of support and parents who have a child with the 'hidden handicap' such as SPD need support, but are more likely met with stares and demeaning comments when their children act differently than other children" (Miller et al, 2006, p.61).

Miller et al., reported a guilt which is common among SPD parents that is accompanied by stress and anxiety that they suggested can be relieved, somewhat, by understanding and validation.

The counseling needs of those living with SPD have not been fully considered nor have they been fully explored in the literature. This study is significant in that it is an attempt to begin to investigate the experiences and perspectives of families affected by SPD.

One essential professional that the families with a child living with SPD are most often in contact with are occupational therapists (Auer & Blumberg, 2006; Kranowitz, 2005). The role of the occupational therapist is central throughout the families' journey and their intervention plays a noteworthy part in behavioral modification as well.

The literature directly addressing the mental health needs of families in which a child has SPD is quite limited. There are however, multiple studies that address the concerns of families with children of special needs and many of these issues are pertinent. For example a families' response to the diagnosis of SPD can also be similar to families of other children with special needs. The literature noted a response of chronic sorrow which is a sadness that is not constant, but intensifies at critical periods in the child's development such as milestones in the child's life (Teel, 1991). Ambiguous loss is also noted in the literature as it involves learning to live with unresolved grief (Boss, 1999). Ambiguous loss is living with an unknown. Families with a child living with SPD often have this fate. Will their child ever eat a proper diet? What about toilet training or going on a family vacation? Can I leave my son/daughter with a babysitter? Will my son be able to go to school? These are just some of the unknowns and contemplated losses for the family. There are also the bigger questions of high school, college, work, the child eventually living on their own, and what will happen when the parents are gone – these questions are thought of late at night or when there is a quiet moment in the day. Thoughts and feelings of loss can steal up when least expected.

Parents of Children with Special Needs

Families of a child living with SPD are like other families of children with special needs. They are on a similar journey of seeking treatment for their child, traveling alongside their child as they strive towards health, and often they seek to find professionals that will understand their child and walk part of the journey with them.

Walders and Drotar (1999) presented "mental health care as prevention and intervention services targeted to address the psychological adjustment, quality of life, social functioning, and related health status of children with chronic health conditions and their families" (p. 120). "Mental health and health care professionals have a responsibility to take an active role in evaluating, designing, and monitoring comprehensive pediatric and mental health services for children with chronic illness to optimize functioning and quality of life" (p. 133). Walders and Drotar (1999) noted mental health care as providing services within this integrated model which tends to the child's mental and physical well-being. According to Walders and Drotar (1999) this integrated model would provide for "a reduction in emotional consequences of some physical complications and the improvement of quality of life" (p. 120).

Those with chronic health care needs often have difficulty accessing proper health professionals. According to Warfield and Gulley (2005) their needs go unmet. Further, the study noted three distinct approaches to identifying children with special health needs:

> "1) categorical approach depends on a list of conditions that are known to be or are presumed to be chronic 2) these conditions may or may not carry a diagnosis 3) non-categorical or functional approaches have been used to identify children in terms of limitations in functioning and/or in carrying out age-appropriate daily activities" (p. 201).

In addition to unmet needs access can be better understood by examining the types of problems families face as they endeavor to receive treatment from a variety of providers (Warfield & Gulley, 2005). "For respondents who said their child needed mental health services, problems finding skilled and experienced providers (27.1%) and problems with referrals (15.2%) were the most prevalent" (Warfield & Gulley, 2005, p. 209).

Warfield and Gulley suggested that parents may not turn to the health care system for mental health support. They recommended further research to investigate where parents are turning for their children's mental health needs. The Warfield and Gulley (2005) study underscores the importance of finding new ways to link children and families to mental health services and implementing the medical home concept. This medical home is defined by "family-centered, continuous, comprehensive, compassionate, and culturally effective care" (p. 214).

Krauss, Wells, Gulley, and Anderson (2001) surveyed parents of children with special health care needs who received a variety of specialty services (i.e., specialist care, prescription medications, speech, physical, or occupational therapy, home health services, and mental health services) and were asked if they had experienced any of a list of six access problems. These access problems included: getting referrals, getting appointments, finding clinicians with the skills and experiences necessary, getting consent for the number of visits needed, coordination of services among clinicians, and the expense incurred by families. According to Krauss et al. the service that was offered the least among those sampled was home health and mental health which displayed respectively (48% and 44%). These two services: home health and mental health; had the highest percentage of families reporting problems.

The Committee on Children with Disabilities (1999) noted that the family's involvement in care coordination is important because the family knows their needs best. The Committee highlighted the value of collaboration of clinicians with family for positive treatment outcome. Possible barriers to care included: "lack of knowledge and information about the condition, community resources, and/or the coordination process, lack of communication among the health care professionals and organization involved in the child's care" (Committee on Children with Disabilities, 1999, p. 980).

According to a study that evaluated an integrated health care program for children with special needs this model allows for "access to mental health so that the mental health provider is able to form a rapport with families over time, and the integration of services within the medical setting may increase acceptability and decrease the stigma associated with mental health care" (Naar-King, Siegel, Smyth & Simpson, 2003, p. 234). It was concluded that by integrating mental health with child medical services psychosocial function would improve.

A pediatrician's perspective on children's access to mental health services study found that pediatricians are concerned about children's access to mental health (Pfefferle, 2007). Suggestions from pediatricians included "forums for dialogue between mental health clinicians, schools, state agencies, this then would help pediatricians and mental health specialists to develop closer working relationships" (Pfefferle, p. 432). Also suggested was "integrated practice models, where mental health specialists would then be placed in pediatric practices" (Pfefferle, p. 432).

Families of a child living with SPD would benefit greatly from this approach as they would find a medical home first with their primary care physician, or pediatrician. Then their occupational therapist would join and if needed their mental health provider as well as other specialists based on the child's needs.

Diagnostic and Statistical Manual of Mental Disorders

Auer and Blumberg (2006) noted that to be classified as a disorder, "problems with sensory processing must be both pervasive (occur in a variety of settings) and interfere with daily activity (or to be more technical, a major life activity, e.g., learning, walking, seeing, etc.)" (p. 17). SPD often occurs with many other disorders, including autism, mental retardation, ADHD, and speech disorders. In part the journey for families of a child seeking treatment for sensory processing disorder is made more challenging because SPD is not included in the Diagnostic and Statistical Manual (DSM) which classifies official mental health diagnoses for physicians, mental health professionals, and third-party payers.

Inclusion and recognition will support multidisciplinary research and services, funding, early intervention, better outcomes, plus improve quality of life (Kranowitz, 2005; SPD proposal summary, 2007; Cohn et al, 1999). Data presented in an update for the DSM includes: "a discussion of a nosology for diagnosis, diagnostic validation of SPD, assessments for SPD, the relation of SPD to functional behaviors such as daily care activities and motor skills, neuropathology of SPD, studies related to the developmental course of SPD, studies on the outcomes of treating SPD, and utility of the new diagnosis" (Scientific Work Group [SWG], 2008, p. 3). Cases of "pure" SPD have been identified in which subjects did not meet criteria for other DSM-IV conditions, but did meet criteria for SPD (SPD proposal summary, 2007). Noted in this same presentation is a case study of three individuals who failed to meet the criteria for existing medical or psychological diagnoses including ADHD, autistic spectrum disorders, and other diagnoses, yet had atypical sensory response as described in this application (Reynolds & Lane, 2008). This case study provides solid evidence of a stand alone diagnosis of SPD.

Occupational Therapy

Health care services involving children with SPD and their families provide a challenge to our health care system. It is complex to offer coordinated care.

Occupational therapists have for sometime known the importance of involving families in the treatment of their own children (Hanna & Rodger, 2002). The new trend has been to involve parents and family in planning and intervention.

According to Rosenbaum, King, S., Law, King, G., and Evans (1998), services for children with developmental disabilities or chronic health conditions had been provided with a child-centered focus, in which health professionals set goals separate from the family. This saw the parents as passive rather than active.

A more recent focus according to Hanna and Rodger (2002) is parents' individual needs and preferences and the importance of considering these when making a diagnosis, planning therapy, and treatment. In a family-centered approach the parent is viewed as an expert on their child and then is part of a team of professionals. Goals are set together. This is a "parent-therapist partnership" (Rosenbaum et al., 1998, p. 5).

Dunstan and Sian (2008) in a single case study using sensory integration at home noted that the "time occupational therapists spend supporting parents may be just as important as the time spent in direct therapy with the child" (p. 10). It was suggested that therapist's interventions should take this into account.

According to Jean Ayres (2005) the occupational therapists' role is to work in collaboration to support the family rather than the individual child. Further, the chief principle in sensory integrative therapy is to provide the child with experiences rich in sensory input, in a guided manner to create functional behavior deemed more effective than previously observed behaviors (Ayres, 2005).

In a study on parental hopes for therapy outcomes concerning children with sensory modulation disorder (SMD) it was found that occupational therapists should endeavor to understand parents' priorities and hopes for treatment outcomes (Cohn, Miller, & Tickel-

Degnen, 2000). This same study also noted that a connection must be considered between the child's sensory difficulties, the impact of difficulties on behavior, the effect of living with the disorder, parenting issues involved with raising a child with the disorder, and the effect that has on the entire family system (Cohn et al., 2000).

The Family

Ferguson and Asch (1989) stated "the most important thing that happens when a child with disabilities is born is that a child is born" (p.108). They also said "the most important thing that happens when a couple becomes parents of a child with disabilities is that a couple becomes parents" (p. 108). A review of research on the parental reactions to having a child with a disability looked at the history of professional's responses to the birth of this child and "found patterns of research and practice that assume the disability itself inevitably overwhelmed all other considerations" (Ferguson & Asch, 2002. p.124).

A family's strengths, weaknesses, and emotional reactions to their child's disorder can affect treatment progress (Power & Dell Orto, 1980). Family reactions to a child's diagnosis can vary and often take time to be processed and expressed (Power & Dell Orto, 1980; Ziolko, 1991). Most parents have hopes and expectations for their children when they are born and a disorder such as SPD can alter the possibility of those hopes.

Diagnosis of a child can be traumatic not only for the child but for the entire family and a period of adjustment may be necessary (Ziolko, 1991). The support and information provided by counselors, parent support groups, and advocacy groups can facilitate the adjustment process and help ease the family's progress through a distressing portion of their journey.

Ziolko (1991) noted that marriages suffer, there is financial strain, struggles with self-esteem, resentment can build as well as stress. In addressing counseling parents of children with disabilities, the literature regarding implications for practice suggests four tasks: "grief work, acknowledgement of their failure to deliver a 'normal' child, the resumption and continuation of the parental attachment after hope is given for the infant's survival, and development of an understanding and acceptance of the infant's difference from other children" (Ziolko, 1991, p. 30).

Ziolko adapted a six stage counseling process from Gilliland, James and Bowman (1989). The first stage included building a trusting relationship which will allow the family to "verbalize their feelings, fears and worries" (Ziolko, 1991, p. 32). The second stage included the "verbalization of the emotional and factual aspects of the client's problem" (p. 32). If the parent of a child living with SPD were in this stage they might include talking about test results, monitoring family reactions, assessing strengths and burdens. The stages three, four, and five involved "identification and evaluation of alternatives and a commitment to a plan of action" (p. 33). Ziolko stressed the importance that counselors be aware of community resources for the family. For a family affected by SPD that could mean knowing not only about occupational therapy but about speech therapy, educational services, nutritional services, and respite care options. In the sixth and final stage the "client summarizes progress made and the client and counselor evaluate the level of goal attainment then cycle back through the family's stage of adjustment, changes in strengths, needs, and pertinent available resources" (Ziolko, 1999, p. 33).

One review of a father's account, *Experiences of Parenting Children with Disabilities*, written by Garry Hornby (1992) documented the story of Charles Hannam. Hannam shared his experience of his then eight year old son, David, who had Down's syndrome. Hannam reported experiencing: shock, guilt, resentment, disappointment, anger, and denial. He discussed the hurt experienced due to the "insensitivity" not only of others around him but specifically of professionals. Hannam noted the beneficial effects of the supportive counseling he received and of the assistance obtained from the special school which David attended (Hornby, 1992). His account finished with Hannam discussing the benefits of professional counseling and talking with other parents.

Hornby (1992) also documented the story of Roos, a clinical psychologist who went through an agonizing process in order to confirm that his daughter was mentally retarded. Roos stated that they experienced a series of traumatic interactions with professionals which echoed the complaints he had heard from other parents and from which he went on to develop phrases such as "referral ad infintum," "professional ignorance," and "the deaf ear syndrome" (Hornby, 1992, p.369).

Of the themes that Hornby mentioned, negative feelings fathers have towards the professionals involved in their child's care is important to note. Hornby (1992) stated that fathers do not have the same contact with professionals serving their children and "therefore do not develop productive relationships with them so that much of the information they get comes to them secondhand via their wives which is a communication process that can lead to misunderstandings" (p. 372). This is also another important component in the father/family dynamic.

A study on the parental perception of the level of support needed to care for children with special needs found that "fathers experience intense feelings and reactions to their child's condition and diagnosis and that these feelings can be intensified throughout the child's life, leading to resentment and that one surprising reaction was the negativity fathers felt towards professionals" (Hall, 1996, p. 514). Hall quoted an American study that addressed provision of service as well as community nursing and health care provision (Horner et al. 1987). The results of this study were that the greatest needs identified by 164 respondents "were in the areas of information to plan for their child's future (55%), identifying appropriate community resources (49%), understanding the affects of the condition on the child's development (45%), and finding ways to provide for the child's emotional, social and intellectual needs (43%)" (Hall, 1996, p. 515). Hall (1996) suggested that nurses can provide for the emotional needs of the children. It is important to highlight that in a survey seeking to find the greatest needs identified, 43% of the participants noted the child's emotional, social and intellectual needs. These are all concerns and areas explored in the counselor's domain. An effective counselor would be willing to help a parent to consider plans for their child's future, appropriate community resources, how their child's development would be effected by SPD, as well as providing for their child's emotional, social and intellectual needs. Or if their client were the child, explore these avenues age appropriately depending on client concerns.

Revisiting Ferguson's (2002) review of research on family's reactions to having a child with a disability it was noted that "guilt, anger, and denial were replaced by stress, loneliness, and chronic sorrow" (p. 126). In discussing coping strategies that a family with a child with a disability may adopt, "event-focused problem-solving" is a coping strategy that takes attention from family needs because all energy is given to the child in need (Friehe, Bloedow, & Hesse, 2003, p. 212). "Self-focused emotional adaptation strategies center on the family's emotional responses to the loss" they have experienced (Friehe et al., 2003, p. 212). There would always be a tension to balance the two strategies. Ideally both strategies would be in place and functioning so that the child's needs and the family's needs are all being met.

In a study of 96 children with moderate to severe traumatic brain injury and 96 children with orthopedic injuries parents reported they did not receive the types of supportive counseling they needed in the early stages of the disorder (Wade & Taylor, 1996). The authors speculated about the absence of counseling and suggested that families may fail to communicate their needs as well as realize how important it is to acknowledge them (Wade & Taylor, 1996).

Analyzing emotionally close relationships Teel (1991) reported that when a relationship or that hoped-for child is changed, chronic sorrow is frequently the response. Teel (1991) also noted "chronic sorrow is recurrent, permanent, varies in intensity between situations and person, and is interwoven with periods of neutrality, satisfaction and happiness" (p. 1311).

Boss (1999) found that considerable stress is caused by situations of ambiguous loss. These situations are unpredictable and unsure. The loss experienced is confusing and because of this most people attempt to put as much order in their lives as possible. Resolution of the situation is not possible and the outcome is not predictable (O'Brien, 2007). O'Brien (2007) noted that diagnosis may be accepted by the parents but they also will "never entirely let go of their image of their child *before* they learned of the diagnosis" (p.145). The diagnosis is a difficult fundamental moment of time. O'Brien suggested that helping parents to increase their tolerance for living with ambiguous loss may effect whether children receive appropriate clinical intervention. This could then in turn affect long term, not only mental health care but overall care. O'Brien also proposed that an understanding of ambiguous loss could help clinicians who work with "families of children with chronic conditions to be more supportive and empathetic" (p. 145).

For those experiencing ambiguous loss there is little support and community assistance so that they receive very little validation of what they are experiencing and feeling (Boss, 1999). Boss found that in trying to make sense out of ambiguity, people have infused what looks like a tragic situation with hope. So while parents and their child live with a disorder that is chronic they somehow find ways to help others who have similar experiences or begin to work within the system to make the journey easier for the next person. Boss (1999) called this using their "powers of mastery to make changes, not always to alter the tragedy of their own loss, but to help others" (p. 119).

Summary

In chapter II the literature on sensory processing disorder in relation to the mental health needs of children living with SPD was reviewed. Information on SPD's diagnostic status was introduced. Then the literature concerning the role of occupational therapists was considered. Because little direct literature is available in regard to SPD, applicable literature related to parents of children with special needs was explored. This included parents' reactions to their child's diagnosis some of which was recorded in journals and books. A counselor's six stage counseling process for parents was noted (Ziolko 1991). In regard to loss, both chronic sorrow and ambiguous loss were examined and found to be applicable.

CHAPTER III

METHODOLOGY

Research Design

A qualitative interview approach was utilized to explore the rich and detailed descriptions of individuals with life experience as a family of a child living with SPD. Seidman (1991) stated interviewers listen at three levels: first they must listen to what the participant is saying and concentrate on the substance to understand all of the details to allow for follow up questions. At the second level, interviewers must listen for the "inner voice" as opposed to the public voice which people will sometimes use as if they were talking to an audience in an effort to guard themselves (p.56). Seidman suggested searching for ways to get to the "inner voice" and to encourage "a level of thoughtfulness" (p. 56). At the third level: "interviewers must listen while remaining aware of the process as well as the substance" (p. 56). This is difficult in that the interviewer must balance the participant's content with the overall progress of the interview. This requires an attunement with the participant and the interview as well as listening skills that will inform the interviewer when to talk and when to remain silent.

The interviewer utilized Seidman's three levels of listening. The challenge of first level listening, concentrating on substance, is not in the listening but rather in being selective in choosing follow up questions. Therefore the interviewer must choose those areas that are of central focus or of primary relevance. In this study the length of the interview, 30-45 minutes, did not allow the interviewer to follow up on every area of questioning. This time frame was chosen to allow enough time for the participant to answer all 12 questions and also avoid possible emotional fatigue given the subject matter that the participants would be sharing.

Second level listening occurred throughout the interviews. The interviewer attempted to discern between the participants "inner voice" and public voice (Seidman, 1991). Public voice was most apparent at the beginning of each interview, especially in the greetings. Public voice was sometimes apparent during fact based questions and the interviewer then asked questions such as "So what was that like for you the first time you were there?" or "Yeah, it sounds like it has grown quite a bit. How would you say it grew that large [Parent's Group]?" This was done after factual information was collected in order to encourage the participant to further explore their own experience rather than maintain a distance by sharing facts or another person's experience.

One example of third level listening, balancing process and substance, was attempted by moving participants through all 12 questions, highlighting to them which question was being used as the interview progressed, and inserting subset questions when deemed appropriate and time allowed. Another example of the third level listening was the interviewer deciding when the participant was ready to move to the next question. This required the ability to judge the energy of the conversation or the topic at hand. The qualitative research interview is semi-structured. It is neither an open discussion nor is it a very structured fill in the blank survey (Kvale, 1996). Gilgun, Daly, and Handle (1992) point out that with qualitative methods, the "focus is not on identifying structural or demographic trends in families, but rather on the processes by which families create, sustain, and discuss their own family realities" (p. 4). The topic of this qualitative research study was the lived world of the participants and the significance they place on their experiences.

In the semi-structured interview research process, the researcher keeps a focus on learning the meaning that the participants hold about the problem or issue, not the meaning that the researcher brings to the research (Creswell, 2007). As the qualitative researcher enters the participants' "life worlds," rather than imposing a formal experiment, we are allowed access to the private meanings of families (Gilgun et al., 1992, p. 5). "Interviews are particularly suited for studying people's understanding of the meanings in their lived world, describing their experiences and self-understanding, and clarifying and elaborating their own perspective on their lived world" (Kvale, 1996, p. 105). Lincoln and Guba (1985) stated that interviews can be categorized further by their "degree of structure," their "degree of overtness," and the "quality of the relationship between the interviewer and the respondent" (p. 268).

When Kvale talked about the interviewer establishing an atmosphere so that the participant feels safe enough to talk freely he also stated that the interviewer must avoid allowing the interview to turn into a therapeutic situation. The counselor/researcher must be especially aware of this caution. This is a delicate balance in that the interviewer must encourage the expression of emotion while at the same time not encourage therapy. Some differences to note are that "the interviewer defines the situation, introduces the topics of the conversation, and through further questions steers the course of the interview" (Kvale, 1996, p. 126). Throughout this the interviewer offers no therapeutic input.

Procedure and Data Collection

Participants were purposely chosen as they had the knowledge and experience of being parents of a child living with SPD. The goal of the research study was to examine the perspectives and experiences of families in the process of seeking treatment for their child's sensory processing disorder and the availability of family mental health support (defined as counseling). Purposive sampling or criterion-based selection, bases the selection of study settings and participants on features and characteristics that will enable the researcher to gather in-depth information on the areas of research interest (Miles & Huberman, 1994). "Interview participants must consent to be interviewed so there is always an element of self-selection in an interview study" (Seidman, 1991, p. 42).

In an effort to obtain interviews from families that included children who were seeking treatment for SPD, which is the focus of this study, participants were sought from the Sensory Processing Foundation's Parent's Connection Groups. These groups were listed in the public domain on the SPD Foundation's website. Each Parent's Connection Group has a Parent Host whose email address was listed on the Sensory Processing Foundation Website. The Parent Host is responsible for the Parent Connection Group which is a support group of other parents whose children are affected by SPD. Parent Connection Groups consist of parents and sometimes their children gathering together to learn more about sensory processing disorder and to share their experiences in order to support each other. These groups are spread all across the United States in a variety of cities. There are a total of 75 groups currently and new groups continue to form each month.

Parent Hosts were initially contacted with a recruitment email (see Appendix A) which requested their participation in a 30-45 minute telephone interview. The email described the purpose of the study, outlined the participant's involvement, detailed how to proceed if interested in participation, and included informed consent (see Appendix B). A reply from the participant implied informed consent as noted in the recruitment email. If the Parent Host responded, a follow-up email was sent with available times for the interview, further description of the interview, and protocol information concerning the questions of the interview which would be forthcoming once the time and date for the interview were set (see Appendix C). When the Parent Host set the date and time then the questions for the interview were sent with a confirmation email (see Appendix D) so that the participant could prepare for the interview if they so desired.

Following the interview, two of the Parent Hosts forwarded the recruitment email to their Parent Connections Group. They invited the Parents in their group to participate in the interview process. A few parents within those Parents Groups, once IRB approval was received (see Appendix H), consented to be interviewed and participated in the study. The telephone interview questions were designed from the Research Objectives listed below.

Research Objectives:

- To examine the impact of a child living with SPD on the family system.
- To examine the needs of families with a child living with SPD.
- To understand how the needs of the families are being met. To find out what services are being used.

- To explore how to best support with counseling the family system of a child living with SPD.
- To investigate what services have been made available and if mental health support (counseling) was among them.
- To investigate the effect on families of a child's SPD being misjudged or misdiagnosed as a behavioral problem or other disorder.
- To examine the competing needs of families with a child living with SPD, including mental health.

These objectives were formulated into qualitative questions to best consider the experiences of the families of children living with SPD. Because the participants had the questions prior to the interview they then had the option to include other members' experiences and opinions from their group. The telephone interview took approximately 30-45 minutes. Please note that as the interviews progressed the study expanded to include not just Parent Hosts but Parent Group Members as well.

A total of 75 recruitment emails were sent out to Parent Host/Parent Group Member participants. In addition there were two Parent Group Members that forwarded the invitation to their entire Parent Group whose total membership is unknown. There were approximately 100 invitations to participate in this research study. Seven Parent Hosts/Parent Group Members responded affirmatively and were interviewed.

Interviews began on January 3 and were completed on February 22, 2010. All participants were living in the United States: four were from the Northeast, two were from the Southeast, and one was from the Northwest. Invitations were sent out in waves to 12-20 hosts/parents at a time, beginning in December 2009. With each wave reminders were sent after two weeks to those that had not replied (see Appendix E).

Each interview was digitally recorded. The recordings were then transcribed by this researcher into text documents and names and identifying information were concealed. After transcribing, the recorded files were destroyed. Only the primary researcher was allowed access to identifying information.

Interview Questions

Interview questions were created to have participants involved as early in the interview as possible; therefore the first questions were fact based. Please note questions one to three. The questions were: How many parents and children with sensory processing disorder do you have in your parent's group? How long has your group been together? And what are the ages of the children with SPD in your parent's group? (see Table I). It was also helpful to ask about the present before asking about the past. Ordering the questions in this way allowed the participant to become more at ease with the process, to being on the phone, and with the interviewer. Question four is also about the group: What different diagnoses are represented in the group? This gave the participant an opportunity to talk about the group experience as well as their personal experience. There is freedom in this question and the participants chose if they would speak to the diagnoses of the group or of their own child. This also allowed the opportunity for greater information gathering.

It is at question five that the participant is first asked to look back. The participant was asked which professionals they had seen prior to and following the SPD diagnosis. By the time the interviewer and participant reached question six the interview had turned to the participant's family and their particular journey. Question six asked about the particular services their family had been offered since diagnosis. This is then followed with question seven about the family's experience as to which service was most helpful. This is again a request for the participant to look back on their journey and their particular experience. Question eight inquires if counseling had been offered to the family in any form along their journey, whether they would find it helpful or not, or if they have had the need met elsewhere. It is at question nine that the participant is asked to look back and consider what help they could have used.

The most personal question is number ten which asked the participant to tell of the emotional impact of the SPD diagnosis upon the family/child. This has to be asked at a suitable time in the interview and the interviewer must be aware that trust has been established and the interview is well under way. Question eleven usually follows well as a companion. If the participant was to consider counseling now what type of counseling support would suit them best? The final question asked what the participant would offer as advice to professionals in regard to counseling a family in a similar situation.

Seidman (1991) noted that the interviewer should "talk less, listen more and ask only real questions." (p. 62). The real question is one that the interviewer does not know the answer to already. Real questions are life experience questions. Other "real questions" include open-ended ones that the participants continued to answer with the experiences of their journey and the interviewer provided impromptu follow-up questions where appropriate to allow participants the opportunity to fully tell their story.

Kvale (1996) mentioned the importance of the use of direct questions so that the interviewer may introduce topics keeping in mind that the interviewer must have an extensive knowledge of the interview topic in order to do so and remain trustworthy and credible. Questions eight through twelve are the most direct and personal (see Table I). They asked the participants to tell of their experience with counseling, their needs, their child's needs, their current situation, the impact of SPD on their family as well as themselves, and what advice they would give for helping others on their journey. By the time the participants have answered these questions they have given a great deal of themselves and their stories.

Trustworthiness and Credibility

Qualitative research recognizes and affirms the role of the instrument, the human interviewer (Seidman, 1991). The interviewer must demonstrate trustworthiness and credibility as a researcher and interviewer. Kline (2008) stated that researchers have the responsibility of describing how their biases influence their interpretation of data and findings.

Lincoln and Guba (1985) speak of "degree of overtness," that ethical practice and trustworthiness requires the interviewer to be fully overt (p. 269). Kvale (1996) emphasized that even though we are overt we must acknowledge the interviewer's bias as an influence on results. He also stated that recognized bias may highlight specific aspects of the study and bring new information forward, contributing to the construction of further information. "Particularly in qualitative research the role of the researcher as the primary data collection instrument necessitates the identification of personal values, assumptions and biases at the outset of the study" (Creswell, 1994, p.163).

Table I
The Interview Questions

Number	Questions
1	How many parents and children with Sensory Processing Disorder do you have in your Parent's Group?
2	How long has your group been together?
3	What are the ages of the children with SPD in your Parent's Group?
4	What different diagnoses are represented in the group?
5	What health professionals have you and your child seen as you have traveled the journey toward diagnosis and since diagnosis?
6	What services have been offered to you and your family since diagnosis?
7	What services have you found most helpful?
8	Have counseling (family, couples, or children's mental health counseling) services been offered? If so please describe your experience. If not offered, would you find them helpful? If you feel the need is being met elsewhere please explain.
9	At what point in the journey would counseling have been most helpful?
10	What has been the emotional impact of the SPD diagnosis upon your family/child?
11	What type of counseling support would best suit your needs at this time?
12	If you were to offer advice to professionals on how to best support a family in the journey that you are taking what would say? Especially in regards to counseling support? For children?

What we believe in strongly is what we study. Sensory processing disorder is a subject that I have been studying for years now. At the same time I have also been studying to become a licensed counselor. The confluence of these two lines of study prompts my methodology – qualitative research. It is important to this researcher that the participants are allowed to explore their experiences and perspectives. There are three key elements that drive me in this research: the needs of the families on their journeys, the challenges and complexities of SPD, and the great need for counselors and other clinicians to enter the fray of understanding for the families of children living with SPD.

According to Lincoln and Guba (1985), "unless the interviewer began as an accepted member of the group or agency being studied distortions can never be overcome" (p. 302). Kvale (1996) noted that interviewing does not follow tight rules of method, but rather relies on the judgments of a competent researcher. He added that this role of the researcher does not imply a neglect of techniques or knowledge. Therefore one would suppose that knowledge of the problem or issue being studied would help to ease distortion or bias. Lincoln and Guba also added that the building of trust takes place over time. This process began with the initial recruitment email which included the informed consent, a statement of confidentiality, and a description of the purpose of the study (see Appendix A).

As noted by Kvale (1996) the researcher is the ethical decision maker in the research study. He noted the "integrity of the researcher - his or her honesty and fairness, knowledge, and experience - are decisive factors" (1996, p. 117). Credibility is continually carried throughout the research process as names were kept confidential in transcribing interviews, pseudonyms were assigned to interview transcripts, and all is done solely by the researcher in order to maintain confidentiality. Notice was given so that participants had the right to withdraw voluntarily at any time without penalty. This freedom is another aspect of continued trustworthiness. Lincoln and Guba (1985) also referred to credibility being accomplished by the interviewer being involved deeply enough in the data so that distortions are not allowed to creep in (p. 302). This is what is referred to as "prolonged engagement" (p. 303). This engagement can refer to the study's participants as well as a study's subject topic such as SPD. While the interview length was not prolonged it was important for the interviewer to be knowledgeable about the subject matter which required prior comprehensive study.

Analysis

A qualitative interview approach was implemented to discover the rich and detailed descriptions and perspectives of individuals with a child living with SPD. Qualitative research produces rich amounts of data which need to be systematically analyzed in a logical fashion (Miles & Huberman, 1984). Analysis takes place within the interview itself (Kvale, 1996) when the interviewer uses questions such as, "I hear you saying" or "You mean…?" This is an attempt to clarify or analyze the meaning of the participant's statement. This view of analysis allows for an ongoing process. These statements were used several times within interviews in order to have the participants give further detail to their description, or to confirm or disconfirm what had been heard. Taking memos during the interview in order to highlight an idea or connecting concept that comes to mind is also recommended (Maxwell, 2005; Seidman, 1991; Miles & Huberman, 1984). This was done to note reoccurring themes or topics that were unique or of particular importance to the participant.

After the interviews were completed but before the transcripts had been analyzed I reflected along the following lines: "I think I heard them saying…" This produced several themes and thoughts that were noted and set aside to be referred to later after studying the transcripts. Some of the topics that were heard and noted initially included isolation, not knowing where to go for help, pediatricians who would not listen, being "Lucky", occupational therapy is pivotal, school can be complicated and dreaded, and counseling would be welcomed if offered. This proved to be an excellent prelude to a deeper experience with the transcribed interviews.

Creswell (2007) noted the interviewer, when analyzing, must begin to look for themes, "surprising information," or to "look for stories" (p. 153). Creswell suggested reducing data to five to six themes. Seidman (1991) mentioned that the interviewer during analysis will begin to notice passages of text from one participant that is echoed in another participant's text. This recognition comes from reading and rereading the interview transcriptions.

After having read through the transcriptions, categories stood out and it was as if they emerged. These categories are entitled emergent (Taylor-Powell & Renner, 2003). The emergent categories come from the data showing comparative importance – did these particular topics or themes appear often? Did this reveal significant information to the study? This was considered. These relationships were noted – were they similar in other families? Were these similar characteristics of notable importance or seen as woven throughout each family's journey? This information was noted. The data was searched for exceptions to themes and topics as well. And it was also important during analysis to investigate whether two or more themes occurred together consistently (Taylor-Powell & Renner, 2003). What might this relationship mean?

During the second stage the transcripts were reviewed for factual information which was gathered and can be found in Appendix F. Participants answered questions about Parent Connections Group size, different diagnosis represented within their groups, how long groups had been together, and ages of children represented within their groups. Fact based questions were some of the first questions asked of the participants.

During analysis the text was sorted into themes while also looking for surprising information or stories and then the categories were reduced to a more manageable number (Creswell, 2007). During this process themes began to emerge as commanding more prominence in the texts (Taylor-Powell & Renner, 2003). The third stage included reading and rereading. This enabled further categorizing of the text information as Taylor-Powell and Renner suggested and eight categories or themes emerged as significant. These themes are noted in Chapter IV.

CHAPTER IV

RESULTS AND DISCUSSION

The purpose of this study is to examine the perspectives and experiences of families in the process of seeking treatment for their child's sensory processing disorder and the availability of family mental health support (defined as counseling).

Research Objectives:

- To examine the impact of a child living with SPD on the family system.
- To examine the needs of families with a child living with SPD.
- To understand how the needs of the families are being met? To find out what services are being used.
- To explore how to best support with counseling the family system of a child living with SPD.
- To investigate what services have been made available and if mental health support (counseling) was among them.
- To investigate the effect on families of a child's SPD being misjudged or misdiagnosed as a behavioral problem or other disorder.
- To examine the competing needs of families with a child living with SPD, including mental health.

The following eight themes emerged during the third stage of analysis: “Something Different,” Pediatricians, Not Knowing What To Do or Where To Go, Isolation, Occupational Therapy, School, “At the Beginning,” and “Lucky.”

“Something Different”

Six out of the seven participants noted within their children that “something was different.” This often happened early on when their children were young or during the preschool years. Participants sought after their child’s overall health and that is when their journey began. It was important to participants that they were the ones that noted this “something different.” Participants knew something was “different” even in the face of others telling them that it wasn’t or that they themselves were the cause of the problem.

Tonya: She was just so uncomfortable in her own skin and her life...everything was so hard and in ways continues to be...but that’s scary for her...

Tonya: Because everybody I talked to before she was suicidal... Said she’s fine...it’s in your head...you’re pushing her...you’re...she’s not as perfect as your other daughter.

Tonya: Her other sister is a hard act to follow and I’m an only child I’ve never been around kids until I had my own two and I didn’t know what was wrong but I knew something was wrong.

Stefanie: ...it has been devastating...it has put my job at risk, it has put our marriage at risk...and to go to professionals and try to fight to help your child because you know something is wrong and for them to look at you and tell you that you're the cause of it... that's been hard...getting the answer of what it was...was almost a relief...okay that makes sense...that's not as devastating as getting to the diagnosis...its difficult.

Jane: I knew from about the time that [child's name], who's my son that has SPD, was six months old... something was different.

Jane: I went to the doctors three different times saying I think there's a problem. The first time it was he's just a boy he needs boundaries. Umm, the second time she told me that my husband and I needed to be more consistent with our discipline.

Jane: And the third time she informed me that she would not medicate a four year old. And I said I'm not looking for medication. I'm looking for help.

"Something different" also held another meaning: that the children living with SPD came to realize and recognize that they were not the same as the others around them. In recognizing this participants noted that their children may need assistance processing and accepting who they are as well as support during times of transitions.

Kathy: ...that once your child is especially transitioning to school you should ahead of time get them into somebody to start talking because lots of changes are happening because that's when the child...I find that now that my daughter is starting to understand that she is different that she needs some things throughout the day that other children might not.

Kathy: ...and then I also wrote down...to have the child have some counseling to help through the process especially to start figuring out what's going on with them...and that although it's a blessing when your child starts to understand and help you out with trying to cope with it and that they learn to start coping with these things...it's also when the anxiety starts to hit...cause that's when they start to notice that they're different.

Stefanie: ...encouraging him to ask when he needs brushed...encouraging him to...not keeping it from him but there is something different and it doesn't have to be a bad thing...

Interviewer: He understands?

Stefanie: On a level...it's gotten better...we've noticed that he doesn't listen to his music as loud and there are times when he'll say, "Well, I don't want to be different now"..."Well, [child's name], you need to crawl through your tunnel right now or you need to do your animal walk because Ms. [Teacher's name] says this is going to help you and you need to do that right now" an sometimes there is some resistance but a lot of the times we can make him hop to the back of the room or jump and we try to get him encouraged...

Tonya: ...she is in some ways starting to embrace her more unusual qualities as far as her friends and she's got a really good friend that is pretty non-judgmental and she'll tell her, "hey, [child's name] you're being out-there a little bit" and she'll pull it in and she's kind of gotten by in the social world...

Tonya: Yeah, I'm very amazed and very proud of her...over time...and we were finally able to say this is what's different about you...she has actually walked up to people that have given her a hard time... "I have a sensory processing disorder...this is my way of calming myself in this situation."

Pediatricians

Participants most often began their journey in the pediatrician's office and did not report a positive experience. Many participants spoke of not being heard. Participants were frustrated by communication difficulties with pediatricians. Participants told of repeated visits, lack of support and pediatricians' "discounting" what was being said.

Tonya: We started out with the pediatrician...thought it's the second child thing...never got very far there...saying something was different...something wasn't right...we tried at the school…the school said, "oh, she's eccentric"…my daughter was seven and she was talking about suicide…and outlining ways to pull that off.

Tonya: …it took to the point of suicide to get someone to listen to me…if the OT is the one that encounters them…but honestly if the pediatrician had ever actually listened instead of discounting …there's an awful lot of the worried mother, frantic mother…

Tonya: …it's like pediatricians just close up and they don't hear behavioral problems because that's not what their dealing with…the psychologist or psychiatrist or somebody else is going to deal with that…not them.

Tonya: …that's where the segmentation doesn't work in medicine.

Jane: I went to the doctors three different times saying I think there's a problem.

Jane: …I think though the pediatricians have to be more trusting of a parent's intuition.

Jane: …almost every story starts out with, "I always knew something was wrong"…"I went to the pediatrician" …three times, four times…

Interviewer: What services would you like to be provided that haven't been provided or maybe you had them provided at one point and you would like them to continue?

Kathy: Umm, I don't know…good question. The only thing I would love for the doctor to support…you know regular pediatricians…to support us…

Interviewer: What do you mean by that?

Kathy: Well, I find that a lot of doctors in this area because it's not in the diagnostic manual…that they…well, even insurance companies are giving people a real hard time and they have to kind of blame it on other things…and not call it sensory issues because it's not a diagnosis…I don't know I just want more counseling…I will say that I think sensory issues tend to be brushed off to the occupational therapists…

Not Knowing What To Do or Where To Go

Participants spoke most passionately about providing a support group for the families that do not know what to do or where to go for help. This is the group of families that participants relate to most strongly; they remember what it was like to be in that position, can see a clearer path on their own journey, and have a desire to help someone else on the journey.

Tonya: …it's crushing…it's so overwhelming they're paralyzed…and they come into these groups and they're just crying to hear someone say, "Oh, yeah, we've been there and done that"… "What do we do next" …that should be coming from the medical profession…that shouldn't be coming entirely from a support group.

Tonya: ...Most of them seem to fall in the direction that I was...of nobody's told them where to go or what to do...and one lady came in and just looked at me and she said, "Well, what do I do now?" and the speaker said, "Well I don't know"...and I don't remember what professional was there whether it was pediatrician or somebody else...but nobody seems to tell them where to go...

Matthew: ...a lot of people on the internet and most mothers not knowing what to do with their kids... so my wife will talk to them about resources or approaches with the school that type of thing...

Matthew: Right and they read an article or someone will give them a diagnosis of SPD and then they say, "Now what?"...

Jane: ... there is not much information...there's information on what sensory processing disorder is...

Jane: Some tools you can use to fix it but not how to get help.

Jane:... you have to dig so much with this disorder...to find a therapist that knows...and it's because it's kind of newer and some people aren't even sure that it is a disorder...and that it's not a bunch of frantic moms making things up...

Jane: ... I know what my path is now...at this point I think we're fighting for the parents that don't.

Isolation

Participants spoke about those first years of being with their child when they were searching for answers or they had just been diagnosed. They spoke of feeling alone, isolated, and even like prisoners. Participants named the Parent Connections Group as an important source of support.

Jane: ... I would have welcomed one of the preschool teachers coming to me and saying I think that he has sensory processing disorder...or maybe you should have him evaluated by the pediatrician. I would have welcomed that because I would have felt like I wasn't alone.

Jane: You know through the whole process we felt like we were alone. And that's the reason that...that's one of the reasons that we started the support group.

Matthew: ... people make comments to you...you know thinking that they're being considerate...friends or what not...but they're not...they'll question, "Why does your kid eat like that"...you already feel like you're under a microscope...what your child does...and so I was hoping you wouldn't have to educate you're friends...and you go to a big family dinner or you go to Christmas or something like that and he just goes berserk...in front of everybody...

Matthew:... there's no greater feeling than numbers...knowing that you're not alone...knowing that you're not the only family dealing with this...

Kristen: I can honestly say that it's the first time in my life that I've ever felt completely alone.... (Pause)

Kristen: ...you kind of feel isolated...you really do...and that's among own family...and when you take that and put it in a different context with you just trying to take your kid to the park and your kid did something because of the sensory and that impacts with the other parents...a lot of it is looked at so much like behavior...people don't understand it and that's really hard because they're looking back at you like why can't you control your child...and it really has nothing to do with you [slight laugh].

Stefanie: ...everywhere we go that's somewhere new we take two vehicles now in case one has to leave with him...and so that has been a huge...and our daughter...we took them to an indoor water park...and I looked at her and I said, "we're going to take two cars" and I said "if he can't do it and one of us will stay so you can stay and play and the other will have to leave"...she wanted to go to a concert..."we're going to take two cars or if we don't then one of us will have to sit in the car with him"...and it's been emotional with her...and having to explain to her that even though you can't see it...it exists...but her life has changed...it's been hard on all of us...we just can't go and do...we feel like prisoners in our own house...

Stefanie: ...our nearest relative is four hours away...we're here by ourselves...and it's a very hard thing to deal with...even if you have other people...we have become prisoners...we take turns leaving the house...to get away because we are not sure what he can do and what he can't do...

Occupational Therapy

Occupational Therapy is the common thread for those living with SPD. Each participant spoke of their OT experience. The occupational therapist at times provided emotional support as well as traditional therapy. All participants spoke positively of their overall occupational therapy experience.

Tonya: ... our OT is just absolutely wonderful...we probably went a good six-eight months past when she was ready to let [child's name] go...because she was so very attached to her...and when she wouldn't be going she would get very frantic and her sensory stuff seemed fine but mentally formed that bond and they still email back and forth. And yeah we have an absolutely wonderful OT.

Matthew: I think it would have to be a tie between the speech therapy and the occupational therapy...I think the occupational therapy has given him the confidence to venture out ...

Kathy: ... the occupational therapy has been incredible and wonderful...and they have been…you know, they'll bend over backwards for us…if it's a weekend they provide their cell phone numbers…if I have a problem on a late Friday night I can actually call them and they are very willing to work with me at any time for any amount of time…they have been wonderful…they have worked with the schools…really gone above and beyond I would ever expect them to do…

Carrie: I definitely think that the occupational therapy was priceless …I could never put a value on somebody who knew why she was spinning…to explain to me why she was spinning…in a certain direction or in a position…you know like what makes her brain work differently…that this is okay for her and in certain other ways its not…so I think the occupational therapy has been amazingly priceless…

School

All of the participants mentioned school; either preschool, preparing for school or situations within school. They brought up the importance of parents knowing their rights in order to advocate for their children and a worry and dread that their children may have difficulty adjusting and being accepted at school. Participants spoke of the need to "push" in order to get their children the help they needed within the school system and to gently "push" their children through their developmental stages so that they might continue to grow.

Tonya: ......we tried at the school...the school said, “Oh, she’s eccentric”...my daughter was seven and she was talking about suicide...and outlining ways to pull that off.

Tonya: One lady, she couldn’t get her head around the whole thing and she kept trying to go through the school system and trying to get the school system to help. And I don’t know if you know anything about [city name] school systems but they’re god-awful. And they’re especially god-awful if you try to say you need help for anything. Which is why I never tried to get OT or anything...for my daughter through the school system. So I think the vast majority of them muddle through...

Jane: ... I went through the school system... [Name of school], because they have an early intervention program...and I had to jump through all these hoops...and register him for school at four and take copies of the mortgage and the power bill ...prove that we were citizens...medical records and blah blah blah...and all this other stuff so I did all that...Finally in two months we got in.

Jane: ...we did one evaluation and then a month later we did another one. And for the final conference they said that they couldn’t offer us any assistance because he had no learning delay. Well, I could have told him that.

Jane: When he was three he had a five year old’s vocabulary.

Jane: At three he was saying things like, “Actually Mommy I don’t think that’s going to work for me.” Just like astounding...

Matthew: So the auditory sections don't communicate…and the problem too is like with an IQ tests with auditory processing he…you couldn't test IQ…you'd come out brain dead pretty much on an IQ test…all the testing we've had shows him to be intelligent…but learning disabled and he is in the public school right now…public schools, the private school, there is really not a good place for someone with SPD…the public school with resources… he's been amazing…reading, doing math…

Kathy: …how to deal with schools…the public schools and the process…and rights, to know your rights…because that is a tremendous need and a constant discussion in our support group…parents DO NOT know their rights…what they have that can be offered to them through the school systems…and what even though it's not a diagnosis and schools will not give services to children just because of sensory issues…you can still keep pushing…

Carrie: We made it through the elementary school transition and she is just thriving currently…but in three years she'll be getting ready to enter Jr. high and we already know that's going to get worse before it gets better…but when it gets better it gets sooo much better…on the other side…every developmental stage has gotten worse before it got better…and when you start to see it go bad you know its going to get way worse so we're just always dreading the its going to get way worse before it gets better…it's like they fight developing…because it brings anxiety…but then once you kind of gently push them through the developmental stage its like they explode on the other side of it…and because these kids need so much more prodding to develop that when they come through the other side they maybe have more tools in their pockets and experiences and resources on the other side of it than most normal kids do …so they sometimes end up with an empathy or an understanding…

"At the Beginning"

Participants were asked at what point counseling would have been most helpful. Each of the seven participants suggested that counseling would be important at the beginning of the journey, meaning either when they felt that something was different about their child or they encountered the SPD diagnosis.

Interviewer: So, when you look back on it now…at what point…you know I'm looking at question number nine, at what point in the journey would counseling have been most helpful do you think?

Tonya: At the very beginning.

Interviewer: At the very beginning.

Tonya: Yes, I think it would have been most helpful for all of us...

Interviewer: Okay. So if someone had offered it to you at the very beginning...

Tonya: I would have taken it in a heartbeat.

Tonya: I think that counseling for everybody involved should be right there pretty immediately.

Matthew: Umm, counseling would have been beneficial probably when he was about two and a half...

Matthew: Umm, when he wasn't really talking or you know noise bothered him...and I personally worried that there was something wrong with him...the fact that, umm, I think that with the acceptance issues...that's a big thing...that's why we have these parent's groups...rarely any men show up...it's all women...men can't accept it...my wife accepted it a lot better than I did...at first...that would have helped me...cause everyone wants their kid to be perfect...and so I wasn't...I had no problems in school...I did understand...I couldn't accept it...when he was around two and a half to three...the first couple years we had problems with preschool teachers...and times when the other kids would be talking with each other and he'd be off in a corner...all alone.

Matthew: That would upset me...he went to school birthday parties where I left crying, you know all the kids were talking and he was just sitting there. I think those times would have been helpful...probably at the beginning at about age two.

Kristen: ...honestly everybody should be offered counseling...they don't have to take it...if they don't really want it or whatever...each kid...the whole point of early intervention and preschool services is to get them to a better point for elementary school...so there's a lot of emotional baggage that comes through this ...

Kathy: If I could do it all over again I would have our family...even more so my husband and I maybe go and talk to somebody just to help us understand this and wrap our head around it...and figure out a way to have it become a part of our family...with a little more ease...and to help us with the marriage too...because it does ...having two children with these kind of issues is a strain...and now on top of all the other activities we now have all kinds of therapies and psychologist visits and all kinds of things like that now...so I think that it would have been helpful to have someone to kind of ease us into the process...

"Lucky"

Five out of seven participants spoke of being "lucky" in some regard to their child's disorder or some aspect of their current life circumstance. The other two participants referred instead to a "blessing" or to being "fortunate." Participants seem to have a heightened awareness of how far they have traveled on their own journey and the cost of each step along the way.

Tonya: ...I [was] actually...lucky...I had it the opposite way... [Child's name] was oral under-responsive...so she ate anything and everything...and spicy.

Interviewer: Oh, really. So she liked it all.

Tonya: Yeah that was the easiest part of her SPD.

Tonya: I've been very lucky in that her dad is very on board with all of this...umm, you know we have people in the group saying that "my husband won't talk to me"...they think it's my fault...

Tonya: I think it would make it so much easier the less hit and miss we seem to have now. I'm lucky that once I had a name for something I knew the direction to start trying to go...

Jane: And then I'm lucky enough to be a stay at home mom...I work part time but I work from home. So at least I'm here with the kids...but we have kids and parents that I feel so sorry for them ...both have to work and kids are in daycare...and the daycare is like "We're not doing therapy with them"...

Matthew: ...we're very fortunate he doesn't throw temper tantrums...beautiful manners, he's the sweetest boy...he never has temper tantrums...and the other thing that he's unlike other SPD kids he's got awesome coordination...he's always been the best athlete...

Stefanie: And they have qualified him for services…so we're lucky…and they're paying for him 100%….so we've been in it for about three weeks…

Carrie: Yes, her preschool teacher kind of clued us into the fact that [child's name] was just a little bit off of normal development…and she said here's somebody who I think you would benefit from talking to…and gave us the play therapist name and she just happen to have a patient moving out of state and had time slot open and we just made it work…you know sometimes I think it was a huge blessing sent our way…
Carrie: You know in the right moment at the right time with the right people …so we were lucky…we still are thankful for that…
Carrie: Really at the right time…she was really wanting to work with more kids with that and…yeah we got lucky…

Kristen: …initially the speech was such a factor because we were having trouble communicating…we were very lucky that we had a speech therapist that understood sensory kids a lot…
Kristen: …mom's trying to get what the kid needs and dad's not agreeing there's anything wrong so I was lucky in that respect because my husband is on board and he trusts me…

The Final Four Themes

After continued reading and rereading of the transcriptions four themes stood out as significant, some of which echo the first eight categories listed, and some of which are also related to the literature review. These four themes are: The Challenge and The Trauma; Friends and Family; Denial, Blame, and Grief; and Was Counseling Offered. Each of these themes will be discussed in Chapter V.

Summary

The first review of the interview material was a reflection exercise using the question, "I think I heard them saying." This brought several themes and topics to mind. Each was written and kept for later reflection. The second review of the transcriptions gathered the factual information which can be found in Appendix F. The third review of the transcriptions involved reading and rereading and then coding or marking prominent emergent themes, topics and categories some of which overlapped with prior noted themes. Eight themes were prominent: "Something Different," Pediatricians, Not Knowing What to Do or Where to go, Isolation, Occupational Therapy, School, "At the Beginning," and "Lucky." The concluding and fourth review of the transcriptions is included in Chapter V.

CHAPTER V

CONCLUSIONS, IMPLICATIONS, AND RECOMMENDATIONS

The purpose of this study is to examine the perspectives and experiences of families in the process of seeking treatment for their child's sensory processing disorder and the availability of family mental health support (defined as counseling).

Overview of Methodology

This qualitative interview study gathered information from parents with a child living with SPD who were involved in a Parents Connections Group sponsored by the Sensory Processing Foundation. A total of seven parents were interviewed. The length of each interview was between 30-45 minutes. The strength of qualitative research is demonstrated not in its numbers but rather in the detail, depth, and description. These were semi-structured interviews. Each participant was asked approximately twelve questions (see Table I). The transcription material was analyzed in a four stage process. The first stage was a reflection exercise using the question, "I think I heard them saying" which brought several themes to mind that were kept for later use before revisiting the transcripts of the interviews. The second stage included compiling the factual information which can be found in Appendix F. The third stage included multiple readings of the transcripts while coding and marking prominent emergent themes, topics and categories some of which overlapped with prior noted themes. Eight themes were prominent: "Something Different", Pediatricians, Not Knowing What To Do or Where To Go, Isolation, Occupational

Therapy, School, “At the Beginning,” and “Lucky.” The fourth and final stage included reading and rereading the transcripts as the final four themes emerged.

These final four themes were: The Challenge and the Trauma; Friends and Family; Denial, Blame, and Grief; and Was Counseling Offered. Many of these themes held echoes of the previous eight as well as a relationship to the literature review.

The Challenge and The Trauma

A difficult part of each participant’s experience was the obtaining of a diagnosis and its effect on their own and their families well being. Heard here is the echo of the themes of Isolation, Not Knowing What To Do or Where To Go, the experience with Pediatricians, and the dread and worry of School. All of this is part of the Challenge and the Trauma. Miller (2006) found that parents of children living with SPD frequently do not receive validation of their struggle or support in it because the disorder is often a “hidden handicap” (p. 61). Some in searching for answers to their child’s behaviors pondered whether it was their fault. This was painful for them. Jane pushed for diagnosis for her child. Kathy and Kristen stated that many in their groups have not officially had a diagnosis because professionals are unwilling to diagnosis SPD.

Jane: Because it’s been such an ordeal for us to even...Because I mean that’s what it is...

> Jane: Ya-know just to get a diagnosis...was...it took forever.
>
> Jane: ...I know a lot of the people from my group have said this too before we had a diagnosis and it was all “he’s a boy” or “it’s terrible two’s” I just thought I was a crappy parent.

Jane: You know and it's a long time…when you beat yourself up for a couple years for what a terrible parent you are…takes a long time to get over it. You know and I think with the counseling it's beneficial not just for the behavioral issues but also to heal some of the parental issues.

Participants spoke of the challenge and the distress as they looked back on their journeys. It was demanding for the parents but also challenging as they watched their child struggle. Every participant expressed a desire for help in coping not only with parenting demands but in adapting to the challenges of SPD in its many forms.

Kathy:…I just remember my husband and I…we would chase…we would chase all day long and try to find…you know I would say that was probably one of the biggest times…to have somebody to talk to us…so that we could cope a little bit better with it…with him…because it was hard…because he wasn't doing anything that was himself…he was trying to adapt to the world with an impaired sensory system…

Participants were aware that SPD was not in the DSM and that became another challenge in their journey towards diagnosis and treatment. Four of the seven participants mentioned that diagnosis was difficult or not possible because SPD was not in the DSM. Kathy told of her "biggest dream in the world" which revealed not only her hopes but the challenges that the family faces on their journey. Horner et al. (1987) found parents are concerned not only with current care but the future as well. The worries and concerns of participants in this study reflect what was found in the literature. They identified a need for information to plan for their child's future and the need for appropriate community resources. They also expressed a desire to understand the affects of the condition on the child's development, and to help find ways to provide for the child's emotional, social and intellectual needs (Horner et al., 1987). Ziolko (1991) noted that lack of information is cause for further anxiety in parents. All of this is a greater challenge because SPD in not yet a diagnosis listed in the DSM.

Interviewer: So you said that diagnosis isn't something that happens in your area...do you know why that is?

Kathy: Because it's not in the DSM yet...

Kathy: Well, I find that a lot of doctors in this area because it's not in the diagnostic manual...that they...well, even insurance companies are giving people a hard time and they have to kind of blame it on other things...and not call it sensory issues because it's not a diagnosis...

Kathy: ...my biggest dream in the world is that it gets to be an official diagnosis...and everybody's working hard towards that...it will be a huge thing...I always tell people, "I don't think you understand it's only every ten years and the last time the book came out was the first time that autism and ADHD were in the diagnostic manual...and that's what hits people...and they go, "really?" and I go, "yes!"...before that those people weren't getting services...and now everybody knows about ADHD and everybody knows about autism now..."oh"...like yeah, exactly...could you imagine if those weren't in there?...so, hopefully that will be taken care of...

Other parenting challenges were worry and acceptance. Matthew illustrates these concerns as he speaks about the well-being of his son and then further contemplates his son being at birthday parties and on the playground at school. Acceptance of a child's disorder is difficult and provides great challenge to a father/son relationship (Hornby, 1992).

Matthew: Umm, when he wasn't really talking or you know noise bothered him…and I personally worried that there was something wrong with him…the fact that, umm, I think that with the acceptance issues…that's a big thing…that's why we have these parent's groups…rarely any men show up…it's all women…men can't accept it…my wife accepted it a lot better than I did…at first…that would have helped me…cause everyone wants their kid to be perfect…and so I wasn't…I had no problems in school…I did understand…I couldn't accept it…when he was around two and a half to three …the first couple years we had problems with preschool teachers…and times when the other kids would be talking with each other and he'd be off in a corner…all alone.

Matthew: That would upset me…he went to school birthday parties where I left crying, you know all the kids were talking and he was just sitting there.

Matthew: It's just a constant state of worry…I know my wife drives by the school playground everyday to look and see if he's interacting with other kids…

In reflecting on her journey Jane expressed a need for counseling support in "the uphill climb." Jane contemplated the nature and endurance of her commitment as a parent. Her child is traveling a long journey that includes "uphill climbs," a series of transitions and times when parents must let go. She suggested counseling support as a necessary link in the chain of resources for a child with SPD.

Jane: …Cause we as parents always nurture our children.

> Jane: You know if I get the flu my mom calls me everyday to find out have I gone to the doctor yet, why haven't I gone to the doctor? Am I taking vitamin C, am I getting lots of rest? The nurturing doesn't stop when you're a parent. And I think that even …because he's going to have this is his whole life…he's going to have to learn how to regulate and my husband and I will always be…will have to be more supportive. It will be harder for us to let go and it's definitely an uphill climb.
>
> Jane: Absolutely, not just helpful but needed. I think that every occupational therapy clinic should have an on staff behavioral psychologist. Because it's not just about the therapy [occupational therapy]…that's just such a small link in the chain…of SPD…it helps…but there is so many other needs…

The literature refers to trauma related to diagnosis as well as challenge to relationships (Kranowitz, 2005; Ziolko, 1991; Boss, 1999; Hornby, 1992; Hall, 1996; O'Brien, 2007). All seven participants spoke of these challenges. Stefanie reflected deeply when asked about the emotional impact SPD had on their family. She spoke of "trauma" in getting a diagnosis, the pain of knowing that "things hurt her son," and that it has been "risky" to both her job and their marriage. Stefanie's son is also diagnosed with oppositional defiant disorder. Stefanie also revealed that if she and her husband had known their son had SPD they would have chosen not to have him. This was difficult for her to even speak aloud, came with great emotion, and an immediate allegiance of love to their son.

Interviewer: What would you say has been the emotional impact of SPD on your family?

> You've talked a little bit about it…but what would you say overall it's been…
>
> Stefanie: Umm, my husband and I both …with both his diagnoses…if we had known this, we would not have had our son (tears)…we love him dearly…
>
> Stefanie: But the trauma we've been through in getting the diagnosis …to know that things hurt him…we planned both of our children…we sat down…we planned it, discussed it, tried, hoped, thought out and planned…we did everything to ensure the health of a child because we did not want a special needs child…and four years later…we realize he has them all along…
>
> Stefanie: …it has been devastating… it has put my job at risk; it has put our marriage at risk …

Family and Friends

The support of family and friends is noted as extremely valuable and a source to be nurtured to help face the challenges of raising a special needs child (Auer & Blumberg, 2006; Boss, 1999; & Ziolko, 1991). In this theme of Family and Friends I heard the echo of the theme of Isolation and of "Something Different." Tonya noted sibling reactions to dealing with the challenges of living with a family member who is struggling with SPD. Family life can be a challenge. "Something Different" can at times be terrifying for a younger brother or sister who does not understand what SPD is, what is happening, or why.

Even an older siblings who understands more, still may struggle with the demands of the disorder. Ziolko (1991) noted that siblings frequently may have feelings of anger, frustration or resentment toward their parents or their brother or sister. As noted in Auer and Blumberg (2006) siblings often are without sufficient information to assume the responsibility or understanding that is expected of them. They also found that siblings are further challenged because they typically are without a peer support group.

Tonya: …there are times her sister just can't take her anymore…she was complaining right before school was out for Christmas… "I wake up every single day to her screaming"…

Tonya: And the last few weeks…she probably has…umm, and her brother like I said was terrified of her…for years…he's older now…he's not terrified of her…but there are days he can't take her either.

Tonya expressed a recurrent sadness at the loss of relationship between her children and yet she exhibited a need for hope. This verifies the research of Teel (1991). According to Boss, "maintaining hope in the face of long-term ambiguity requires ceaseless effort" (1999, p. 118). Tonya wondered what this struggle meant for her daughter's future and for them as a family. Would this daughter be accepted as part of the family when her children were adults, or would she be all alone?

Tonya: And yeah, you know they…what happens when they're adults? There are times when I feel a little bit of a bonding with her sister but they are few and far so what

> happens when they're adults…you know and three-quarters of the time they can't stand to be around her is she just going to be cut off?

Family and friend support is sought and needed on the journey. According to participants they were often disappointed by the fundamental lack of understanding of SPD. Matthew spoke of not being in sync with friends and of the disappointed hope of a parent he thought would understand and how "they're not there at all."

Matthew: … most of our friends we're never in sync with them in anyway…we love them

> to death but people who aren't used to him…he talks to himself all the time..
>
> Matthew:…my father graduated from [name of prestigious school]…but can not comprehend what SPD is…just doesn't get it…he'll come into the house and pick up my son and try to hug him…and so the most intelligent people are the people you hope… you take for granted are in the position of understanding…and they're not there at all…

According to Kathy there were several issues to note – relationships with the extended family, understanding SPD, helping grandparents to understand and then to deal with the disorder while being in a healthy relationship with their grandchild. Kathy spoke about her Parent Connections Group and parents that are also concerned with their children that do not have SPD. Parents are trying to find ways for the non-SPD child to cope with family life. Kathy stated that "the family takes the biggest abuse from the SPD child." This was understood to mean that the family sometimes pays the biggest price from the consequences of SPD.

Kathy: ......extended family...it's a very hard disorder to understand...to wrap your head around...it is...and it's very hard... And I would say that the amount of information I have read and the amount of talking about it that I have done and the amount of books that I've read ...all these groups...I think I'm just now making sense to people....when I talk about it...now people say, "oh, now...I kind of get what you're saying"...I don't think people can explain it easily ...grandparents always have a hard time with it...I have a number of parents that come to my group - mainly in the group to try and help their other children...like they're already doing therapy for the child that has SPD but they're trying to figure out how to not ignore the quote/un-quote "normal" child...how to have them not be overlooked or how to have them cope with what's going on in the family....but sometimes the family takes the biggest abuse from the SPD child.

There were two participants that stated exceptions in regard to family and friends. Carrie noted grandparents ready and able to make adjustments that are necessary for her daughter. Kristen found friends that are very supportive with similar needs and interests though she noted that it "definitely changes things though."

Carrie: We've had a couple grandparents offer to read those books...to better understand and being willing to make accommodations when we go to visit or when they come

> to visit...you know just to understand that she just needs stuff to be a little different...than what her brother needs...
>
> Kristen: You know most of our friends ended up becoming people like me...[laughs] I run the support group with another girl and you know and we turned to each other because we were looking for parents who are interested in talking about sensory processing in [name of city] webpage and that's how we found each other...and we talked and we had so much in common and most of the friends that I have are friends that have kids like mine and completely change the dynamics of everything really...not in a bad way cause they're wonderful friends really...definitely changes things though...

Denial, Blame, and Grief

Matthew spoke of husbands being in denial of their child's SPD and their unwillingness to accept that their child may be "flawed." He felt that this denial was especially true with a boy. Matthew also mentioned that "a lot of husbands" decide that treatment is not a valid expense. His observations are congruent with the results of other studies. It was found that in trying to accept their child's disorder and deal with their grief, parents withdraw, sometimes become emotionally uninvolved and then will enter into denial (Ziolko, 1991; Boss, 1999). Here again is the echo of the themes of "Something Different" and of Isolation. According to Boss denial can provide a short-term healthy oasis from the shock of the reality and impact of a diagnosis. It is when denial continues that there is a problem. What was reported by Matthew would validate this research.

Denial

Interviewer: Have many people in your groups talked at all about their friendships or relationships with their spouses...

Matthew: Spouses, there's two issues, number one - the husbands are in denial they don't want to accept it...the child is flawed...especially with a boy...number two a lot of them ... my wife had to spend a lot of money at the name children's center...a lot of husband's will decide it's not a valid expense... it's very expensive and not covered by insurance so a lot of husbands will decide they don't want to pay for it.

Blame

Boss (1999) stated that blame is a common reaction when faced with a loss or traumatic experience and that it can stem from a "view of people feeling like they are getting what they deserve" (p. 126). Boss concluded that people hold dearly to these views as they have a great need for the world to be a just place because if it is not then they would not be able to control the ambiguity of their loss. Again as Matthew spoke about his group experience he described his perspective that women carry a burden of guilt and responsibility for SPD. Matthew spoke of "a lot of the women" blaming themselves. He stated it caused him to get mad that women blame themselves and that they "feel responsible for it." Matthew suggested counseling as a resource of support.

Matthew: ...I don't know if you've come across this but a lot of the women blame themselves...for the kids having SPD...to a degree where I get mad where this is a fluke or genetic thing...it's just not your fault...but they go, "Did I have too many diet cokes?" "Was I sick and I should have gone to the hospital?" so all these women have guilt...they're all ravaged by guilt...so in addition to having a child with SPD...they feel responsible for it...the men don't have that because they're not the mom and they don't carry the baby...

Matthew: But all these women are ravaged with guilt and feel responsible for this..."I've made this mistake and I'm going to going to rectify it"...and they can't and so I think counseling would be beneficial...all these women often have husbands not supporting them...you know going, "Oh, you're overreacting"...they're blaming themselves... they're with the child most of the day...the spouse is at work...and so the women truly are needing the counseling... a lot of them just need someone to talk to someone who understands them...

Grief

Participants shared that grieving took place as they realized that their child was not what they had expected. The literature suggested that with ambiguous loss grieving takes place on a recurrent basis rather than a linear stage model (Teel, 1991; Boss, 1999; Friehe, Bloedow, & Hesse, 2003). Carrie shared that it was not just parents that grieved but extended family as well. Tonya suggested that families need counseling during this process of grieving. She mentioned - how do you deal with the other kids in the family, how do you deal with the diagnosed child who is now not what you expected and never will be, and how do you process a changed long term perspective? Jane suggested counseling to deal with parental issues. She also referred to some of the "good things" of the journey such as – "you develop a stronger bond with your child." Participants turning grief into hope and finding benefits in their circumstances agreed with the literature (Boss, 1999).

Carrie: You know the play therapist …I worked with her one-on-one and my husband …like he and I would go in there and work with her…a lot of the grieving that we were doing...because the child wasn't what we had expected…because she wasn't quote/unquote "normal" and so you lose…an you know that grief you have to go through…and so we did speak with her…

Carrie: …she was the first grandchild on both sides…so I think there was also some grieving for the grandparents as well...you know having to watch their kids struggle with their first kid…and that whole process I think was a little tough but it's a very open topic among the adults in the family we don't …the grandparents don't talk with her about it as much but the adults still talk about it and they still ask how it's going…you know they all live out of state and have lived out of state for my daughter's whole life so they just kind of come and see her when they do …

Tonya: … I think if they can get the families the counseling…you know how do you deal with the other kids…how do you deal with this child who's all of sudden not everything you thought…you know it's not something that's going away…what do you do with that?…that changes your long term perspective…

Jane: You know and I think with the counseling it's beneficial not just for the behavioral issues but also to heal some of the parental issues. I think too [child's name] doesn't have severe sensory processing disorder and I'm only mentioning this because you're going into counseling but I think one of the issues is that some parents are faced with is grief. ..Because you expect …and I'll forward you an email from one of my friends…it's called going to Holland…it compares having children to planning a trip to Italy and you get your guide book and you learn the language and your so excited and when you get off the plane and the stewardess says welcome to Holland…and you're like "what the Hell"…and it's kind of like that with…especially I think the parents with autistic children…or children with cerebral palsy…or the major disorders that come with SPD…I do think they go through kind of a grieving process…this is not what I expected…

Jane: And there are good things that come out of that…of course, you know…you learn…it makes you stronger…you develop a stronger bond with your child…I could go on and on about the benefits...

Jane: But I do think that with some parents there is some grief that needs to be addressed as well.

Was Counseling Offered?

In answer to question eight of the interview - Have counseling (family, couples, or children's mental health counseling) services been offered? Five of seven participants stated that counseling was not offered or suggested by professionals. The two exceptions are noted below. The participants' journeys included pediatrician visits, occupational therapists, play therapists, psychologists, psychiatrists, speech therapists, behavioral therapists, listening programs, schools programs, and trips to the emergency room. These professionals were most often sought and found by the families themselves. Participants also stated that there was a lack of referral and basic information available from providers. This is an echo of the theme of "Not Knowing Where to go or What to do." Looking back on her journey Jane recommended counseling for herself, her family and her son. She realized they "needed external help" and that as parents they had issues as well as their son who was living with SPD.

Jane: I think when I called the preschool director and found out that he had problems all the year before.

> Jane: That day... we should have started counseling...for me...for everybody. Not just for him...because then it dawned on us that it wasn't us...that there was a problem and that we needed external help...and a counselor could have pointed us in what direction to go...could have worked through some of the...parents have issues too I think.

Matthew stated that he and his wife rely on each other for therapy. This was true even though for a long time he was in denial concerning his son's disorder. Note too that his wife also experienced denial, though not as long according to Matthew. It has been helpful for them to work together as a team to benefit other families. Matthew's report of denial and seeking to benefit others because of what he has been through would validate current research (Boss, 1999).

Matthew: It's never been offered to my wife and I [counseling]...we are each other's

> therapy...and we work pretty strongly together as a team...and that's kind of been our therapy...that's why we work so hard to help other families with it...it was upsetting to both of us...I was in denial a little longer than my wife was...but I realized that I certainly wasn't helping him by being in denial and dove right into it...

The two exceptions of counseling being offered were Stefanie and Carrie. Stefanie stated that though she was not offered counseling in the beginning when first seeking a diagnosis for her son, once her son was diagnosed she had several therapists in place that were coming to her home. All of the services Stefanie's son received came after a stressful process which culminated in an SPD diagnosis.

Stefanie: ...the intensive home people come to us in the afternoons because they're not

> only helping him...but they're there to help our daughter who struggles because she saw a lot of things she shouldn't have seen...a lot of scary behaviors ...a lot of scary things from him....
>
> Stefanie: They have a licensed therapist who works with him once a week...the other two ladies are qualified professionals I don't know what their qualifications are...one lady works with me and my husband on the parenting and marriage aspect...she has a 44-year old daughter with special needs and she knows...she's been there...the lady who comes on Tuesdays works a lot on his

> behaviors...helping to separate what's sensory and what's ODD... when to do the discipline ...and then the third lady is one who works with me and my husband the most...

Carrie was another exception to the lack of counseling. She stated that she received supportive care which she considered analogous to counseling through both an occupational therapist and a play therapist that her daughter saw when she was younger.

Carrie: ...sometimes during the therapy sessions with my daughter when it was challenging for us she would have [child's name] go into the other room and play with some of the other toys...and we would sit and talk with her...and we actually did that with the occupational therapist too because we were ...you know it was like a process that all three of us went through...

> Carrie: ...but we did use the counseling through the play therapist quite a bit and she was real good...we really benefited from her knowledge and her understanding and her saying that this isn't going to be this disabling forever...it is going to get easier and you're going to understand...and you will learn...and at one point she even offered us to consider that she could write prescriptions for depression medication if we felt that would help us...

Not only were counseling services not offered to most of the participants, but other pertinent information and referrals were lacking as well. This echoes the earlier theme of Not Knowing What To Do or Where To Go. Participants had to seek out services and find their way along the journey as they sought a diagnosis and the needed services for their children. Stefanie calmed her son's fears of returning to the hospital by telling him that he didn't have to go back "because we're fixing it." Jane told of the elimination process which led to her diagnosing her son. Kathy revealed her "light bulb" moment of understanding her daughter after much research and the fact that she had to "hunt down and find" information that led to that discovery.

Stefanie:…he's like a kid that melts down in public and keeps it together at home… he melts down where it's safe… so he would hold it together at the hospital…completely for a week… when he came home it all came flooding out…and that's why he would be ten times …twenty times worse the minute he got home from being discharged from when he went in….

Stefanie: But we understand that now…but he'll even look at us now and he'll even cry and say, "Mommy do I have to go back to the hospital?"… "No, you go to the hospital when you're sick and the doctor doesn't know what's wrong…when the doctor knows what's wrong we don't have to go back cause we're fixing it."

Jane: He's fine in school but not at home…that leads you to believe that the problem is at home. You know when you do the elimination process. So anyway when the director told me that it all clicked. Actually at that point is when I started really reading and I was like I'm going to figure out what this is.

Jane: Ultimately, I'm the one that diagnosed him.

Kathy: …once I started looking into it, it answered a lot of questions for me…a light bulb went off…it was the answer to what was going on with her…but everything…we utilized I have had to hunt down and find…so that's the only thing…and I've said that to a lot of people that I come across that are professionals in this area is that nothing is suggested so if I wasn't the type of parent that did a lot of research and jumps in with both feet I'm not so sure I would have found any of these things…besides maybe the occupational therapy.

Implications for Counselors

"Counseling is an interpersonal process involving a professional with the requisite graduate education and experience in counseling, using scientifically validated methods, working with an individual, family, group, organization, or segment of a community that is seeking assistance (the client)" (Hershenson, Power, & Waldo, 2003, p. 6). This process also involves helping the client to imagine, and reach goals. Depending on the client this may include "assisting healthy growth, preventing a difficulty from arising, redirecting a maladaptive pattern of development to a healthy course, assisting the client to compensate for existing limitations in ability to cope by promoting the use of other strengths that the client possesses and improving the client's quality of life above its present level" (Hershenson et al., 2003, P. 6). Matthew stated, "we need people who understand it [SPD]…it's the most wonderful feeling in the world …to not have to keep explaining and explaining…if I was meeting a counselor and she knew what SPD was and that would be wonderful." These poignant words from Matthew and the other information within this study prompt the naming of implications for counselors to consider.

All seven of the participants suggested that counseling would be important and it would be most significant at the beginning of the journey, meaning either when they felt that something was different about their child or when they encountered the SPD diagnosis. This would imply both that counselors be familiar with SPD and that they be available at the beginning of the family's journey. Collaboration with other professionals, such as occupational therapists and/or pediatricians would be recommended in order for this to take place.

In the interviews the participants spoke very openly of their experiences. Twelve themes emerged.

The first eight themes:	"Something Different" Pediatricians Not Knowing What To Do or Where To Go Isolation Occupational Therapy School "Lucky"
The final four themes:	The Challenge and The Trauma Friends & Family Denial, Blame, and Grief Was Counseling Offered

Awareness of these themes will help counselors be familiar with the issues SPD families are facing. From the interviews other implications arise for counselors.

1. Issues for counselors to consider in regard to parents:

a. Counselors may anticipate the need to help parents in adapting to life with a child with SPD. Especially important is the task of coming together on the same "parenting page." Several participants mentioned this was important while also noting that when parent's are not on the same page this can make it difficult for a family to function.

b. Counselors may anticipate the particular problems fathers often face. Many experience denial of the child's disorder and negative reactions towards professionals. It was noted by participants and in the literature that fathers experience denial and negative reactions towards professionals (Hornby, 1992). One father also developed terms such as "referral ad infintum," "professional ignorance," and "the deaf ear syndrome" based on his experience with seeking help for his child (Hornby, 1992). Counselors should be aware that parents may have had this experience or these feelings.

c. Counselors may anticipate the need to help parents in the grieving process. It is important counselors are familiar with the concept of ambiguous loss and the idea that grief is not a linear process but rather recurrent (Boss, 1999). Parents are grieving for the child that will never be. "The devastation wrought by unresolved grief is only intensified when no one validates it" (Boss, 1999, p. 59). Ambiguous loss is confusing not only to the families themselves but also to those around them. Listening and validation are what is needed by an effective counselor as part of the therapeutic process.

d. Counselors may anticipate the need to help parents in regard to issues of guilt and blame. According to Miller (2006) guilt is common among parents of children with SPD and it is understanding that brings relief. Counselors should be prepared for the mixed emotions of denial, blame, and grief that are possible when parents are dealing with the challenges of living with SPD.

2. Issues for counselors to consider in regard to the family:

a. Counselors may anticipate the need to help families in regard to sibling issues. One participant shared that her child was "terrified" of his sister. Other parents wondered how strong the bond was between siblings and whether they would have a bond in the future. Because day-to-day family dynamics are based on the child living with SPD parents struggle to counter the effects for the non-SPD siblings. Counselors can provide the siblings the opportunity to express their experience in a safe therapeutic environment.

b. Counselors may anticipate the need to help families in regard to extended families. For example, grandparents are also on this journey with the parents and the child living with SPD. Carrie shared that her grandparents found it difficult because their granddaughter was the first grandchild on both sides. Carrie said that both sets of grandparents were grieving and watching their kids struggle with their first child. Counselors should be prepared for family therapy to include extended family or the possibility of just counseling extended family.

c. Counselors may anticipate the need to help families in regard to issues concerning isolation and lack of understanding from friends. Tonya shared that the support group is not enough. It meets only once a month.

d. Counselors may anticipate the need to help families in regard to issues that parents have concerning their children's future. While this may in part include grieving the future that they could have had participants mainly shared concerns of the future that the child may have ahead of them. One participant was concerned that her child living with SPD may be cut off from her siblings when they were adults due to lack of bonding or relationship. She wondered what the future would be like for her daughter. An effective counselor could help this participant process these thoughts and any feelings she has with this issue as well as working to strengthen the relationship.

3. Issues for counselors to consider in regard to the child living with SPD:

a. Counselors may anticipate the need to help in regard to issues that children living with SPD have with acceptance and being "different." Several participants shared that their children realized they are "different." Some of those children have begun the process of acceptance. Counselors can aid in this process of self acceptance as well as the building of self-esteem.

b. Counselors may anticipate the need to help in regard to issues that children living with SPD may have concerning social and emotional functioning. Some of these issues include but are not limited to inflexibility, poor communication, seeking attention in negative ways, difficulty keeping friends, difficulty with transitions, frustration, attachment problems, stress, anger, anxiety, and academic problems. Participants shared that they would like more social skills training for their children and often it is social situations that are difficult and emotionally taxing not only for the child with SPD but for the parents as well.

c. Counselors may anticipate the need to help in regard to having access to referral services that would be of benefit to the child living with SPD. This requires listening to the client and finding out their particular needs, abilities, and interests. For a sensory child this may also mean collaborating with an occupational therapist.

d. Counselors may anticipate the need to help children living with SPD have concerning their self-exploration and self-expression. The child may need to find ways to express themselves that may be different from his/her siblings and peers. This will require exploration for both the child and the counselor and the involvement of the parents. A child with SPD may need to move more than other children or may need to be still and in a quiet place. The child may also be sensitive to the fluorescent lights in your office. This will depend on their particular subtype of the disorder and a variety of needs.

Exceptions within the Current Study

While the predominant experience of the participants with providers was a lack of awareness of SPD, and a lack of referral to essential resources including counseling, there were notable exceptions to each of these. Stefanie shared that after a traumatic journey to diagnosis they now had in-home therapy that included counseling (from an identified "licensed therapist" and "qualified professionals") for themselves as parents, as a couple, and their children. This therapy included parenting issues, marriage counseling, sibling counseling, and behavioral counseling for their child with SPD. These services came about in part because their son also has a diagnosis of oppositional defiant disorder.

Carrie shared that her family received counseling through a play therapist and occupational therapist that their daughter saw when she was younger. This therapy helped them with the process of accepting that their child was not "normal," grief issues, and parenting issues.

Kathy shared that her daughter's school was very knowledgeable and eventually provided referral ideas for occupational therapy and psychologists but she still states, "No one ever suggested it...it's come about because of my concern...in her...I have kind of searched it out." But it is an exception to be noted that the school did provide some helpful resources.

Jane mentioned that in rare cases she has known from her Parents Connections Group that there were pediatricians... "that are on it...and then immediately know to spot it." The "it" would be SPD. From the seven interviews these pediatricians would be an exception.

Summary of Exceptions

Exceptions found within the seven interviews of this study included two families that received counseling as part of the care they received through other providers. Stephanie, whose son was diagnosed with oppositional defiant disorder (ODD) as well as SPD, received in-home counseling due to their son's ODD diagnosis. Carrie whose daughter received services from both a play therapist and an occupational therapist received counseling from both therapists. There was one school noted as "knowledgeable" and one group of pediatricians that were noted as being able to "immediately spot SPD" according to a participant.

Limitations of the Current Study

Although the participants volunteered in this study, based on the literature review and the participation of the one father in this study, it would be recommended for further research to involve more fathers in future. It was a circumstance of this study that there were more female participants than male participants.

The length of the interviews was 30-45 minutes which did not fully allow for the freedom of follow-up questions. Although this was a practical compromise it is an item to consider for future research. Participants' story of their experiences sometimes covered many years. This telling took time that needed to be allotted for within the interview.

Question four (What different diagnoses are represented in the group?) proved to be more confusing for participants than informational for the interviewer. Participants did not know if they should answer that there were children that were sensory seekers or that there were children with ADHD. The question would need to be refined or removed. This question was originally included to give the participants opportunity to talk about their group experience as well as their personal experience and to gather data on the variety of diagnoses within each group. It did give the participant the freedom to speak to the diagnoses of the group or of their own child as intended, once the interviewer provided clarification.

Suggestions from Participants

Four of the seven participants were asked the following subset question: What services would you like that has not been provided or maybe you have thought of along the way that would be like to have provided?

Carrie had two suggestions. The first was that professionals such as pediatricians or counselors provide lists of other professionals such as dentists and hair professionals that are aware of and serve people with special needs. Carrie shared that, "the dentist is like the scariest place on earth for my daughter." If these professionals are willing and able to provide services for a child with SPD this could ease a potentially traumatic experience.

Carrie's second suggestion was to have an occupational therapy gym that was open to the public two Friday nights a month. This would enable parents to bring their children to use equipment they were already familiar with. Carrie reasoned that her daughter still had sensory needs that could be fulfilled through the OT gym, but that she no longer qualified for OT. She also stated that many other children would probably like the gym experience.

When Kathy was asked this question her response was that she just wanted doctors to support the SPD diagnosis. She stated that, "sensory issues tend to be brushed off to the occupational therapists." She would like doctor's support and would also like more counseling.

Matthew's son at one time had a socialization class which he described as amazing. It lasted about an hour and they would have meals or would do things that "we take for granted." Matthew stated, "But not enough people would pay for it so we couldn't do it...that's one that we missed." Matthew felt that teaching socialization skills would be important.

Kristen suggested counseling services. She stated, "Just to know that somebody other than us is keeping an eye on his psyche...I don't even know if that's the right word but...just on where he is self-esteem-wise and emotionally, socially...you know...because my husband and I are not trained professionals...we've done the best we can..."

Recommendations for Further Research

1. Counselors, pediatricians, occupational therapists, and other professionals that parents with children living with SPD come in contact with should explore ways to collaborate so that they may be involved in the referral process "At the Beginning." The participants said that this was when counseling services were most needed and welcome. This could include further research into the possibility of a medical home model that would fit best the family of a child living with SPD.

2. Research to explore the "At the Beginning" period which participants noted as highly significant. It would be important to get a clearer picture of what this period of time is like for the family and for the child living with SPD. From this more detailed picture the researcher could then a draw needs based assessment plan and have a better idea how to best offer counseling.

3. Research to explore ways to provide sibling support. Being labeled the "normal" one is not an easy mantle to bear and it usually comes with responsibilities. Siblings of children with special needs have different responsibilities and expectations than their peers

(Auer & Blumberg, 2006). Researchers and counselors can help siblings find ways to express themselves, learn good self-care, and establish healthy family relationships.

4. Future research to include more fathers. This study included one father which gave an added perspective. It could be significant to have several more fathers to examine their perspectives. Hornby (1992) mentioned negative feelings fathers have towards professionals involved in their child's care based on limited contact as well as issues of denial and acceptance. These are all areas that could be further examined.

5. Further explore the concept that participants brought forth of being "Lucky." Would this concept hold true if the interviewer were to interview a new group of participants? Would they also consider themselves "Lucky?" What would this mean? This concept bears further exploration because it was not asked but rather was volunteered by each participant and is supported in the literature. Boss explains that often those who have experienced ambiguous loss find benefits in their circumstances (1999).

6. Increase the time of each interview to allow for follow-up questions and for participants to further tell of their experiences and perspectives.

7. Consider in-person interviews as an alternative to telephone interviews. All the participants in this study seemed fully at ease on the telephone. Some people however, may be more comfortable meeting in person. This would require travel for most interviewers and therefore cost must be taken into consideration. Several participants extended invitations to the interviewer to attend their Parents Group. This could be considered, with appropriate permission, a research forum.

Summary

This chapter presented the final four themes that emerged from the analyzed interviews. The themes are: The Challenge and The Trauma; Friends and Family; Denial, Blame, and Grief; and Was Counseling Offered. Some of these themes held echoes of the initially identified themes of: "Something Different," Pediatricians, Not Knowing What To Do or Where To Go, Isolation, Occupational Therapy, School, "At the Beginning," and "Lucky." Several of the final four themes were also linked to the literature review. One particularly important discovery was that most were not offered counseling. Out of the themes and topics shared by the participants, implications for counselors were noted. This chapter also incorporated exceptions to the experience of the majority of the participants as well as noting particular limits of this study. Suggestions from participants about potential services and recommendations for future research were also discussed.

Conclusion

Recent literature on sensory processing disorder has been focused on establishing a diagnostic classification in order to assist parents with treatment options for their children. As a researcher and future counselor I often felt there was also a need to know more about how the families were coping. There were three key elements that motivated me in this research: the needs of the families on their journey, the challenges and complexities of SPD, and the great need for counselors and other clinicians to enter the fray of understanding for the families of children living with SPD. Counselors are professionally trained to provide for the needs of their clients which include families of children living with SPD. However, there still is a bridge for the families to cross and that is getting to the counselors office. Collaboration with other professionals in part is a possible answer to this question. It is not the complete answer. Participants have said in this study they are not being offered or being referred to counseling. Participants have also said that they feel a need for counseling. The next question is how can that bridge in their journey be crossed and what role will we as counselors play in helping them to cross it?

Summary of Research

This qualitative interview study explored the experiences and perspectives of seven parents with a child living with Sensory Processing Disorder (SPD) and the role of counseling. Counseling was not offered to five of seven of the participants. As they described the challenges they faced all the participants recommended that counseling be offered to the family at the beginning of the journey either once diagnosis took place, once treatment began, or once they sensed something was “different” about their child. Implications for counselors and further research were discussed.

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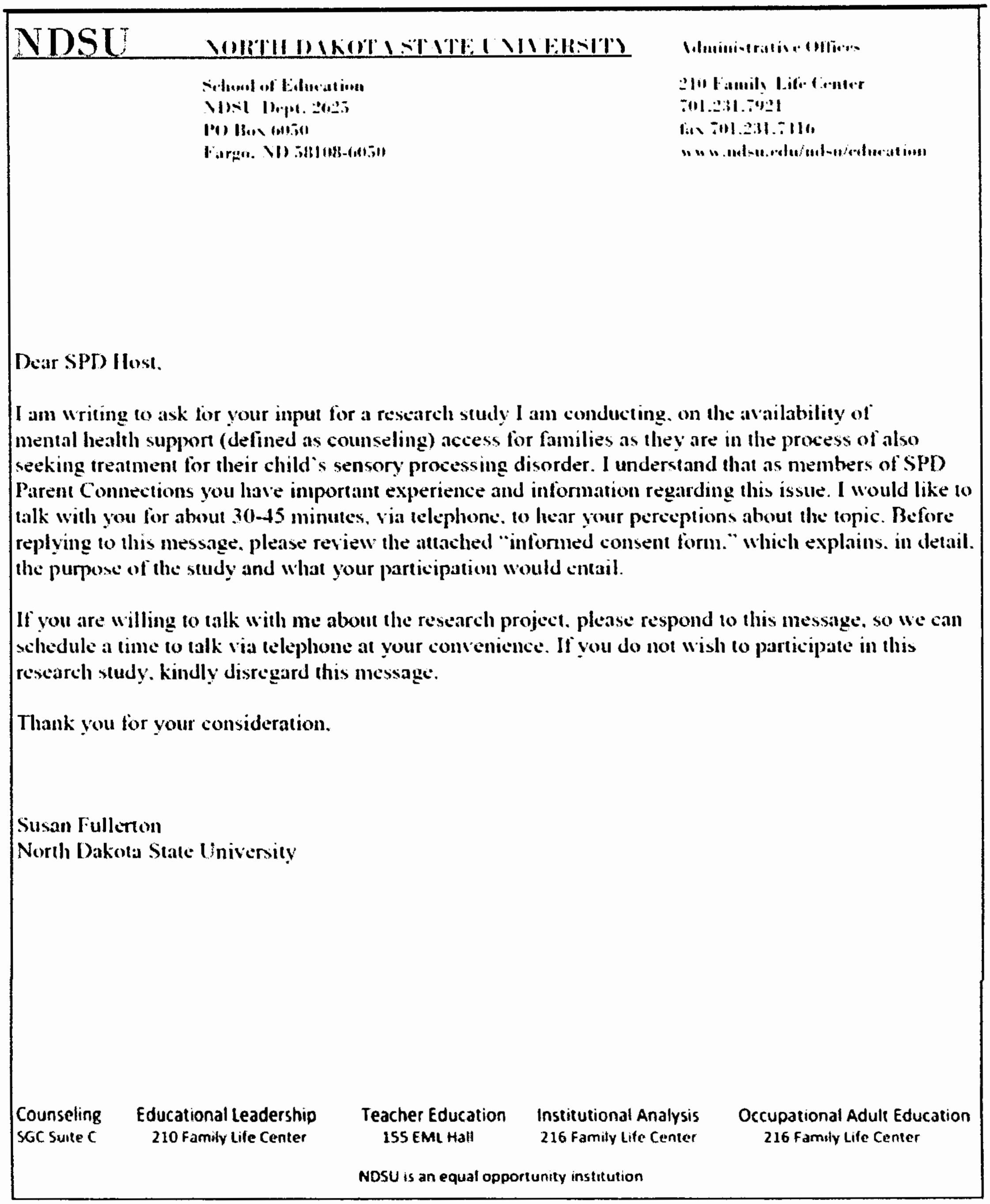
APPENDIX A

RECRUITMENT EMAIL



NDSU NORTH DAKOTA STATE UNIVERSITY
Administrative Offices

School of Education
NDSU Dept. 2625
PO Box 6050
Fargo, ND 58108-6050

210 Family Life Center
701.231.7921
fax 701.231.7116
www.ndsu.edu/ndsu/education

Dear SPD Host,

I am writing to ask for your input for a research study I am conducting, on the availability of mental health support (defined as counseling) access for families as they are in the process of also seeking treatment for their child's sensory processing disorder. I understand that as members of SPD Parent Connections you have important experience and information regarding this issue. I would like to talk with you for about 30-45 minutes, via telephone, to hear your perceptions about the topic. Before replying to this message, please review the attached "informed consent form," which explains, in detail, the purpose of the study and what your participation would entail.

If you are willing to talk with me about the research project, please respond to this message, so we can schedule a time to talk via telephone at your convenience. If you do not wish to participate in this research study, kindly disregard this message.

Thank you for your consideration,

Susan Fullerton
North Dakota State University

Counseling	Educational Leadership	Teacher Education	Institutional Analysis	Occupational Adult Education
SGC Suite C	210 Family Life Center	155 EML Hall	216 Family Life Center	216 Family Life Center

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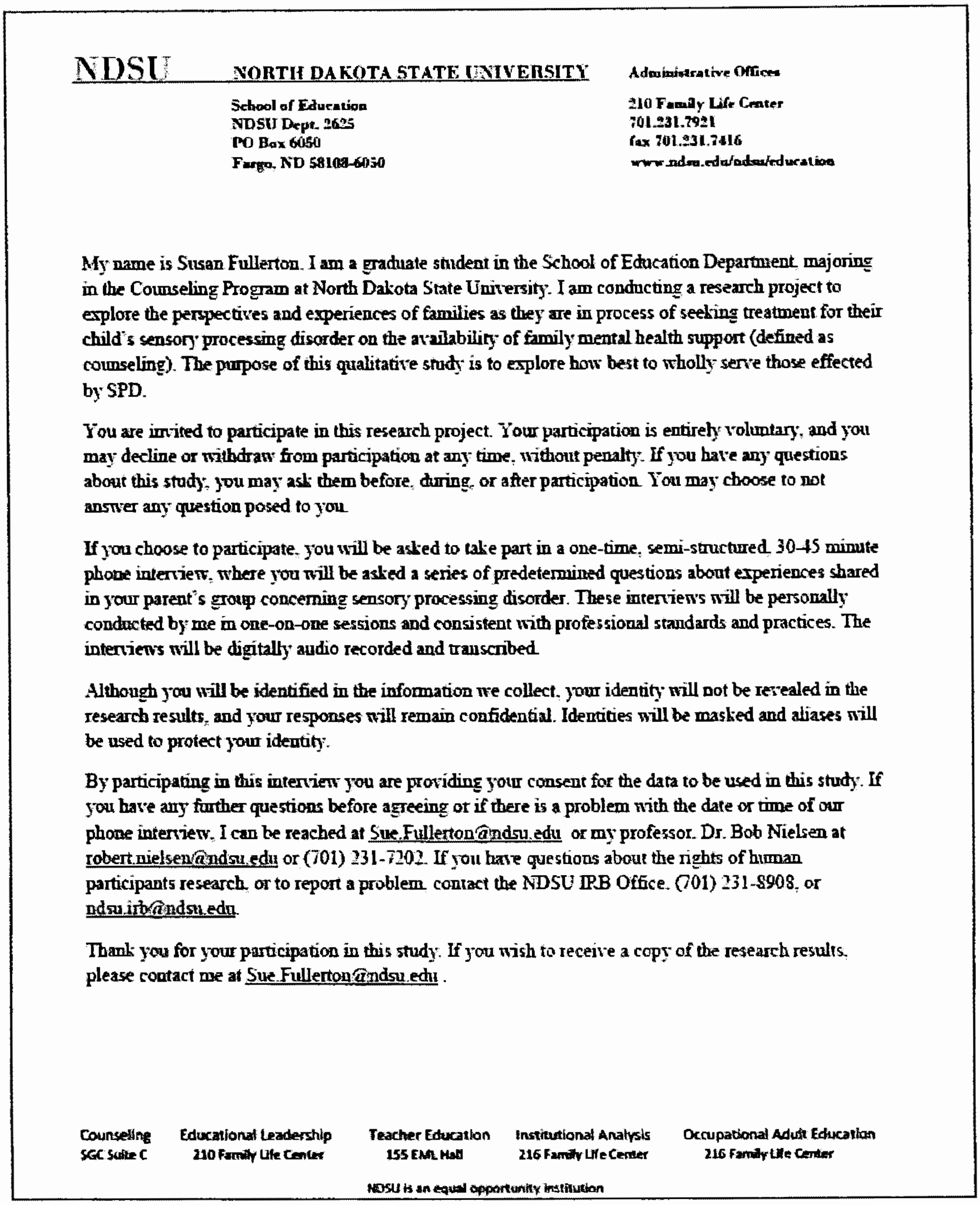
APPENDIX B

INFORMED CONSENT DOCUMENT



NDSU NORTH DAKOTA STATE UNIVERSITY

School of Education
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PO Box 6050
Fargo, ND 58108-6050

Administrative Offices
210 Family Life Center
701.231.7921
fax 701.231.7416
www.ndsu.edu/ndsu/education

My name is Susan Fullerton. I am a graduate student in the School of Education Department, majoring in the Counseling Program at North Dakota State University. I am conducting a research project to explore the perspectives and experiences of families as they are in process of seeking treatment for their child's sensory processing disorder on the availability of family mental health support (defined as counseling). The purpose of this qualitative study is to explore how best to wholly serve those effected by SPD.

You are invited to participate in this research project. Your participation is entirely voluntary, and you may decline or withdraw from participation at any time, without penalty. If you have any questions about this study, you may ask them before, during, or after participation. You may choose to not answer any question posed to you.

If you choose to participate, you will be asked to take part in a one-time, semi-structured, 30-45 minute phone interview, where you will be asked a series of predetermined questions about experiences shared in your parent's group concerning sensory processing disorder. These interviews will be personally conducted by me in one-on-one sessions and consistent with professional standards and practices. The interviews will be digitally audio recorded and transcribed.

Although you will be identified in the information we collect, your identity will not be revealed in the research results, and your responses will remain confidential. Identities will be masked and aliases will be used to protect your identity.

By participating in this interview you are providing your consent for the data to be used in this study. If you have any further questions before agreeing or if there is a problem with the date or time of our phone interview, I can be reached at Sue.Fullerton@ndsu.edu or my professor, Dr. Bob Nielsen at robert.nielsen@ndsu.edu or (701) 231-7202. If you have questions about the rights of human participants research, or to report a problem, contact the NDSU IRB Office, (701) 231-8908, or ndsu.irb@ndsu.edu.

Thank you for your participation in this study. If you wish to receive a copy of the research results, please contact me at Sue.Fullerton@ndsu.edu .

Counseling	Educational Leadership	Teacher Education	Institutional Analysis	Occupational Adult Education
SGC Suite C	210 Family Life Center	155 EML Hall	216 Family Life Center	216 Family Life Center

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APPENDIX C

SECOND CONTACT EMAIL

Greetings,

Thank you for your interest in my research study. You are now receiving this follow-up email because you responded positively to my initial invitation. Thank you. It is because of your willingness that projects like this can continue. The original email explained that the project would include a phone interview which should last approximately 30-45 minutes. This interview will be scheduled at your convenience. The initial dates of availability for interviews are as follows:

Please email me at either fullertonsue@msn.com or Sue.Fullerton@ndsu.edu with a specific time (hour) that works best for your schedule. Please include the phone number you can be reached at for the interview. Once the interview hour has been set I will send you a list of the questions that we will be discussing. That way if you would like to prepare or ponder your response in advance you will have that opportunity. The idea is not to have the "right" answers in as much as it is to just be comfortable to share your experiences.

Date	*Time*
3-Jan	Evening
4-Jan	Morning
5-Jan	Evening
6-Jan	Evening
7-Jan	Evening
8-Jan	Daytime
9-Jan	Daytime or Evening
10-Jan	Evening
11-Jan	Evening

KEY	
Daytime	8 am to 5 pm
Morning	8 am to Noon
Evening	5 pm to 9 pm

Once again, thank you for your willingness to consider this project and this important topic. This is completely voluntary and you may at anytime opt out of the project. These interviews will be personally conducted by me in one-on-one sessions and consistent with professional standards and practices. The interviews will be digitally audio recorded and transcribed.

Although you will be identified in the information we collect, your identity will not be revealed in the research results, and your responses will remain confidential. Identities will be masked and aliases will be used to protect your identity.

I look forward to our "meeting" on the phone and our conversation.

Sincerely,

Sue Fullerton

APPENDIX D

CONFIRMATION EMAIL

Greetings,

Saturday, January xx at 3pm Central/4pm Eastern we are set for our interview. I will call you at your number: xxxxxxx. I will strive to keep our interview to the time schedule of 30-45 minutes. Attached you will find the list of questions for you to look over. Again do not feel you have to come up with exact answers. Some you may not know the answers to and in that case just say so and we will move on from there. I am hoping for a conversation which you feel comfortable enough to converse about your experiences with your child in regard to SPD and any experiences you feel free to share concerning your Parent Connection group's experiences. Please remember that although you will be identified in the information I collect, your identity will not be revealed in the research results, and your responses will remain confidential. Identities will be masked and aliases will be used to protect your identity.

Thank you,

Sue Fullerton
Fargo, North Dakota
North Dakota State University

APPENDIX E

REMINDER EMAIL

Greetings,

I am following up on the previous email you have received. I know this is a busy time of year and I appreciate that your time is valuable. I would like to emphasize how important your input would be in my research endeavor – and how you could help to develop better ways to serve children with SPD and their families. Please consider participating! Scheduling will be at your convenience.

Thank you,
Susan Fullerton
North Dakota State University
Fargo, ND

APPENDIX F

FACTUAL INFORMATION FROM INTERVIEW QUESTIONS

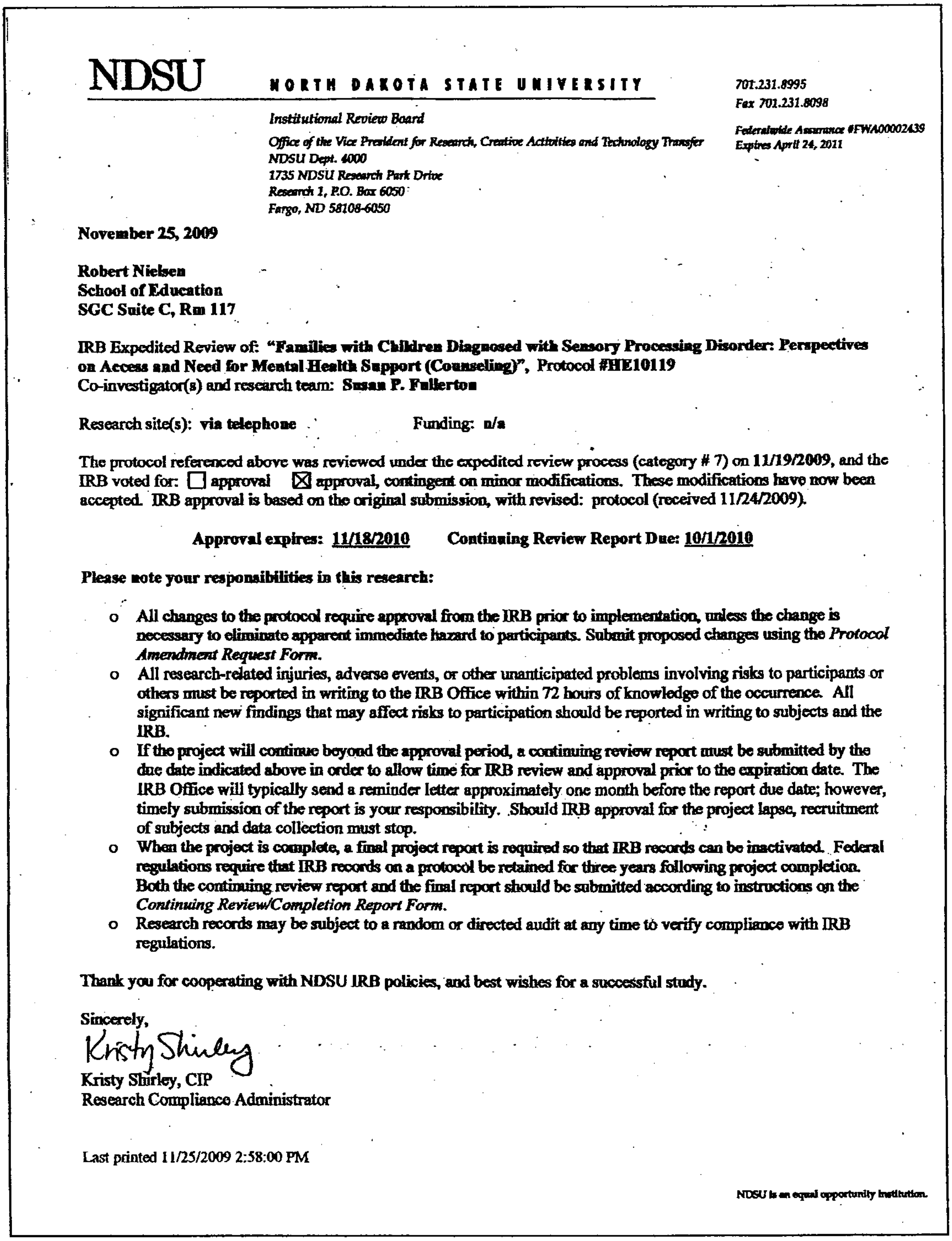
Table II

Factual Information From Interview Questions

	How many parents and children with Sensory Processing Disorder do you have in your Parent's Group?	How long has your group been together?	What are the ages of the children with SPD in your Parent's group?	What different diagnoses are represented in the group?
Interview 1	7-10 regularly (125 in contact with)	since Jan 2007, 3 years	3-7 years, a few 12-15 years	ADHD, autism, PDD, OCD, sensory seekers, and sensory defensive
Interview 2	n/a	n/a	n/a	n/a
Interview 3	10-15 regularly ("lots")	since Sept 2009	10 years and under	The whole gamut, no autism, ADHD
Interview 4	20-25 ("growing")	since Sept 2009	2-11 years	Sensory seekers, autism, Asperger's, mainly SPD
Interview 5	23 regularly (5-8 new members /1st mtg)	1st meeting attended	n/a	n/a
Interview 6	0 can't get group started in new area	No meetings/ community resource	n/a	"Don't want to confirm diagnosis"
Interview 7	20 regularly (60-70 contact)	Jan 2009	18 months - 20 years	". . . Don't have diagnosis other than sensory processing disorder, not solid in area"

APPENDIX G

INSTITUTIONAL REVIEW BOARD APPROVAL



NDSU NORTH DAKOTA STATE UNIVERSITY

Institutional Review Board
Office of the Vice President for Research, Creative Activities and Technology Transfer
NDSU Dept. 4000
1735 NDSU Research Park Drive
Research 1, P.O. Box 6050
Fargo, ND 58108-6050

701.231.8995
Fax 701.231.8098

Federalwide Assurance #FWA00002439
Expires April 24, 2011

November 25, 2009

Robert Nielsen
School of Education
SGC Suite C, Rm 117

IRB Expedited Review of: **"Families with Children Diagnosed with Sensory Processing Disorder: Perspectives on Access and Need for Mental Health Support (Counseling)"**, Protocol **#HE10119**
Co-investigator(s) and research team: **Susan P. Fullerton**

Research site(s): **via telephone** Funding: **n/a**

The protocol referenced above was reviewed under the expedited review process (category # 7) on **11/19/2009**, and the IRB voted for: ☐ approval ☒ approval, contingent on minor modifications. These modifications have now been accepted. IRB approval is based on the original submission, with revised: protocol (received 11/24/2009).

Approval expires: 11/18/2010 **Continuing Review Report Due: 10/1/2010**

Please note your responsibilities in this research:

- All changes to the protocol require approval from the IRB prior to implementation, unless the change is necessary to eliminate apparent immediate hazard to participants. Submit proposed changes using the *Protocol Amendment Request Form.*
- All research-related injuries, adverse events, or other unanticipated problems involving risks to participants or others must be reported in writing to the IRB Office within 72 hours of knowledge of the occurrence. All significant new findings that may affect risks to participation should be reported in writing to subjects and the IRB.
- If the project will continue beyond the approval period, a continuing review report must be submitted by the due date indicated above in order to allow time for IRB review and approval prior to the expiration date. The IRB Office will typically send a reminder letter approximately one month before the report due date; however, timely submission of the report is your responsibility. Should IRB approval for the project lapse, recruitment of subjects and data collection must stop.
- When the project is complete, a final project report is required so that IRB records can be inactivated. Federal regulations require that IRB records on a protocol be retained for three years following project completion. Both the continuing review report and the final report should be submitted according to instructions on the *Continuing Review/Completion Report Form.*
- Research records may be subject to a random or directed audit at any time to verify compliance with IRB regulations.

Thank you for cooperating with NDSU IRB policies, and best wishes for a successful study.

Sincerely,

Kristy Shirley

Kristy Shirley, CIP
Research Compliance Administrator

Last printed 11/25/2009 2:58:00 PM

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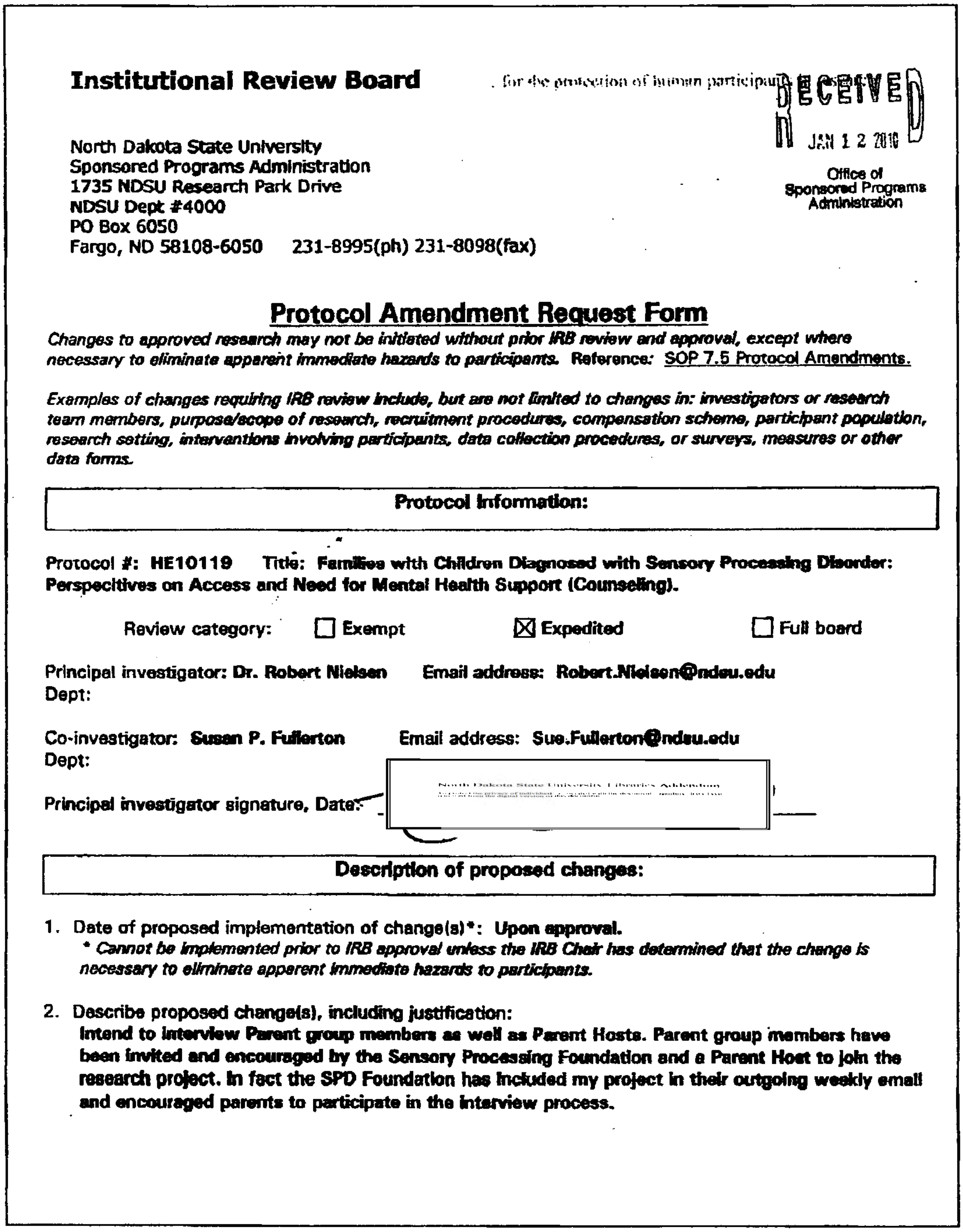
APPENDIX H

PROTOCOL AMENDMENT REQUEST



Institutional Review Board for the protection of human participants

RECEIVED
JAN 12 2010
Office of Sponsored Programs Administration

North Dakota State University
Sponsored Programs Administration
1735 NDSU Research Park Drive
NDSU Dept #4000
PO Box 6050
Fargo, ND 58108-6050 231-8995(ph) 231-8098(fax)

Protocol Amendment Request Form

Changes to approved research may not be initiated without prior IRB review and approval, except where necessary to eliminate apparent immediate hazards to participants. Reference: SOP 7.5 Protocol Amendments.

Examples of changes requiring IRB review include, but are not limited to changes in: investigators or research team members, purpose/scope of research, recruitment procedures, compensation scheme, participant population, research setting, interventions involving participants, data collection procedures, or surveys, measures or other data forms.

Protocol Information:

Protocol #: **HE10119** Title: **Families with Children Diagnosed with Sensory Processing Disorder: Perspecitives on Access and Need for Mental Health Support (Counseling).**

Review category: ☐ Exempt ☒ Expedited ☐ Full board

Principal investigator: **Dr. Robert Nielsen** Email address: **Robert.Nielsen@ndsu.edu**
Dept:

Co-investigator: **Susan P. Fullerton** Email address: **Sue.Fullerton@ndsu.edu**
Dept:

Principal investigator signature, Date: [redacted]

Description of proposed changes:

1. Date of proposed implementation of change(s)*: **Upon approval.**
   ** Cannot be implemented prior to IRB approval unless the IRB Chair has determined that the change is necessary to eliminate apparent immediate hazards to participants.*

2. Describe proposed change(s), including justification:
   Intend to interview Parent group members as well as Parent Hosts. Parent group members have been invited and encouraged by the Sensory Processing Foundation and a Parent Host to join the research project. In fact the SPD Foundation has included my project in their outgoing weekly email and encouraged parents to participate in the interview process.

3. Will the change involve a change in principal or co- investigator?
   ☒ No
   ☐ Yes: *Include an Investigator's Assurance (last page of protocol form), signed by the new PI or co-investigator.*

   Note: If the change is limited to addition/change in research team members, skip the rest of this form.

4. Will the change(s) increase any risks, or present new risks *(physical, economic, psychological, or sociological)* to participants?
   ☒ No
   ☐ Yes: *In the appropriate section of the protocol form, describe new or altered risks and how they will be minimized.*

5. Does the proposed change involve the addition of a vulnerable group of participants?
   Children: ☒ no ☐ yes – include the *Children in Research* attachment form
   Prisoners: ☒ no ☐ yes – include the *Prisoners in Research* attachment form
   Cognitively impaired individuals: ☒ no ☐ yes*
   Economically or educationally disadvantaged individuals: ☒ no ☐ yes*

   **Provide additional information where applicable in the revised protocol form.*

6. Does the proposed change involve a request to waive some or all the elements of informed consent or documentation of consent?
   ☒ no
   ☐ yes – include the *Informed Consent Waiver or Alteration Request* attachment form

7. Does the proposed change involve a new research site?
   ☒ no
   ☐ yes – include a letter of permission/cooperation, IRB approval, or grant application or contract

Attach a copy of the approved protocol, with highlighted change(s) incorporated within the relevant section(s).

Impact for Participants (future, current, or prior):

1. Will the change(s) alter information on previously approved versions of the recruitment materials, informed consent, or other documents, or require new documents?
   ☐ No
   ☒ Yes - attach revised/new document(s)

2. Could the change(s) affect the willingness of *currently* enrolled participants to continue in the research? ☒ No
   ☐ Yes - describe procedures that will be used to inform current participants, and re-consent, if necessary:

3. Will the change(s) have any impact to *previously* enrolled participants?
☒ No
☐ Yes - describe impact, and any procedures that will be taken to protect the rights and welfare of participants:

Request is: ☒ Approved ☐ Not Approved		
Review: ☐ Exempt, category#: ___ ☒ Expedited method, category # 7 ☐ Convened meeting, date: ___		
IRB Signature: [redacted]	**Date:** 1/12/2010	
Comments:		

Protocols previously declared exempt: (Allow 5 working days) If the proposed change does not alter the exemption status, the change may be administratively reviewed by qualified IRB staff, chair, or designee. If the change(s) would alter this status, Expedited or Full Board review will be required.

Protocols previously reviewed by the expedited method: (Allow 10 working days) Most changes may also be reviewed by the expedited method, unless the change would increase risks to more than minimal, and/or alter the eligibility of the project for expedited review.

Protocols previously reviewed by the full board: Minor changes (not involving more than minimal risks, or not significantly altering the research goals or design) may be reviewed by the expedited method (allow 10 working days). Those changes determined by the IRB to be more than minor will require review by the full board (due 10 working days prior to next scheduled meeting).