

**March 16, 2008**  
**Appendix B**  
**Update for Diagnostic and Statistical Manual Application:**  
**New Peer-Reviewed Publications related to Sensory Processing Disorder**

**Introduction**

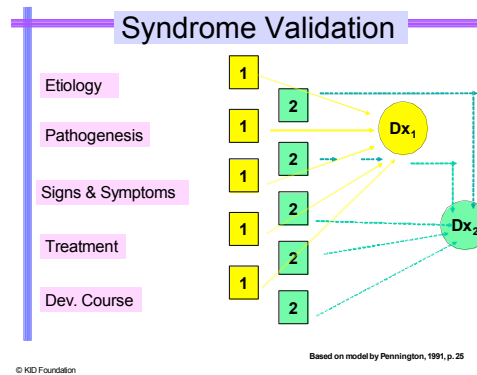
In January 2007 the Sensory Processing Disorder (SPD) Scientific Work Group (SWG), submitted an application to the DSM-V committee to consider adoption of Sensory Processing Disorder as a new diagnosis in the revised DSM. The proposal (one page) and a detailed Appendix was submitted on behalf of the SPD SWG, a multidisciplinary collaboration of leading scientists from research institutions who are conducting cross-disciplinary research into sensory processing and sensory processing impairments, supported by the National Institutes of Health, the Wallace Research Foundation and other Foundations. Areas included in past and ongoing research include: pathophysiology of the disorder (e.g., neurophysiological reactions to sensory stimuli in children and adults as well as animal models); phenotypes of the disorder (e.g., sensory-related behavior, attention and emotion regulation), genetic studies, and studies related to clinical issues such as the utility and sensitivity/specificity of the SPD diagnosis, diagnostic validity of SPD (e.g. discrimination from other disorders, developmental trajectory of SPD, and treatment effectiveness of occupational therapy with children who have SPD). Members of the SPD SWG and most relevant and new literature is cited at end of Appendix B.

***Pennington's Model of Syndrome Validation***

This second Appendix (B) to our application is organized by Pennington's model of syndrome validation<sup>1,2</sup> as was Appendix A (submitted January, 2007). Pennington suggests that empirical data, when provided in five areas, increases the likelihood that a new syndrome is valid. The five domains are: neuropathology, signs and symptoms, developmental trajectory, etiology, and treatment effectiveness (see Figure 1 below). "If a syndrome is valid, it will satisfy

tests of both convergent and discriminant validity across [these] levels of analysis”<sup>1</sup>. Thus, if a condition is homogeneous across these five domains, and can discriminate the condition from other disorders across these five domains, likely it is a syndrome.

**Figure 1. Pennington’s Model of Syndrome Validation**



Adapted from Pennington, 1991, p 25

Pennington suggests that most disorders are first defined behaviorally with a set of signs and symptoms that comprise a phenotype of the disorder<sup>2</sup>. He further suggests that while genetic and neuropathology studies cannot progress without designated behavioral phenotypes, brain and genetic studies can force revision in phenotype descriptions, thus refining the syndrome definitions and subtypes. Also needed to verify a syndrome is evidence that the condition is *universal*, e.g. all individuals with the condition exhibit similar patterns, and evidence that the condition is *specific*, e.g. individuals without this disorder do not exhibit these signs to an extent that they interfere with daily life.

***New Research on SPD***

Empirical data on sensory processing and SPD published since our application in January 2007 are briefly noted below. Areas are divided into in areas of Pennington’s model plus discussion of a new nosology, diagnostic validation of the disorder, and utility of creating a new

disorder based on a survey completed by over 700 participants (parents of children with SPD).

This document is organized into seven categories below:

- a) Discussion of a new nosology for diagnosis;
- b) Diagnostic validation of SPD;
- c) Assessments for SPD and relation of SPD to functional behaviors such as daily care activities and motor skills;
- d) Neuropathology of SPD;
- e) Studies related to the developmental course of SPD;
- f) Studies on the outcomes of treating SPD;
- g) Utility of the new diagnosis: results from survey data on 700 families living with a child who has SPD

#### **A. Proposed Nosology for Diagnosis**

A new classification scheme to enhance diagnostic specificity has been published in 2007.<sup>3</sup> The classification scheme encompasses and broadens that of two recently published diagnostic manuals, DC-0-3<sup>4</sup> and the Diagnostic Manual for Infancy and Early Childhood<sup>5</sup>. In particular, the nosology identifies a pattern termed *Sensory Modulation Disorder* that encompasses the two subtypes in the DSM application, *Sensory Over-Responsivity* and *Sensory Under-Responsivity*. The publication details the behavioral phenotype for each SPD subtype, which is similar to information provided in Appendix A of the 2007 application to the DSM.

In brief, individuals with Sensory Over-Responsivity exhibit exaggerated responses to one or more types of sensory stimuli not perceived as threatening, harmful, or noxious by typically developing children and adults. The fight, flight, or freeze reactions manifested by

individuals who are over-responsive has been associated with anxiety, hyperactivity, and inattention. The slow, perseverant, and hyper-focused reactions manifested by individuals with Sensory Under-Responsivity are associated with poor self-esteem and a lack of internal drive to move and play. Both subtypes interfere with engagement in social interactions and participation in home and school routines.

### **B. Diagnostic validation of SPD**

A study evaluating the relation between brain function and behavioral symptoms of the two subtypes of SPD, e.g. Sensory Over-Responsivity and Sensory Under-Responsivity, were conducted with 53 children<sup>6</sup>. Using electroencephalography (event-related potentials of auditory stimuli), sensory gating (P50) and sensory registration (N100, P200) were compared in children with SPD and matched controls. The children with SPD showed significantly less sensory gating and registration.

The sensory gating paradigm evaluates brain mechanisms that filter sensory information. The sensory registration paradigm measures the ability to discriminate different intensities and frequencies of information. This study is the first to demonstrate the behavioral manifestations of SPD are correlated with atypical central nervous system processing.

The study also evaluated the ability of sensory gating to predict SPD. Found was that responses to the sensory registration paradigm predicted outcome on the sensory gating measures for 86% of the typically developing group. Authors suggest that a difference between actual and predicted sensory gating is a marker and may be diagnostic for SPD. Children with SPD appear to be deficient in their ability to suppress irrelevant sensory stimuli, not regulating their cortical responses to additional incoming sensory stimuli. Proposed is that this phenomenon explains the distractibility, impulsivity, disorganization, and emotional dysregulation observed in children

with SPD. If the child can not inhibit incoming sensory information, he/she is likely to become inundated and overwhelmed with the incoming information.

The prediction equation was sensitive in discriminating both Over-Responsive and Under-Responsive SPD subtypes. This finding lends credence to data reported in Appendix A (submitted January 2007) that indicates both Over-Responsive and Under-Responsive subtypes of SPD are predicted using the *Sensory Challenge Protocol*, which evaluates autonomic nervous system function with electrodermal activity<sup>7</sup>.

This study suggests that SPD is not a quantitative difference or a developmental delay in processing but rather a *deviance* in processing, thus suggesting that SPD is a diagnostic entity. The brain function measures on children with SPD were not just extreme ends of the normal spectrum, neither were they delayed e.g. immature responses that would change with increasing age. The responses are qualitatively different from normal responses. Further research is needed to identify what factors might account for these differences. These psychophysiologic findings provide initial evidence to support the validity of SPD as a diagnostic category, which previously has been defined only through behavioral and autonomic nervous system measures.

Second, a careful multiple case study was published describing 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 responses as described in this application<sup>8</sup>. Authors suggest that if SPD exists in populations without comorbid conditions, a mechanism of SPD likely would have an independent etiology from existing diagnoses. These cases provide preliminary evidence to support the suggestion that Sensory Over-Responsivity can occur as a sole diagnosis.

### **C. Assessments for SPD and relation to function**

Crucial to codifying a new diagnosis is a reliable method to diagnose the disorder. For decades the lack of a standard evaluation tool to evaluate SPD has hampered research and clinical practice. Empirical research-based evaluations are needed so that decisions are based on objective data rather than on clinical experience and belief systems. Research suggests that a combination of performance assessment findings and behavioral report-measures are the most predictive and have the greatest utility for developing intervention plans.

An evaluation of Sensory Over-Responsivity in all seven sensory systems has been published, which was tested in two separate samples ( $n > 100$  in each sample)<sup>9</sup>. The SPD Assessment is an examiner administered performance evaluation, and the companion measure, the SPD Inventory, is a caregiver or self (depending on age of client) rating scale. Research with two unrelated samples showed statistically significant discrimination between a group ages 3-60 with Sensory Over-Responsivity and a typically developing control group ( $p < .001$ ). High internal consistency reliability was demonstrated for subtests (.53-.90) and the total test (.94). The preliminary psychometric integrity of the scales and its clinical utility provide an important contribution toward development of a “gold-standard” to evaluate Sensory Over-Responsivity and Sensory Under-Responsivity.

Construct validity was suggested by the significant relations between the Assessment subtest and its corresponding Inventory subtests as well as by factor analyses, which demonstrated groupings consistent with the theoretical compilation of items into groupings. Evidence that both the performance measure and the report measure are needed is highlighted by their moderate correlation, near .40, suggesting that different information is provided by the respondent versus direct observation scales.

In 2007, an assessment of Over-Responsivity in the vestibular (e.g. reactions to movement) system has been developed and field-tested<sup>10</sup>. Discriminant analysis classified 83% of children with Over-Responsivity and 100% of controls correctly, with significant differences between groups noted.

Another new measure, the Sensory Processing Measure<sup>11</sup> has been nationally standardized and published, to meet the need for a rating of participation, sensory processing, and praxis in school and home environments. With good psychometric properties, this tool has potential to accurately identify children with SPD in an educational environment so that interventions consistent with the Individuals with Disabilities Education Act and No Child Left Behind can be implemented e.g. educationally relevant accommodations, modifications, etc. A useful feature of this new tool is ratings by a wide variety of staff members including bus drivers, art teachers, lunchroom aides, etc. This enables information about sensory challenges to successful functional performance in school to be compared across environments.<sup>12</sup>

Important is whether SPD creates functional difficulties e.g. problems with daily care activities and motor skills, for individuals ascertained to be positive on the disorder. A 2007 study highlighted the association between SPD and difficulties with daily life activities including self-care or personal activities of daily living and domestic or instrumental activities of daily living.<sup>13</sup> Found was that motor skills that tap into physical aspects of function (e.g., bending, grasping, holding, and modulating force/movements) are areas particularly affected by disorders of sensory processing. Another study found a significant difference in play skills between elementary school-aged children with sensory processing impairments and controls, with particular problems manifested in active play and on measures of engagement.<sup>14</sup>

#### **D. Neuropathology of SPD**

Knowledge of possible etiologic factors and neurobiologic correlates of SPD is furthered by two nonhuman primate studies published in 2007. These studies sought evidence about the neural substrates of Sensory Over-Responsivity. The dopamine system (DA) in the striatum was targeted due to previous animal research showing the relation of impaired inhibitory control and learning, which are both described in SPD and are known in animals to be associated with suboptimal DA functioning. Positron emission tomography neuroimaging permitted examination of post-synaptic receptor binding and dopamine synthesis in the striatum, which is rich in dopamine and part of the neural loop involved in behavioral inhibition (basal ganglia, thalamocortical loop).<sup>15</sup> Specifically the study evaluated the association between repetitive tactile stimulation and DA function in the striatum. Researchers developed a Sensory Processing Measure for Monkeys<sup>16</sup> adapted from the Sensory Challenge Protocol administered to children and adults and detailed in Appendix A (Jan 2007 application to DSM committee). Found was: 1) a relation between reduced habituation and 2) exaggerated withdrawal responses to repeated tactile stimulation correlated with 1) increased striatal D<sub>2</sub>R binding and 2) increased ratio of D<sub>2</sub>R binding to DA synthesis. Authors propose one contributing factor to SPD might be alterations in the dopamine regulatory system, since high striatal D<sub>2</sub>R density reflects a hypersensitive DA receptor system. Current studies are examining other brain regions (e.g. prefrontal cortex) and other DA functions (e.g. DA transporter binding) and serotonin functions. The presence of a behavioral phenotype in nonhuman primates that mimics SPD, in particular Sensory Over-Responsivity in humans provides additional evidence that SPD is a valid syndrome.<sup>16</sup>

### **E. Studies related to the developmental course of SPD**

The relation of age and brain maturation was evaluated using EEG/Event Related Potential measures<sup>6</sup>. Found was that whereas most of the variation in sensory gating (84%) was accounted for by age in typically developing children, almost none of the variance in children with SPD (1.4%) was accounted for by age. Children with SPD did not show improved sensory gating with age as expected based on normative developmental age trends in this type of functioning.

### **F. Studies on the outcomes of treating SPD**

An ongoing controversy exists regarding the effectiveness of treating SPD. In the last 35 years over 80 studies have addressed this issue, however previous studies were not rigorous enough to make valid conclusions about treatment effectiveness. The limitations of previous studies were studied to prevent internal and external validity issues in a pilot treatment effectiveness study and a randomized controlled study of occupational therapy with children who were identified with SPD. One or more of the following four criteria were missing from previous outcome studies of SPD: a homogeneous sample, a manualized treatment with fidelity to treatment measures, sensitive and meaningful outcome measures, and rigorous methods e.g. randomization to groups, blinded examiners.

The pilot treatment effectiveness study published in 2007 selected a sample based on physiologic measures, a set of consistent observations during standardized assessments, and parent-report scales.<sup>17</sup> A manualized approach to treatment was field tested as well as a Fidelity-to-Treatment Measure, which had more extensive development after the pilot treatment outcome study was completed.<sup>11</sup> The pilot study permitted a variety of outcome measures to be field tested for sensitivity and appropriateness in measuring treatment effects in SPD in the following

domains: attention, sensation, anxiety, self care, social-emotional behaviors, changes based on parents priorities, as well as physiologic functioning. Results demonstrated significant changes in five major outcomes (effect sizes .29 to 2.16). The discussion highlights the need for pilot studies to ascertain criteria for selection of a homogenous sample, methods to implement a replicable treatment, and data suggesting sensitive outcomes that predict treatment effects before initiating a randomized trial.

The same group then conducted a randomized controlled trial of occupational therapy (OT) with children who met criteria for Sensory Over-Responsivity.<sup>18</sup> Subjects were randomized to OT, an active placebo called Activity Protocol, or a passive placebo, wait list treatment condition. Both the experimental OT methods and the alternative Activity Protocol were manualized and fidelity to both treatments was evaluated. The OT treatment group made statistically significant gains compared to the other two groups on measures of attention, social/cognitive functioning, and non-statistically significant but meaningful trends in the hypothesized direction on measures of sensation, psychological functioning, and physiologic measures of reactivity to sensory stimulation. Though small numbers were recruited, this is the first rigorous treatment trial with adherence to the four main principles of RCTs: homogenous sample, manualized treatment, sensitive and functional outcomes and methodologic rigor. The findings suggest that OT may be effective in ameliorating difficulties of children with Sensory Over-Responsivity.

Two areas of increased research resulted from these two intervention studies: 1) the intensive development and validation of a fidelity measure to ascertain that the OT intervention is true to the treatment administered; and 2) further development and studies to establish a reliable method to conduct Goal Attainment (GA) Scaling, a method which incorporates

individualized parent priorities for outcomes. GA scaling had by far the largest effect size in the 2007 studies (2.16) compared to the effect size of other measures (.50 was the next most effective measure) after treatment. Authors note that reliability is a key issue as the scale items are individualized for each client, and spacing between the five levels of each item is a function of the examiner's knowledge of development. Below two key issues which were tested and published in 2007 are reported: Fidelity to treatment and GA Scaling.

1) The lack of attention to fidelity measures in previous OT research with children who have SPD compromises the extent to which conclusions can be drawn regarding the effectiveness of OT from these early studies. However, notable is the new research on measuring treatment fidelity undertaken by a collaborative OT group funded by the NIH.<sup>11</sup> A fidelity to treatment scale was developed based on intensive review of treatment constructs in the literature and expert review, which classified elements of treatment into two main structural features and ten core therapeutic process features. A detailed review of the 70 previous studies studying OT effectiveness with SPD found that 34 articles purported to adhere to criteria for treating children who had SPD. These 34 studies presented sensory opportunities as part of their intervention methods but many were lacking in most process elements identified as crucial in the Fidelity to Treatment measure. Some studies had intervention procedures that were actually inconsistent with core process elements. Hence, the only valid statement of related to treatment effectiveness based on the previous 70 studies was that the past literature (prior to 2007) neither confirmed nor refuted the effectiveness of OT with SPD. The structural and process elements were gathered into a single Fidelity Measure to provide a method of evaluating adherence to a manualized protocol for future studies.<sup>11</sup>

2) GA Scaling is a standard methodology that permits individualized goals related to unique and diverse functional outcomes to be assessed with collective overall scoring. The variability of outcomes anticipated from OT with children who have SPD dramatically effects the power (sensitivity of measures) to detect changes with norm-referenced standardized scales even when changes in function are clearly present. When families' priorities are evaluated instead of using a standardized scale, the meaning of changes from intervention (validity) increases for individual clients, but the issue of measuring changes reliably across individuals increases.

GA Scaling involves writing individualized outcome goals based on a precise scaling method which assigns specific numeric values to five levels of outcome performance (the distance between the five scale ratings is equal and distributed around the probability of achieving that goal based on a bell-shaped curve). Using GA scaling, examiners can develop goals that differ in content but have the same probability of being achieved for each person.

An NIH R21 grant allowed a study of GA Scaling specifically for children with SPD in preparation for a multi-site study. A standard GA assessment and scoring manual was developed<sup>19</sup> and the reliability and validity of these GA methods were tested in a multi-site study. Results show that GA scaling has potential to capture the individuality of changes in function if examiners are specifically trained to write goals based on the probability of achieving expected behaviors. Thus, the highly statistical significant finding in the randomized controlled trial<sup>17</sup> was studied for utility for subsequent studies.

Finally, several case study articles related to the effectiveness of OT with SPD were published since our previous application was submitted to the DSM committee

(January, 2007). These studies use a variety of methods e.g. qualitative, ABAB, and others to look intensively at the elements of the therapeutic process and the types of changes made after treatment (no control subjects). In general, changes in abilities to modulate sensory information appears related to meaningful and purposeful participation in a full range of daily activities affecting behavior, functional abilities and general development.<sup>17 20</sup>

### **G. Utility of the new diagnosis: Results of survey data on over 700 families living with a child who is identified with SPD**

#### **Introduction.**

In 2006, the SPD Foundation put a parent survey on the organization's website and began to make parents aware of opportunities to provide information related to diagnoses and treatments their children had undergone, and the associated costs. The goal was to provide information about the utility of providing a new DSM diagnosis for the Review Committee.

#### **Demographics of Respondents.**

As of February 15, 2008 the survey was completed by 716 parents (89% mothers) of children identified as having Sensory Processing Disorder. Characteristics of the children of the respondents included:

- all were identified with SPD
- 70% were male
- 50% were 5 years old or younger
- 66% had parent-identified problems by the age of 2 (25 % by 6 months).

The respondent samples were well-educated (60% bachelor's degree or higher) largely Caucasian, living in suburban communities. Most of the children attend public schools (58%) or private schools (38%) with 4% home schooled.

**Subtype Endorsed.**

Sensory Over-Responsivity and Sensory Under-Responsivity were both endorsed. Sensory Over-Responsivity was endorsed most often to sound (77%), touch (52%) and taste (50%). Sensory Under-Responsivity was endorsed most often to movement, touch, and vision stimuli.

**Symptom Endorsement.**

Over 45% of the respondents indicated that their child's atypical reactions had a significant negative impact on the child/family 10 or more times within a 4-week period. The most common behaviors identified were:

- 85 % Easily upset or overwhelmed, emotional lability, low frustration tolerance
- 79% Meltdowns and tantrums, extended or constant crying
- 77% Trouble with transitions or non-compliant
- 76% Controlling or demanding, stubborn, resistant or inflexible
- 70% Impulsive, poor attention
- 67% Poor at following multi-task directions, delay in verbal skills
- 67% Extreme negative reactions to noise, haircuts, fingernail clipping, sticky hands and/or tight clothing
- 63% Explosive, angry, aggressive
- 63% Picky eater, gags from odors or foods
- 61% Unaware of social cues, poor eye contact

- 61% Difficult to soothe, fussy or picky
- 57% Problems falling or staying asleep
- 55% Clingy
- 53% Uncoordinated, clumsy, slow motor development, weak, poor endurance

Many of the children had also received a wide range of alternative initial diagnoses prior to receiving the diagnosis of SPD. Half of the respondents felt that the diagnosis initially received was not an accurate reflection of their child's issues and had additional diagnostic testing completed. The most common alternative diagnoses (in descending order) were: ADHD, Autistic Spectrum Disorders, Generalized Anxiety Disorder, Expressive language disorder, PDD-NOS and Mixed receptive-expressive language disorder.

#### **Medication Usage.**

The number of children receiving medications and the changes perceived from the medications is delineated in the following table:

| General Category  |           | N  | % Improved | % Worsened | % No Change |
|---|-----------|----|------------|------------|-------------|
| <b>Stimulant</b>  | Adderall  | 36 | 25         | 64         | 11          |
|   | Ritalin   | 18 | 45         | 50         | 5           |
|   | Concerta  | 27 | 45         | 33         | 22          |
| <b>SSRI</b>   | Prozac    | 18 | 66         | 28         | 5           |
|   | Zoloft    | 15 | 80         | 13         | 7           |
| <b>SNRI</b>   | Stratera  | 21 | 39         | 19         | 43          |
| <b><math>\alpha</math>2 adrenergic agonist</b>              | Clonidine | 19 | 53         | 21         | 26          |
| <b>Anti-psychotic</b>                                       | Abilify   | 11 | 64         | 18         | 18          |
|   | Risperdol | 25 | 44         | 32         | 24          |
| <b>Psychotropic agent:<br/>dibenzothiazepine derivative</b> | Seroquil  | 11 | 73         | 18         | 9           |

Forty seven percent of parents whose children were on medications felt that the medications had a deleterious effect (30%) or no effect (17%).

### **Cost of Assessment and Treatment.**

Of the 716 respondents, 537 (75%) contributed information about their costs for medical and therapeutic interventions for their child from birth to the present. The general range was \$20,000 to \$30,000 (with several families reporting costs over \$100,000).

### **Qualitative Data.**

Respondents answered an open-ended question about whether and how an earlier diagnosis of SPD could have changed the lives of their child and themselves. A brief survey of some key themes follows:

#### ***Life altering changes for children.***

- My child suffers such low self-esteem and low self-confidence. She struggles socially. She doesn't feel like she fits in with anyone plus she knows she's "different" ... different clothes, different interests. If my daughter's SPD had been recognized in her preschool years...it would've made a huge difference because she wouldn't have to work so hard to overcome sensory obstacles and possibly she wouldn't be experiencing so many emotionally issues.
- My son would have had more options on how to deal with his disability and how to prevent it from inhibiting his ability to learn and be socially accepted. This really is something that really injures his self-esteem because no one wants to play with him, yet he's a sweet and sensitive kid. It breaks my heart.
- We would have "had our child" sooner. Now she is not responding to her environment. Therefore she suffers from low self esteem, cannot connect with peers, struggles in school. She gets yelled at by all people around her. She actually talked about suicide at 8 years old. Our whole family has to deal with this struggle every single day...its so so so hard.

#### ***By obtaining accurate diagnosis could started services earlier.***

- We would have probably received an accurate diagnosis earlier instead of stumbling around for 6 years looking for a fit.
- It would have greatly changed our family's life. I do not think my son would have been shuffled from doctor to doctor, because I knew the diagnoses we had been given didn't fit him.
- The people who were assessing him prior to five would have read the signs differently and we would have gotten help earlier.
- We would have had an earlier diagnosis with earlier intervention. We would have avoided two or more years of dealing with a very frustrating circumstance.
- It would have enabled us to get help earlier when I brought his behaviors to the attention of his doctor at 18 months.

#### ***Decreased stress/Improved quality of life***

- It was like a light went on in our lives. We have gone from a family that felt overwhelmed every day to a family that enjoys the quirks of our child. Giving us the language to talk about the behaviors and struggles and to be able to understand the WHY behind some of the behaviors has been huge. Now that we have received treatment and a

plan of activities to follow we have seen tremendous improvements in our child's life. He is able to communicate to us what is happening and we can share what he needs with teachers. His confidence has soared and his ability to learn has taken off. For the first time in five years, we have been able to kiss our son on his soft cheek and he welcomes it!

- The stress over through 1st and 2nd grade (especially 2nd) would have been more manageable for my son and our family. We would have begun OT immediately, and would not have put him on Adderall.
- It would have simplified our lives. For years, we searched for a diagnosis and tried to get help. Finally, a pediatric neurologist told us it didn't matter what we called it, it would be treated the same -- by symptoms. So, we started with speech/language therapy, another mother there pointed us towards Sensory Integration Dysfunction information and occupational therapy, the schools finally intervened with language therapy but won't help with any occupational therapy. We know our child isn't autistic but he gets labeled as that or as ADHD, just so we can get some services.

***Decreased perceived "bad parenting".***

- I wouldn't have made the mistakes I did in parenting her that I did make, because I had no idea what was going on. I would have pointed our family in the right direction sooner. We would have had the opportunity to enjoy family life more and sooner.
- We tried for two years to find out what was wrong with our daughter. We just couldn't figure it out alone. If we had known sooner that she had SPD, we could have helped her cope better with life in general.

***Increased awareness and acceptance.***

- There would be increased awareness. I would have had to deal less with friends, family members, teachers and doctors who did not get it.
- Recognition of SPD as a "real" issue, a better understanding within the school district that a bright kid with a willful temperament does not equate to a behavioral problem, seeing the "whole child"
- Mainstream recognition of the disorder, through actual diagnoses, would help enormously in the area of social relations with friends, neighbors and family, and have the same impact on educational quality.
- Also, more people would be aware of SPD which would help more understanding of what is going on for us.

***Validation of Self-Perceptions***

- As a parent it has been pure hell. Doctors and schools think I am making excuses for my child's "behavior". One pediatrician wouldn't write a prescription for speech and OT because he wasn't going to "look like a fool to his colleagues."
- Now that SPD has been diagnosed, I feel validated that yes, there is something amiss here. For so long, everybody said "he is just being a 3 year old", suggesting that I was over-reacting. Now I can actually get help for him, and for us.

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**This application is submitted by the SPD Scientific Work Group (SWG). The research interests and summaries of the SPD research projects of the SPD SWG are below in alphabetical order by last name of researcher.**

### **Sensory Processing Disorder Scientific Work Group**

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#### **Research Interests**

Dr. Bauman's Research Interests include the study of the microscopic brain structure in autism, Rett syndrome and other disorders of neurological development, including Sensory Processing Disorder.

#### **SPD Research Summary**

Dr. Bauman and colleagues are completing histoanatomic observations of the brain in nicotine treated rats. Previous studies have shown that nicotine improves auditory sensory gating as measured by pre-pulse inhibition in animals. Additional studies suggest that GABA agonists may attenuate symptoms of sensory defensiveness. This study is neuroanatomically surveying the brains of nicotine treated Sprague Dawley rats in comparison to age and sex-matched controls using histoanatomic and immunocytochemical techniques. She suspects that in the nicotine treated rats, microscopic structural abnormalities will be found in specific brain regions and will co-exist with cholinergic and GABAergic systems differences compared to controls. Identification of specific brain regions and neurotransmitter systems associated with auditory sensory gating will localize these areas and expand our understanding of the neurobiological mechanisms of processing of sensory information.

**Brett-Green, Barbara, Ph.D.**

Title: Director, Psychophysiology Research  
Department: SPD Research Institute  
Institution: Sensory Processing Disorder Foundation  
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**Research Interests**

Dr. Brett-Green has a long-term program of research studying multi-sensory integration in animal models and currently in children.

**SPD Research Summary**

For the past several years Dr. Brett-Green has investigated EEG activity in children with sensory processing disorder (SPD) compared to those with attention-deficit/hyperactivity disorder (ADHD) and Autistic Spectrum Disorder. In addition, Dr Brett-Green is undertaking EEG (event related potential) research evaluating the effect of multi-sensory stimulation at the cortical level on typically developing children and adults compared to those with SPD and autism. Her article on multi-sensory integration in typically developing children is the first to study MSI in pediatrics and has recently been accepted to the journal IBrain Research.

**Brout, Jennifer, Psy.D.**

Title: Director  
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Mailing Address: 4 Trails End, Rye, New York 01580  
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**Research Interests**

Dr. Brout develops and supports interdisciplinary projects and programs that increase sensory processing disorder (SPD) knowledge. Her projects combine research in psychology, occupational therapy, psychiatry and neuroscience. Dr. Brout further supports research and advocacy efforts by serving on the Board of Directors of the SPD Foundation.

**SPD Research Summary**

Dr. Brout founded the EMB Brout Sensory Processing and Emotion Regulation Program at the Duke University Medical Center under the direction of Dr. M. Zachary Rosenthal. The goals of this program are to identify impacts of atypical sensory processing impact on emotion regulation and to identify sensory processing problems as possible mediating variables in psychiatric

disorders. Current studies are addressing auditory over-responsivity in patients with borderline personality disorder.

**Carter, Alice S., Ph.D.**

Title: Professor

Department: Department of Psychology

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**Research Interests**

Professor Carter researches the identification of infants and toddlers at risk for problems in social, behavioral, and emotional functioning; developing preventive interventions; and understanding the role of family functioning in the developmental course of children at genetic risk for clinical disorders such as Tourette's Syndrome, Obsessive Compulsive Disorder and depression. She is also studying young children with autism spectrum disorders and their families as part of the Boston University Studies To Advance Autism Research (START).

**SPD Research Summary:**

Dr. Carter is examining the prevalence of sensory over-responsivity (SOR) in a representative longitudinal birth cohort of children in the Greater New Haven area who have been followed from either 1 or 2 years of age and assessed with the Sensory Over-Responsivity Scale in second grade. Data about early emerging social-emotional problems and competencies, including a measure of sensory sensitivities at ages 1, 2, and 3 years of age and psychiatric diagnostic status in kindergarten and second grade is already available in the larger longitudinal study. This project is providing data on the prevalence and correlates of SOR behaviors in a representative community sample. It is also examining associations between infant/toddler and concurrent social-emotional and behavior problem correlates of SOR behaviors in school-aged children.

**Davies, Patricia L., Ph.D., OTR, FAOTA**

Title: Associate Professor

Department: Department of Occupational Therapy

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**Research Interests**

The long term objective of Dr. Davies' research is to understand the development of neurophysiological mechanisms that underlie cognitive and motor behaviors in children with and

without disabilities. Her research focuses on three primary goals: (1) to examine brain development in children with and without disabilities; (2) to determine the effectiveness of rehabilitation for children with disabilities; and (3) to determine if rehabilitation produces changes in brain structure/function.

### **SPD Research Summary**

Dr. Davies is pursuing research validating the diagnosis of sensory processing disorder (SPD) using EEG technology, evaluating the maturation of sensory processing in children with and without SPD, and using auditory event-related potentials to discriminate between adults and children with and without SPD. Their studies test the assumption of sensory integration theory that states that a relationship exists between brain function and the behavioral manifestations of sensory integrative dysfunction. Findings include that children with SPD demonstrated significantly less sensory gating and more within-group variability compared to typical children. Children with SPD were found to be deficient in their ability to filter out repeated auditory input and failed to selectively regulate their sensitivity to sensory stimuli. Brain activity alone can correctly distinguish children with SPD from children who were typically developing with 95% accuracy. These results suggest that children with SPD display unique brain processing mechanisms compared to children who are typically developing and provide external validity for the diagnosis of SPD. Findings also suggest that there is the maturational course of sensory gating in typical children but not in children with SPD.

### **Foxe, John J., Ph.D.**

Title: Professor and Program Director

Department: Cognitive Neuroscience

Institutions: City College of the City University of New York & The Nathan S. Kline Institute for Psychiatric Research

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### **Research Interests**

Dr. Foxe conducts studies across a wide array of research domains (Selective Attention; Multisensory Integration; Object-Recognition; Executive Control) using multiple convergent imaging techniques (high-density electrical recordings from the scalp; fMRI neuroimaging; intracranial investigations and psychophysics).

### **SPD Research Summary**

The overarching goal of ongoing SPD research is to examine sensory processing and sensory integration in children with sensory processing disorder (SPD) and to compare this to the same in typically developing children and children with attention-deficit/hyperactivity disorder (ADHD). Using electrophysiology as an objective and non-invasive measure of brain activity, Foxe's laboratory measures these processes for auditory-visual and auditory-somatosensory stimulus pairings of differing levels of complexity. At the one end, the integrity of the brain's response to

the most elemental of stimuli (beeps and flashes) presented under the most basic of task conditions is assessed. At the other, the integrity of the brain's response to one of the most complex and important of auditory-visual signals, auditory-visual speech, is assessed.

The development of ordered sensory processing and sensory integration is a necessary component of normal functioning. Some have theorized that failure to develop normal multisensory integration might be at the root of certain childhood neuro-behavioral disorders. SPD, associated primarily with sensory processing abnormalities, also presents in isolation and thus arguably should be considered a unique syndrome. Objective measures that can differentiate between SPD and other disorders with overlapping symptomatology, and allow for a better understanding of the underlying causes, are clearly critical for better diagnosis and treatment of SPD.

One implication of our results will be that if certain basic functions are not achieved automatically, as they should be, compensatory neural mechanisms may need to develop to "fill the gap". That is, higher-order regions of the brain, perhaps in the frontal and parietal cortices, may be recruited to effortfully process this critical information. Our recordings will directly assess whether frontal regions are inordinately recruited during simple multisensory integrations in SPD.

Over the past number of years, this laboratory has undertaken extensive investigations of basic multisensory physiology in healthy adult populations, delineating a number of fundamental processes that can be readily identified using both the evoked potential technique and functional imaging. These metrics of multisensory brain function provide us with a set of objective dependent measures that can now be applied in clinical populations, and we are using two of these previous paradigms in children with Sensory Processing Disorder, with ADHD, and typically developing (TD) children to assess basic multisensory audiovisual processing using electrophysiological techniques.

**Gavin, William J., Ph.D.**

Title: Director, Human Development Lab

Research Scientist/Scholar III

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**Research Interests**

Dr. Gavin has been conducting research on a variety of topics related to child development. His early research focused primarily on speech and language development in infants and toddlers. More recently, he has developed a program of research on sensory processing and cognitive

development in children and adolescents utilizing electroencephalography (EEG) and event-related potentials (ERPs) methodologies.

### **SPD Research Summary**

Drs. Davies and Gavin are pursuing research validating the diagnosis of sensory processing disorder (SPD) using EEG technology, evaluating the maturation of sensory gating in children with and without SPD, and using auditory evoked potentials to discriminate between adults and children with and without SPD. Their studies test the assumption of sensory integration theory that states that a relationship exists between brain function and the behavioral manifestations of sensory integrative dysfunction. Findings include that children with SPD demonstrate less sensory gating than children who are typically developing. Children with SPD demonstrated significantly less gating and more within-group variability compared to typical children. Children with SPD were found to be deficient in their ability to filter out repeated auditory input and failed to selectively regulate their sensitivity to sensory stimuli. Brain activity can correctly distinguish children with SPD from children who were typically developing with 86% accuracy. These results suggest that children with SPD display unique brain processing mechanisms compared to children who were typically developing and provide external validity for the diagnosis of SPD. Findings also suggest that there is the maturational course of sensory gating in typical children but not in children with SPD.

SPD Publications

### **Goldsmith, H. Hill, Ph.D.**

Title: Fluno Bascom Professor & Leona Tyler Professor of Psychology

Department: Department of Psychology & Waisman Center

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### **Research Interests**

The Wisconsin Twin Research laboratories, directed by Dr. Hill Goldsmith, investigate genetic and environmental features of emotional development from infancy to adolescence. Three major research projects are underway. The Genetics of Emotional Ontogeny (GEO) project examines typical behavioral development from birth to age seven. The Wisconsin Twin Project (WTP) considers both typical development and behavioral problems, and it extends from early childhood to adolescence. The Twin Autism Project (TAP) examines development of children and adolescents on the autism spectrum.

### **SPD Research Summary**

Goldsmith and colleagues are studying genetic influences on tactile and auditory over-responsiveness using twin methodology. They have conducted three studies to date: The first study was a toddler study and evaluated 1394 twin pairs (mean age 27 months) using a parental report measure that included a five item scale of auditory and tactile over-responsivity. Initial

results were published in the following paper: Goldsmith, H. H., Van Hulle, C. A., Arneson, C. L., Schreiber, J. E., & Gernsbacher, M. A. (2006). A population-based twin study of parentally reported tactile and auditory defensiveness in young children. *Journal of Abnormal Child Psychology*, 34, 378-392. In this study, auditory and tactile symptoms were reasonably normally distributed in the toddler sample, with a small percent of over-responders clearly observed in the tail of the distributions. Genetic effects for the full range of trait scores, for extreme scores and for tactile and auditory scores by examining twin similarity and parent-offspring similarity. If genetic effects are present, classic assumptions of twin studies imply that identical (MZ) twins, who share 100% of their genes, should be more similar than fraternal (DX) twins, who share only 50% of segregating genes, on the average. Findings in the toddler study were that, for auditory over-responsiveness, 65% of MZ twin pairs as compared with 50% of DZ twin pairs were concordant. For tactile over-responsiveness, 83% of MZ pairs, compared with 32% of DZ pairs were concordant for tactile symptoms. These findings suggest genetic effects, especially for the tactile domain.

The second study was a preschool study and evaluated 282 twin pairs (age 3-6 years) and was a follow-up of extreme and matched control twins from the toddler study and was based on parental report using 54 parent-rated items of sensory over-responsivity and 78 home visits for observational assessment of twin SD and other symptoms. In the subsample followed up two years later, the scores were moderately stable, with 48% of extreme tactile group remaining extreme and 50% of the extreme auditory group remaining extreme (in the absence of intervention). The association of sensory over-responsiveness with other social, emotional and psychological factors was examined. Auditory and tactile over-responsiveness was significantly correlated with anxiety (.20-.24) but appeared to be a relatively independent dimension in the larger population (all other correlations < .20).

The third study (ongoing) has assessed >500 pairs of 7-8 year-old twins, with in-home assessment of >200 pairs. In a preliminary analysis (n=150), auditory and tactile over-responsivity were significantly correlated with Diagnostic Interview Schedule for Children (DISC-IV) scales for agoraphobia, separation anxiety, specific phobia and social phobia; correlations ranged from .18 to .27.

### **Goldson, Edward, M.D.**

Title: Professor of Pediatrics

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### **Research Interests**

Dr. Goldson's clinical interests focus on: Children with Special Needs - Chronic Care, Child Development - Autism, Attention-Deficit/Hyperactivity Disorder (ADHD), etc., Newborn Follow up, Child Abuse, Medical Ethics.

**Kinnealey, Moya, Ph.D., OTR/L**

Title: Professor and Chair

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**Research Interests**

Dr. Kinnealey is interested in early intervention with children at risk for developmental disabilities, sensory integration issues with both specific populations and across the life span and the biological/emotional link in development and behavior.

**SPD Research Summary**

Adults with Sensory Processing Disorders.

**Kisley, Michael A., Ph.D.**

Title: Assistant Professor

Department: Department of Psychology

Institution: University of Colorado at Colorado Springs (UCCS)

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**Research Interests**

Dr. Kisley researches how the person (and their brain) prioritizes sensory stimuli for processing, age-related changes in both bottom-up and top-down stimulus prioritization processes, and the role that emotional factors play in stimulus prioritization in older adults. To study these phenomena, he employs non-invasive electrophysiological measures of brain activity, often referred to as event-related brain potentials (ERPs), in addition to behavioral research methods.

**SPD Research Summary**

Neurophysiological Correlates of Sensory Over-Responding in Adults

Scalp-recorded event-related brain potentials (ERPs) provide non-invasive estimates of neuron population activity with excellent temporal resolution (milliseconds). Consequently these

neurophysiological measures can be used to assess when, in the course of central nervous system processing of a stimulus, abnormalities might arise.

The goal of research conducted in my laboratory has been to investigate whether behavioral sensory over-responding in individuals without potentially confounding clinical disorders (e.g., schizophrenia, attention-deficit/hyperactivity disorder, traumatic brain damage) is associated with impaired sensory gating as assessed by ERPs evoked during paired-stimulus paradigms. We have documented sensory over-responding with a number of instruments including the Sensory Gating Inventory and the Adolescent/Adult Sensory Profile. To investigate multiple stages and sensory modalities of central nervous system processing, we have studied several ERP components (all within about 125 ms of stimulus-onset) in response to both paired auditory and somatosensory stimuli.

The most robust finding from our lab has been an inverse relation between self-reported functional behaviors related to sensory sensitivity/avoidance and the suppression of auditory ERP components P50 and N100 in a paired click paradigm: individuals that endorsed higher rates of sensory over-responding exhibited less efficient “sensory gating.” This is consistent with the hypothesis that sensitive individuals particularly over-process stimuli of low salience, even within the first 100 ms of neural processing. Based on previous studies regarding the neural basis of the ERP components we measure, our results are consistent with the interpretation that sensory over-responders process stimuli differently than typical individuals at association cortex processing stages. This should not be taken as an argument that abnormal neural processing of stimuli in particularly sensitivity individuals first arises at higher cortical areas. Futures studies should be targeted at neural processing at lower brain levels, from the receptor neuron through the brainstem and thalamus to the primary cortical area. Such studies should employ multiple measures including complimentary methodologies (e.g., fMRI) in order to more effectively localize, both temporally and spatially, the point of neural processing at which sensory over-responders first exhibit significant differences from typically developing individuals.

**Koomar, Jane, PhD, OTR/L, FAOTA**

Title: Executive Director

Institution: Spiral Foundation

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**Research Interests**

Dr. Koomar is the owner and co-founder of OTA-Watertown and the President of the Board of the Spiral Foundation. Dr. Koomar is particularly interested in the study of sensory processing disorder (SPD) and affective and post-traumatic stress disorders.

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### **SPD Research Summary**

Drs. May-Benson and Koomar run the Spiral Foundation research program which has a two-fold goal: one) to examine information to define signs, symptoms and etiology of SPD, and two) to examine outcomes related to sensory integrative intervention for SPD. To investigate our first goal area, we conducted a retrospective record review of the birth and early childhood developmental histories of 1000 children aged 3 – 14 years of age who were identified with sensory processing problems. In the area of pre-natal and birth-related factors, children with SPD were found to have a moderate prevalence of mothers with pre-natal problems with 25% complications during pregnancy and 42% complications during labor or delivery. Other birth/delivery problems were greater than available national averages and included 34% assisted deliveries (e.g. vacuum, suction and forceps); 13% pre-term at 37 weeks gestation or less and 5% umbilical cord insults including cord wrap/ prolapse. In the area of developmental factors, children with SPD demonstrated characteristic differences in development of early childhood skills with 47% not going through terrible two's; 37% reported by parents to have brief or absents crawling phases, and 31-32% had sleep or feeding problems. In the area of early childhood health problems, children with SPD demonstrated an increased prevalence of health problems including 62% with chronic ear infections; 27% having serious injuries or illness; 25% jaundice at birth; and 20% colic as infants. No one problem was common to all children but clusters of these difficulties were commonly reflected.

To investigate our second goal, we conducted a multi-site reliability and validity study on Goal Attainment Scaling, a procedure for writing scaled individualized client goals that can be quantified and compared across individuals and groups. The purpose of this study was to examine whether therapists were able to write goals that correctly identify goal areas important to families and clients, accurately identify the client's projected outcome, correctly scale the objectives and accurately rate performance at follow-up after intervention. These issues had to be examined before GAS may be accepted as a valid and reliable research methodology. Results of the study found that, based on parent interview, therapists are able to reliably identify parent goals, rank their importance to parents, and identify children's progress nearly 80% of the time. Similarly, there was good inter-rater agreement between two therapists in identifying and writing intervention goals and objects based on parent interview over 60% of the time. Experienced therapists were able to conduct qualitative interviews with parents and, from those interviews, accurately identify and rank parent concerns for their child's sensory integrative-based intervention. In addition, therapists were able to accurately rate a child's progress on meaningful and functional goals based on parent report. Similarly, two therapists, from different clinical sites who were unfamiliar with the child, were able to identify, write and rank GAS goals and objectives based on the same parent interview demonstrating good inter-rater reliability between clinical therapists. This study presents very promising preliminary reliability and validity evidence for the use of GAS as a meaningful outcome of sensory integrative-based occupational therapy intervention, which may be applicable as an outcome measure in a formal intervention study.

**Lane, Shelly J., Ph.D., OTR/L, FAOTA**

Title: Professor and Chair

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**Research Interests**

Dr. Lane's research concerns outcomes of children at risk for developmental problems, particularly Sensory Processing Disorder.

**SPD Research Summary**

Drs. Lane and Reynolds are studying stress and anxiety in children with Sensory Over-Responsivity (SOR) and Attention-Deficit/Hyperactivity Disorder (ADHD). Sensory Modulation Dysfunction (SMD) is characterized by an inability to consistently and accurately grade responses to sensory information. SMD, and specifically sensory over-responsivity (SOR), has been correlated with stress and anxiety in some developmentally delayed populations and has been associated with structures and functions of the hypothalamic-pituitary adrenal (HPA) axis. Recent attention has been given to HPA functioning in children with Attention-Deficit/Hyperactivity Disorder (ADHD), with a majority of studies identifying blunted or diminished cortisol patterns. In contrast, elevated cortisol has been associated with anxiety and anxious behaviors in both animal and human studies. Drs. Lane and Reynolds are researching whether SOR is a contributing factor in determining stress reactivity patterns in children with ADHD or related to elevated levels of anxiety in children with ADHD with and without SOR. Two pre-challenge and seven post-challenge measures of salivary cortisol were taken. Cardiac and electrodermal response data were also collected.

To date, no baseline differences in salivary cortisol were found between groups. In response to a sensory challenge, there was a borderline significant difference found between the ADHD with and without SOR and a significant difference between ADHD and the typical group, with cortisol levels being significantly lower in the ADHD group. Scores for total anxiety indicated that the ADHD SOR group was significantly more anxious than both the ADHD without SOR and control group. These findings suggest that SOR may alter the stress response seen in children with ADHD and contribute to increased anxiety in this population.

**Levin, Edward D., Ph.D.**

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Institution: Duke University Medical Center  
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**Research Interests**

Dr. Levin's expertise lies in neurobehavioral toxicology, pesticides, marine toxins, lead, mercury, zebrafish, and mammalian toxicology. His primary area of expertise is environmental toxicology. His secondary area of expertise is marine biomedicine.

**SPD Research Summary**

Levin and colleagues are studying neural mechanisms of normal and impaired sensory modulation as well as potential pharmacological therapeutic approaches using pre-pulse inhibition (PPI) paradigms in a rat model. Sensory processing involves successive stages of discarding extraneous or irrelevant information. By studying inhibition of the startle response, neurotransmitter interactions and basic neurobiology and potential pharmacological therapeutic approaches are evaluated. Normally a warning stimulus reduces startle reactions. Both the timing and the intensity of stimulus are relevant to the response which is observed. Levin studied both nicotine effects and the effect of nicotinic glutamate interactions on PPI. He studied both auditory and tactile response modulation. He found that nicotine facilitates prepulse inhibition over various intensities and inter-stimulus intervals. When nicotine and dizocilpine are both administered, there is a decreasing effect on PPI as the dose of dizocilpine increases (65-75 % PPI with no dizocilpine; 60% PPI with 25 mg/kg dizocilpine; 40-50% PPI with 50mg/kg dizocilpine; 0-20%PPI with 100 mg/kg dizocilpine). However, when clozapine is added to nicotine and dizocilpine, the % PPI increases significantly in relation to the dose of clozapine administered. With tactile startle there is also a dose effect of dizocilpine on the intensity of response (increasing dizocilpine relates to decreased startle). As the amount of clozapine increases, the effect of the dizocilpine on reducing the %PPI decreases. In other words, clozapine increases sensory gating when gating has been pharmacologically reduced (reduced using dizocilpine.)

**Marco, Elysa J., M.D.**

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**Research Interests**

Sensory processing in children.

**SPD Research Summary**

Sensory processing disorder (SPD), estimated to affect up to 5% of children, is a complex neurological disorder that leads to the misinterpretation of sensory information from touch, sound, sight, smell, and movement (Ahn, Miller, Milberger, & McIntosh, 2004; Ayres, 1972). There is a growing interest in sensory processing for typical adults as well as children with specific developmental disorders, such as autism and Fragile X (Castren, Paakkonen, Tarkka, Ryyananen, & Partanen, 2003; Gage, Siegel, & Roberts, 2003; Kogan et al., 2004; L. J. Miller et al., 1999; Oram Cardy, Ferrari, Flagg, Roberts, & Roberts, 2004; Rojas et al., 2001; Wilson, Rojas, Reite, Teale, & Rogers, 2007). There remains, however, a dearth of neurophysiologic data regarding isolated SPD. Additional inquiry is needed to understand the etiology of SPD as well as to validate this disorder as distinct from other neuropsychiatric syndromes. This project is a case-control study of sensory processing in children with and without SPD. We will begin by performing behavioral characterization on children aged 9-11 years with IQ > 80 to obtain as homogenous a sample as possible. We will focus this study on children with the sensory over-responsive subtype of SPD (i.e. those children who clinically exhibit exaggerated response to one or more types of sensory stimuli not perceived as threatening, harmful, or noxious by typical children.) We will use magnetic source imaging (MSI), magnetoencephalography (MEG) co-registered with magnetic resonance imaging (MRI), to conduct detailed structural and electrophysiologic maps of brain response to auditory and tactile information presented independently (unimodal administration) and simultaneously (multimodal administration). We hypothesize that children with SPD will have hyper-activation and abnormal habituation in their primary sensory brain regions. In other words, they will not have the expected diminution of neuronal response seen with the repetition of familiar stimuli. We further hypothesize that children with SPD will show suppression of activation in brain regions involved in the integration of input from multiple sensory domains. This pilot project will contribute to the long-range goal of understanding sensory processing in children with SPD and will in turn foster the creation of objective sensory processing measures and rational pharmacologic and behavioral therapeutics to enhance quality of life.

**May-Benson, Teresa A., Sc.D., OTR/L**

Title: Research Director

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**Research Interests**

Dr. May-Benson is interested in autism, particularly in adolescents and adults.

**SPD Research Summary**

Drs. May-Benson and Koomar run the Spiral Foundation research program which has a two-fold goal: one) to examine information to define signs, symptoms and etiology of sensory processing disorder (SPD), and two) to examine outcomes related to sensory integrative intervention for SPD. To investigate our first goal area, we conducted a retrospective record review of the birth and early childhood developmental histories of 1000 children aged 3 – 14 years of age who were identified with sensory processing problems. In the area of pre-natal and birth-related factors, children with SPD were found to have a moderate prevalence of mothers with pre-natal problems with 25% complications during pregnancy and 42% complications during labor or delivery. Other birth/delivery problems were greater than available national averages and included 34% assisted deliveries (e.g. vacuum, suction and forceps); 13% pre-term at 37 weeks gestation or less and 5 % umbilical cord insults including cord wrap/ prolapse. In the area of developmental factors, children with SPD demonstrated characteristic differences in development of early childhood skills with 47% not going through terrible two's; 37 % reported by parents to have brief or absents crawling phases, and 31-32% had sleep or feeding problems. In the area of early childhood health problems, children with SPD demonstrated an increased prevalence of health problems including 62% with chronic ear infections; 27% having serious injuries or illness; 25% jaundice at birth; and 20% colic as infants. No one problem was common to all children but clusters of these difficulties were commonly reflected.

To investigate our second goal, we conducted a multi-site reliability and validity study on Goal Attainment Scaling (GAS), a procedure for writing scaled individualized client goals that can be quantified and compared across individuals and groups. The purpose of this study was to examine whether therapists were able to write goals that correctly identify goal areas important to families and clients, accurately identify the client's projected outcome, correctly scale the objectives and accurately rate performance at follow-up after intervention. These issues had to be examined before GAS may be accepted as a valid and reliable research methodology. Results of the study found that, based on parent interview, therapists are able to reliably identify parent goals, rank their importance to parents, and identify children's progress nearly 80% of the time. Similarly, there was good inter-rater agreement between two therapists in identifying and writing intervention goals and objects based on parent interview over 60% of the time. Experienced therapists were able to conduct qualitative interviews with parents and, from those interviews, accurately identify and rank parent concerns for their child's sensory integrative-based intervention. In addition, therapists were able to accurately rate a child's progress on meaningful and functional goals based on parent report. Similarly, two therapists, from different clinical sites who were unfamiliar with the child, were able to identify, write and rank GAS goals and objectives based on the same parent interview demonstrating good inter-rater reliability between clinical therapists. This study presents very promising preliminary reliability and validity evidence for the use of GAS as a meaningful outcome of sensory integrative-based occupational therapy intervention, which may be applicable as an outcome measure in a formal intervention study.

**Miller, Lucy Jane, Ph.D., OTR**

Title: Executive Director

Institution: Sensory Processing Disorder Foundation

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**Research Interests**

Dr. Miller has a program of research in Sensory Processing Disorder (SPD). She has developed a psychophysiological lab that has collected electrodermal activity (with Dr. Schoen), vagal tone (with Dr. Schaaf) and EEG/Event Related Potentials (ERP) (with Dr. Brett-Green) data on children with SPD, Autistic Spectrum Disorders, Attention-Deficit/Hyperactivity Disorder (ADHD), and Prader-Willi Syndrome in response to sensory stimulation. She has developed the Short Sensory Profile (with Dr. Dunn and others) and is currently working on a SPD performance assessment and parent checklist that evaluates all six subtypes of SPD.

In addition to spearheading the push for psychophysiological research on SPD, Dr. Miller focuses on treatment effectiveness studies for remediation of SPD. She has obtained a National Institutes of Health (NIH) grant to plan a multi-site treatment study and has engaged a team of leading occupational therapists to collaborate. In addition, she started the SPD Scientific Work Group in 2000 and is active in recruiting new members.

Her summary of SPD research was submitted to the DSM-V committee for consideration in Jan 2007 and awaits word of outcome: either “yes” the team can continue to collect data and submit for final consideration in 2010 (DSM published in 2012), or “no” there is not enough information to consider adding SPD to the DSM, reapply in 2025.

Dr. Miller also has a 30+ year career developing norm-referenced, nationally standardized scales. Her tests include: the Miller Assessment for Preschoolers, the Japanese MAP, the First STEP, Primer Paso, the Toddler and Infant Motor Evaluation, the Leiter International Performance Scale – Revised, the Short Sensory Profile, the Miller Function and Participation Scale and the Goal-Oriented Assessment of Lifeskills (in process).

**SPD Research Summary**

Dr. Miller has developed a strong foundation for additional research in SPD. Although she obtained a career award by NIH, and an R21 to plan a multi-site study, her additional R01 submissions were rejected because “SPD” is not a valid disorder and for other reasons. She left the faculty of the University of CO Medical School after 11 years with a double appointment in Pediatrics and Rehabilitation Medicine to open a treatment center and research institute in South

Denver. Her peer-reviewed publications include the first reports of significant differences between SPD and typically developing children through development and analysis of the Sensory Challenge Protocol. She continues to spearhead an intensive program of research in SPD including studies related to SPD differential diagnostic specification, treatment effectiveness and neuropathology. She is convinced that effective SPD research must be multi-site and multi-disciplinary and to this end has started several SPD collaborative research groups.

**Parush, Shula, Ph.D., OTR**

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**Research Interests**

Prof. Parush researches developmental delays in pediatrics, and is especially interested in sensory processing disorders and the impact it has on functioning in children and young adults.

**SPD Research Summary**

With regard to sensory processing, Prof. Parush examines sensory modulation disorder, sensory processing and pain, familial aspects of sensory processing, prevalence of developmental coordination disorders (DCD) and its influence on the functioning of children and young adults, influence of dyspraxia on the functioning of children with learning disabilities, and school function of children with diverse cognitive and sensory-motor capabilities in the mainstreamed school system.

**Pauls, David L., Ph.D.**

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### **Research Interests**

Over the last 25 years, Dr. Pauls' research has focused on understanding the underlying genetic mechanisms important for the expression of human behavior. His primary goal has been to understand the etiologic mechanisms (both genetic and non-genetic) that underlie the manifestation of specific behaviors that begin in childhood and continue over the life course. His research has focused on four different developmental neuropsychiatric disorders: the Gilles de la Tourette syndrome, obsessive compulsive disorder (OCD), high functioning autism/Asperger's syndrome and specific reading disability. In the past decade, the approach has been to examine components of the clinical phenomenology of each of these conditions and their transmission within families. Over the years, Dr. Pauls' laboratory has employed clinical, quantitative and molecular genetic approaches, including:

Family/genetic studies

Segregation studies examining the transmission of specific phenotypes

Genetic linkage and association studies designed to localize and characterize genes that confer susceptibility to these conditions

Prospective longitudinal studies designed to exploit the linkage findings to examine the interactions of identified genes and environmental factors

### **SPD Research Summary**

Dr. Pauls and colleagues are conducting a prevalence and family study of sensory over-responsiveness (SOR) in individuals with Attention-Deficit/Hyperactivity Disorder, Obsessive Compulsive Disorder or Gilles de la Tourette Syndrome. Despite the high prevalence of SOR symptoms in the general population (estimated to be ~5%), little research has been done to understand better the phenomenology and etiology of SOR and its relation to other conditions. This study is collecting SOR data on a sample of 600 children with ADHD (N=200), OCD (N=200) and GTS (N=200) and their first-degree relatives. It will be the first systematic study designed to obtain prevalence data in a sample of children with psychiatric disorders and their families. Since data is being collected from all family members, it will also be possible to examine the familial patterns and test specific genetic hypotheses regarding the transmission of SOR within families. In addition, DNA is being collected from all families participating in this study. Thus future studies can include candidate gene studies once more is known about the underlying etiology of SOR.

### **Schaaf, Roseann C., Ph.D., OTR/L, FAOTA**

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## **Research Interests**

Dr. Schaaf researches physiological (autonomic nervous system) measures in children with sensory processing dysfunction and children with Autism; outcomes of occupational therapy interventions for children with disabilities, brain-behavior interactions; sensory processing; and play.

## **SPD Research Summary**

Dr. Schaaf is studying parasympathetic functions in children with Sensory Processing Disorder and in children with autism and atypical sensory responsivity. For children with SPD, Dr. Schaaf's lab focuses on children with Sensory Modulation Disorder. These children will participate in the Sensory Challenge Protocol, a physiologic laboratory paradigm that exposes children to a series of approximately 50 sensory stimuli for three seconds each while monitoring autonomic nervous system activity (vagal tone or heart period variability and electrodermal activity). They added a prolonged administration of auditory stimuli to the Sensory Challenge Protocol to assess not only reactivity and recovery, but also sustained coping and self-regulation. In addition to the Sensory Challenge Protocol, a number of behavioral assessments are administered including the Short Sensory Profile to assess behavioral responses to sensation and the Vineland Adaptive Behavior Scales, Second Edition, to assess adaptive behavior, and. To control for the heterogeneity within the group of SPD, they will be classified into three groups (over-responsive, under-responsive and seeking) using criteria developed by Miller, et al and these groups will be compared to the other two. A 4 (group) X 3 (condition) analysis of variance (ANOVA) will be conducted to determine any group differences between the groups during each condition. Next, building on work in collaboration with the Miller lab, a series of regression analyses will be used to determine whether VTi is a predictor of adaptive behavior or sensory reactivity. The primary dependent measure is vagal tone, although heart rate and heart period will also be evaluated.

## **Schneider, Mary L., Ph.D., OTR/L**

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## Research Interests

Dr. Schneider's research program focuses on behavioral and neurobiological effects from fetal alcohol exposure alone or in combination with prenatal stress. We study rhesus monkeys, examining growth and development, learning and memory, and stress reactivity across the life span. We also use state-of-the-art neuroimaging techniques to elucidate possible abnormalities in neural processing. We assess dopamine system function, using positron emission tomography, to determine whether altered DA function might underlie some of the motor, learning, and neuroendocrine outcomes associated with these prenatal treatments. We have recently expanded our nonhuman primate model to examine the neurochemical and developmental basis for sensory regulation disorders. Our fetal alcohol work is funded by the National Institute on Alcohol Abuse and Alcoholism and our sensory regulation work is funded by the Wallace Foundation.

## SPD Research Summary

Dr. Schneider is researching Sensory Processing Disorder in a Primate Model. Recently her studies have examined whether disrupted sensory processing occurs in monkeys and if so, whether it is associated with dopamine functioning in the striatum assessed with positron emission tomography (PET) neuroimaging. Little is known about the neurobiological substrates of sensory processing disorders or the developmental precursors. Casey (2001) proposed that disruptions in the basal ganglia thalamocortical circuits underlie poor inhibitory control and viewed disruptions of one or more of these circuits as potential contributors to developmental disorders characterized by poor inhibitory control or difficulty filtering information appropriately.

The primates were tested at age 5-7 with the Sensory Processing Scale for Monkeys (SPS-M); a scale was developed by adapting procedures from sensory processing assessments for children. Prenatal-stressed and/or prenatal alcohol-exposed adult rhesus monkeys and their controls were examined. Positron emission tomography (PET) imaging was used in order to examine post-synaptic receptor binding (D2R) and DA synthesis (DAsyn) in the striatum. The striatum is rich in DAergic innervation and is part of the basal ganglia thalamocortical loop involved in behavioral inhibition. Fallypride (FAL), an F-18 labeled raclopride analog, was chosen to assess D2 receptor binding as an index of D2 receptor functioning because it has a high affinity for D2 receptors and high brain uptake. Findings were: first, reduced habituation to repeated tactile stimulation and higher average withdrawal response was associated with increased striatal D2R binding and increased ratio of D2R binding to DA synthesis. Second, the pattern of habituation/sensitization to repeated tactile stimuli differed as a function of prenatal treatment. Monkeys not exposed to prenatal stress showed the expected behavioral pattern of habituation across trials while exposure to prenatal stress induced slight behavioral sensitization. Moreover, compared to no exposure to prenatal alcohol, prenatal alcohol exposure induced a higher overall magnitude of withdrawal response (average across trials).

Why would up-regulation of D2R binding in the striatum as indexed by FAL and the D2R/DA ratio be related to increased magnitude of withdrawal (aversion) responses and failure to habituate to tactile stimulation? DA is an important neurotransmitter that modulates the activity

of many brain regions, signaling both excitatory and inhibitory messages. Most neural processes in the brain involve delicately tuned feedback mechanisms in that initial responses are either increased or dampened as they are transmitted through the brain. Such feedback systems may be dependent upon developmental processes involving reorganization of interactions between various cortical and sub-cortical regions.

**Schoen, Sarah, Ph.D., OTR**

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**Research Interests**

Dr. Schoen has a program of research studying electrodermal activity and vagal tone in children with sensory processing disorder (SPD) compared to those with attention-deficit/hyperactivity disorder (ADHD) and Autistic Spectrum Disorder. She is also collaborating with Dr. Miller on the development of a Sensory Processing Disorder performance measure and parent checklist that evaluates all six subtypes of SPD.

**SPD Research Summary**

Can a reliable performance assessment be developed to characterize sensory over-responsivity?

Dr. Schoen, Dr. Miller and colleagues are focusing on the development of reliable and valid scales that can be used to diagnose each of the six subtypes of Sensory Processing Disorder. Each scale has two components: 1) an Assessment which is an examiner administered performance evaluation and an Inventory which is a caregiver/self-rated symptom checklist. The purpose of the Sensory Processing Disorder Scales is to accurately diagnose SPD for clinical purposes and to identify homogeneous populations for research purposes. Existing measures are not based on the theoretical conceptualization of SPD and therefore are inadequate for the diagnosis of subtypes of Sensory Processing Disorder.

The measure of Sensory Over-Responsivity is most fully developed and has been validated on a sample of 125 participants with and without sensory over-responsivity. Data has been collected on another cohort and is currently being analyzed for internal reliability, test-retest reliability and discriminant validity.

A caregiver/self-rated symptom checklist exists for all of the other subtypes of SPD. The checklists are currently being piloted at sites across the country in order to determine which items best discriminate each subtype. Also in the process of development are items for an

examiner administered performance evaluation for the other two subtypes of Sensory Modulation Disorder, Sensory Under-Responsivity and Sensory Seeking. Test items will be administered to typically developing children as well as children with each disorder so as to determine which items best discriminate between groups.

**Smith, Sinclair A., Sc.D.**

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**Research Interests**

His primary research interest is the use of non-invasive techniques to study neuromuscular metabolism and function in humans.

**SPD Research Summary**

The purpose of our research was to determine if differences exist in sympathetic response to sensory stimuli between sensory defensive and non-defensive (control) adults, and to determine if deep tactile pressure reduces the sympathetic response to sensory stimuli. In addition we are studying metabolism in sensory-defensive and non-defensive adults using proton magnetic resonance spectroscopy (4 sensory-defensive and 6 non-defensive men and women, ages 37 to 62).

In the no-pressure condition the initial skin conductance response following the tactile stimulus was greater for the sensory defensive ( $68\pm 28\%$ ) vs. the control ( $20\pm 5.6\%$ ) group ( $p=0.04$ ). The pressure condition also reduced the overall peripheral blood flow response to tactile stimuli in both groups ( $p=0.04$ ). The tactile stimulus results produced the greatest differences in skin conductance and peripheral blood flow responses between the sensory defensive and control groups and the pressure and no-pressure conditions. The sensory defensive group had a relatively large initial skin conductance response to tactile stimuli without a relatively large peripheral blood flow response, suggesting that sensory defensive persons may have an attenuated adrenergic sympathetic activation of the peripheral vasculature and/or an elevated cholinergic sympathetic activation of eccrine glands.

**Stein, Barry E., Ph.D.**

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**Research Interests**

Barry Stein has led a broad range of studies documenting the organization, development and plasticity of multisensory integration in the midbrain and in the cerebral cortex. He and his colleagues have been specifically interested in how the brain is able to synthesize information from different senses to guide overt behavior and the principles underlying this capability can be used in therapeutic settings.

**SPD Research Summary**

Overall Objective: To Understand the Processes Underlying the Normal and Abnormal Development of Multisensory Integration

Sensory Processing Disorder (SPD) involves anomalies in processing and properly responding to tactile, auditory and/or visual stimuli. SPD is manifested in disturbances in overt attentive/orientation (or withdrawal) behavior to innocuous sensory (tactile, auditory, visual) stimuli. The fundamental question we are asking is: How does the brain normally integrate these multisensory stimuli to properly initiate and control these attentive/orientation (or withdrawal) behaviors? How are the underlying computations different than those involved in integrating unisensory stimuli? And – what developmental disruptions in the underlying neural circuit could help explain why sensory anomalies like those in SPD are occurring, so we can develop effective strategies for ameliorating them?

The neural circuit responsible for the integration of tactile, auditory and visual cues to initiate and control attentive/orientation behavior has been identified and well characterized in an animal model.

We hypothesize that the overt sensory anomalies observed in SPD involve miscommunication between cortex and midbrain (i.e., SC). Early experience-based adaptations allow the brain to best deal with the environment in which it finds itself.

We predict that if the association cortex is rendered temporally inactive during early life when SC multisensory capabilities are being formed, these multi-sensory integrative capabilities will not develop; however unisensory integration will be unaffected.

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We also have preliminary evidence that SC neurons fail to develop normal multisensory integration when animals do not have early experience with cross-modal cues and, of special interest in this context, when association cortex cannot acquire early cross-modal sensory experience. The data indicate that the development of multisensory integration is highly dependent on early experience acquired by association areas of cortex; thus, abnormal experience produces developmental disorders by disrupting maturation of the cortico-SC axis. Currently we are evaluating the reliability of these data, and understanding how a number of variations in early experience are encoded in cortex and expressed physiologically and behaviorally via the cortical-SC axis. This will help us understand how changes in the brain mediate these physiological and behavioral processes and provide insight into the neural processes underlying the sensory anomalies apparent in individuals with SPD.

**Literature published in 2007 since our previous submission to the DSM committee as well as a few of the key articles related to the validity of SPD as a diagnosis, the pathophysiology of the disorder, the familial heritability of symptoms, and the treatment outcomes are noted below.**

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