

Happy Anniversary to Us!

Read all about our 30 sensational years in this issue and stay tuned for further news as the year unfolds.



Sensations

Celebrating 30 years of sensational research, education and advocacy

Winter 2010

in this issue...[WELCOME](#)[FEATURE](#)[ASK DR. LUCY](#)[RESEARCH UPDATE](#)[EDUCATION](#)[STARLights TIPS](#)[SENSATIONAL FAMILIES](#)[HELP US HELP](#)[BOARD OF DIRECTORS](#)[Subscribe Now](#)[Visit Our Website](#)[Archives](#)[PDF Version](#)

Dear Sensational SPDF Friend:

I was thinking about the 30-year history of the Sensory Processing Disorder Foundation the other day and suddenly found myself remembering all the places we've called home over the past 30 years. There have been a lot of them, and boy have they changed! Please join me for a little tour...

1977 – The seeds of the SPD Foundation were planted on a card table in the living room of the apartment where my husband Bill and I lived in Philadelphia. The US Public Health Service division of Maternal and Child Health ranked me first for a grant to develop the Miller Assessment for Preschoolers (MAP), but they needed a legitimate organization to send the money to. "Oh, I have an idea! Let's create a non-profit foundation," said my husband Bill. So we submitted the paperwork to start a charity and went to work on the MAP, right there on the card table. If ever a mighty oak grew from an acorn, it was the organization that started there. We would occupy many more houses in the years to come, but we date the birth of the Sensory Processing Disorder Foundation from this event.

1979 – We received formal IRS designation as a non-profit charitable organization promoting research, education, and advocacy for developmental disorders, especially Sensory Processing Disorder. (It was called KID Foundation for "knowledge in development.") In a display of perfect timing, our daughter Nicole (now singer/songwriter Coles Whalen) was conveniently born in the three-month time slot between my work on the national pilot study and the national final editions of the MAP.

1980 – With Bill and baby Nicole, we moved back to my hometown of Littleton, Colorado (near Denver), and the Foundation moved into a file room of my dad's law practice. It was just me, my dad's files, a telephone, a folding chair and – oh, yeah. The card table.

Like a young family, for the next 14 years, the Foundation grew through a succession of ever bigger-and-better houses...

- The attic of an old house, where I personally put together and prepared shipments of all the MAP kits. Those rickety attic stairs were the worst for carrying up boxes of toy cars and the huge folding plastic charts for the Stepping Game!
- A concrete warehouse in west Denver, with an office cubicle out front and an assembly area in the warehouse behind the office for assembling the MAP kits. Pretty industrial, but it beat those stairs!
- A four-room office suite overlooking Interstate 25. Okay, it was a tacky suite in a cheap building, but at least it was "professional"! We now had full-time people working on the MAP and were putting on seminars. (See the "[Teaching the world](#)" story in this issue for details of that endeavor.) I was submitting grants to follow up all the children we had identified during the standardization and to find out whether the MAP was accurate in predicting which kids would need help later in school (it was). Oh, and I was working on my PhD. Who cared about the tacky offices? Not us! Then my lovely little baby girl, Marita, conveniently arrived just after I turned in my dissertation and, oh yeah, did I mention that I kept applying for funding?
- Class at last! The Denver Tech Center – In 1990, we finally moved into nice, professional digs. President Reagan had started the Small Business Innovation Research grant program so I started a for-profit business, Developmental Technologies to create an eligible recipient for funding that would allow us to keep working on developing assessments (sound familiar?). The for-profit started getting grants, and we were able to hire some people to help with the assessment development projects. (The First STEP, Toddler Infant and Motor Evaluation, and the revised Lieter International Performance Scale all resulted). I now was the proud "owner" of both a for-profit and a non-profit and guess what? I was still submitting grant applications right and left while traveling in my spare time to Washington University in St. Louis to teach one week a month in Carolyn Baum's OT graduate program. At least the PhD was done!
- The law offices revisited. As an economy measure, we moved back to my dad's law offices in Littleton but graduated from the file room. So what if my assistant was all the way on the other side of the building? I had a nice corner office and a dignified professional presence, and it all came with a family discount and a lovely mountain view.

1994 – After four years of commuting to St. Louis from Denver, I decided that I needed a new plan. After all, I



had two kids, the Foundation, and my husband Bill at home. So I applied for a part-time job at the University of Colorado medical school in Denver. (Of course, it was part-time because I still had the Foundation to keep going). There, I developed an early identification project for the university-affiliated program, and I wrote grants.

1995 – A really big move: same space, new capabilities. The amazing and ever-generous Wallace Research Foundation funded us to create a psychophysiology research laboratory to study Sensory Processing Disorder (then still known as "sensory integration dysfunction") at the university. (Read more about the details of our research in Sarah Schoen's [History of Research at the SPD Foundation article](#)). This was really the beginning of our work as it exists today. I started the Sensory Therapies and Research Center – STAR Center – to conduct research at the medical school and shuttled between there and my dad's Littleton offices, where the Foundation was still based about 15 miles away.

2001 – Your homes became the Foundation's homes away from home. The parent program now known as [SPD-Parent Connections](#) (see parent Carrie Fannin's terrific [Sensational Families story](#) in this issue for the story) was started to provide support and education for families far and wide. Now the Foundation was at work not only in Denver but from the homes of a growing network of families everywhere.

2005 – Our current space in the Denver Tech Center. After I was unable despite my best efforts to land a big grant from the National Institutes of Health to fund more research, I needed to leave the medical school. So my research staff and I decided to leave together and continue the work elsewhere. We were able to take the [STAR Center](#) name, and it now belongs to the clinic I originated at the medical school. (For more about the STAR Center read Lynn Witzen's [STARLights column](#)). The Foundation left the law offices, changed its name to the Sensory Processing Disorder Foundation (because everyone was asking about KID Foundation: What kind of kids?), and the two organizations became neighbors in several rented suites of a big redbrick building not so far from that tacky office we occupied years ago along Interstate 25. If you're registered for [our upcoming symposium featuring Dr. Winnie Dunn](#), you'll be able to see our new home during Friday night's reception and tour.

2011 – Okay, so 2011 isn't in our history (yet). But it's already on our calendar. That's our target year to move the Foundation and the STAR Center to our very own freestanding building. I have dreams for our ultimate home. There are a couple of preschool/kindergarten classrooms, lots of therapy spaces, all with one-way mirrors for use in a myriad of education and mentoring programs that run year-round. There are at least two research laboratories so more than one project can be underway at a time and a big yard with shade trees so STAR can treat kids outside instead of under fluorescent lighting indoors. And, oh yes, I don't want to forget: There are residential suites where [families traveling to STAR Center](#) for treatment or therapists coming for mentorship can stay.

In my dreams, we own this "house" instead of renting it, because rent is high when there's no family discount, and renting doesn't build equity.

It's a big dream, I know. But why not? If there's one thing that 30 years of history has taught us, it's that there's always room for growth, and the best is yet to come.

With warmest regards from our house to yours,



Lucy Jane Miller, PhD, OTR
Founder and Executive Director

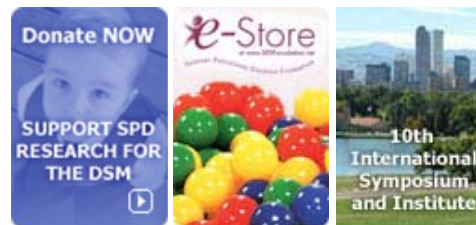


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"It's sensory; he can't help himself!"

"It's behavior; he knows exactly what he's doing!"

And the debate goes on: Is it sensory or is it behavior? Five years ago, I would have listed off the differences to you. I would have said in this situation and under these conditions, it is behavior. Or I would have said given that situation and those conditions, it is sensory. I would have declared either case emphatically and then advocated for understanding on the part of the teacher or parent based on the behavior/sensory issue at hand.



Today, however, I've come to realize that it is impossible to divorce the two. Instead of trying to separate the sensory issues from behavioral issues, think about them as interwoven layers. The first layer is the basic reactions within the nervous system to incoming stimuli-this is called reflexive behavior. The second layer is the child's feelings about responding in this manner, which affects how the child fits within his/her environment and how he or she interacts with people. In essence, it is how the child acts based on knowing how he will react to a given stimuli. This is, for the most part, considered "learned behavior". (Note that "learned behavior" does not equal either "willful" behaviors or behaviors that are "in the control" of the child.) This second layer then is a combination of nervous system adaptation and cognitive problem solving.

"Picky eating" is an excellent example of the sensory/behavior union. The tactile and olfactory stimuli of food cause the nervous system's reflexive reaction, which can be gagging or strong aversion to the smell. The learned behavior comes as parents and caregivers adjust the environment around that reflexive behavior. For example, parents might begin to offer only the foods that they know the child will eat, such as chicken fingers, french fries, and crackers. In this way, the child "learns" that only certain foods do not trigger the undesirable reflexive reaction, so they in turn solidify their limits on what they will eat. Many tactually sensitive children are picky eaters. Long after the tactile defensiveness issues are resolved, the picky eating behavior remains because only the reflexive layer of the behavior was addressed and the learned component of "picky eating" was never unlearned.

The corollary to the "Is it sensory or is it behavior?" debate is the question "What is the "best" method for modifying undesirable behaviors?" The sensory-therapeutic community and the Applied Behavioral Analysis (ABA) community both defend their approaches as better or more scientific. Since most behavior cannot be labeled as purely sensory or cleanly learned, but rather is a combination of the two, sensory and behavioral issues must simultaneously be modified. It makes sense to utilize sensory-based therapy and/or sensory strategies paired with cognitive behavioral strategies, even though a rigid ABA approach is rarely indicated. The basic principles of ABA are often unknowingly employed in OT practice without being labeled as such. Once the jargon of the "behaviorist" is put side to side with the jargon of the OT who has a sensory integration approach, planning sensory treatments while incorporating specific behavior techniques can be seen to be advantageous. While true believers on both sides of the fence debate the merits of each position, incorporating both sensory and cognitive strategies in your treatment is usually required.

The idea of ABA, and of Cognitive Behavioral strategies in general, is to improve maladaptive social behaviors using careful analysis and the basic scientific principles that govern learning and behavior. A systematic therapeutic approach that relies on repetition and reward is created. One of the founders of this field of study is B.F. Skinner, who is famous for his animal experiments showing that food rewards (immediate positive consequences of a target behavior) led to behavioral changes. Skinner's findings are widely endorsed as applied to pets, but are difficult to transfer directly to the far more complex human brain. For one thing, all people are not motivated by the same rewards. Once we discover what motivates a child, these can be used deliberately to help the child learn new behaviors. When a newly learned, desirable behavior is paired with a positive reinforcement, tied to a child's specific motivators, likely the new behavior will be repeated. The opposite is also true: A maladaptive behavior that results in an unpleasant event (negative or aversive reinforcement), that impaired behavior is less likely to be repeated. This then is the basic tenant of behavioral learning theory.

Accepting that basic behaviors can be changed with different reinforcements, a related question surfaces

next: How can sensory behaviors be ameliorated? Of course, many types of sensory behaviors exist. Understanding the origin of the specific sensory issues and how they drive automatic behavior is crucial. This understanding establishes the basis for the third layer, learned behavior. Identifying the sensory processing disorder subtype can be done on a first pass after an evaluation, e.g., determining if the child has sensory over-responsivity, under-responsivity or sensory seeking characteristics for each sensory domain. Once the sensory issues are interpreted, both the automatic and the learned components of the issues can be addressed using both OT with a sensory integration approach and a systematic behavioral approach called "shaping".

Shaping posits that behavior should be changed incrementally, with positive reinforcement until the desired behavior is achieved. Shaping is most likely to succeed when the targeted desired behavior is clearly defined. For example, shaping often works when helping a child overcome his/her fears of specific sensory inputs, or when learning independent self-care skills, or when acquiring appropriate social skills.

Let's revisit the picky eater. A parent or therapist uses a shaping technique when praising the child for tolerating a new food on his plate, even if he doesn't take a bite. The next step is to praise the child for trying one bite, then two bites, and so on. Many other behaviors may also be modified by shaping. For example, a parent could praise her young child for dressing himself even if the shirt is on backwards and the shoes are on the wrong feet. At a later stage, praise might only be offered if shoes are on the correct feet and the shirt is right side out and front is forward (Alberto and Troutman, 2003).

Shaping can be a natural adjunct during treatment with a sensory integration approach. Often when working with special populations rewarding even the slightest improvement is key to encouraging children, including just trying food with a slightly different texture or tolerating just a marginally noisier environment.

Behavior must be systematically and gradually shaped. Aggressive shaping for children with sensory issues is a sure road to failure and often the behavior will worsen. Consider the nervousness that many people have speaking in public. If required to present in front of a few hundred people, a person who has difficulty with public speaking is likely to have the same physiological reactions as a child with sensory over-responsivity issues. The speaker's heart will race, sweat will increase, and their stomach will be "in knots." Poor performance, if met by an indifferent or hostile audience, will further reinforce the perception that public speaking is scary. If instead, the presentation is practiced before a friend who offers positive reinforcement, and practice presentations are made to an ever-increasing audience size, could the speaker acclimate to the idea of presenting to a large crowd? The idea is to associate positive external reinforcement to increased exposure to a specific experience, ultimately leading to internal reinforcement and altering the physiological response to that experience.

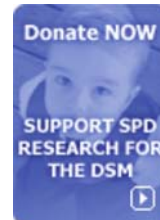
Our nirvana as therapists or parents happens when a child's motivators shift from external to internal. Once motivated by internal reinforcements, e.g., feeling good about mastering a task or participating, a child's progress is likely to speed up. This "virtuous circle" is progress that comes from the internal motivation to succeed, which leads to greater success, which garners greater external reinforcement (praise/reward/social connection) creating an upward spiraling series of events.

In conclusion, combining the neurological advances that can occur from OT with a sensory integration approach and the cognitive behavioral strategies used in ABA as well as other cognitive approaches, while allowing fluidity between and among approaches, will likely lead to greater success in the treatment of children with Sensory Processing Disorder or other conditions that have concomitant sensory issues because both layers are addressed. A child's nervous system can adapt during appropriate sensory based therapy to set the stage for learning. Cognitive strategies that shape behavior capitalize on the sensory-based treatment, which enhances the neurological changes that the child makes. Patty Schetter from Behavior and Training Associates explains it succinctly when she says: "If behavior is changing, then learning is occurring and the principles of applied behavioral analysis are in play."



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Sensory Processing Disorder (SPD) was first identified in the mid 1960s by A. Jean Ayres, Ph.D., an occupational therapist and educational psychologist. The condition was not well researched, nor accepted during her lifetime. In 1977, Lucy Jane Miller, PhD, OTR received funding from the U.S. Public Health Service, division of Maternal and Child Health (MCH) to develop the Miller Assessment for Preschoolers (MAP) to evaluate children with developmental disabilities including Sensory Processing Disorder. The success of the MAP led Dr. Miller to establish the SPD Foundation, originally known as the KID Foundation, which 30 years ago received formal IRS designation as a non-profit charitable organization (501(c)3, later upgraded to a public charity with a mission of promoting research, education, and advocacy related to SPD. The following is a historical overview of accomplishments towards establishing a program of research at the Foundation. For the next 15 years the Foundation was geared toward the development and validation of norm-referenced standardized tests that could provide a method of quantifying developmental and behavioral characteristics in children, needed for rigorous research into SPD. Nine nationally standardized tests for young children, school aged children and adolescents are now available for use by professionals.



In 1995, the Wallace Research Foundation began an initiative to increase knowledge about SPD and advance evidence-based treatment options for those with SPD. The Wallace Research Foundation found us at the Foundation and provided pilot funding for the development of our first psychophysiology laboratory, located at the University of Colorado Medical School where the SPD Foundation staff had part time research professor privileges, which provided a unique opportunity to create a paradigm to investigate underlying mechanisms of SPD. Miller and colleagues call the laboratory paradigm the Sensory Challenge Protocol Space Lab. This paradigm is designed to study reactivity to sensory stimuli across 5 sensory domains (auditory, visual, olfactory, tactile and vestibular). The laboratory is decorated to look like a pretend spaceship and the child sits in front of a video monitor watching a "safe" segment of the movie Apollo 13 depicting the astronauts being hooked up to physiological equipment while the experimenter attaches electrodes to the child. Data is collected during an initial 3 minute rest period and following 8 trials of each sensory stimulus. The experiment ends with another 3 minute rest period. Using this paradigm, multiple studies have been conducted to examine the function of the sympathetic branch (i.e. fight or flight reactions) of the autonomic nervous system in children with SPD compared to typically developing children and children with other developmental disorders. Results suggest that children with SPD have increased reactivity to sensory stimuli compared to typically developing children as well as compared to children with Autism Spectrum Disorder ([Click here](#) to read an entire article) or Attention Deficit Hyperactivity Disorder ([Click here](#) to read an entire article).

Simultaneously, Miller and colleagues received support from the National Institutes of Health (2003-2004) for a randomized controlled pilot study ([Click here](#) to read the entire article) of the effectiveness of occupational therapy using a sensory integration approach (OT-SI), conducted in collaboration with The Children's Hospital in Denver. In this study OT-SI was provided twice weekly for 10 weeks compared to an active placebo (Alternate Intervention) and to a No Treatment wait-list group. Results indicate that OT-SI may be effective in ameliorating difficulties of children with SPD, Sensory Over-Responsivity. Children in the OT-SI group made significant changes compared to the Alternate Placebo Treatment and the No Treatment groups on several key measures including Goal Attainment Scaling Attention and Cognitive/Social Composite of the Leiter International Performance Measure. In addition, trends occurred toward greater improvement in the OT-SI group on Internalizing (as measured by the Child Behavior Checklist) and the Short Sensory Profile Total Score. Physiologically, even with a very small sample, the OT-SI group showed a greater reduction in reactivity to "sensory stimuli" during the Sensory Challenge Protocol Space Lab compared to the other two groups.

With additional support to Dr. Miller from NIH, psychophysiology laboratories were established across the country by leading Occupational Therapists who were interested in studying Sensory Processing Disorder (SPD) and occupational therapy with a sensory integration approach. The Foundation pulled together a collaborative research group, now called, the Sensory Integration Research Collaborative ([Click here](#) to read more about SIRC). The vision of this collaborative is to grow the body of research on evidence-based OT-SI practice so that we will know what aspects of OT-SI treatment are effective and those practices which might not be effective. Specific goals include finding a physiological marker to differentiate children with SPD from

children with other disorders such as ADHD and Autism, identifying clusters of signs and symptoms that might constitute subtypes of the disorder and conducting randomized controlled trials of Occupational Therapy using a sensory integration approach.

In 2002, the Sensory Processing Disorder (SPD) Foundation received an award from the Wallace Research Foundation to formalize an interdisciplinary collaboration called the SPD Scientific Work Group ([Click here](#) to read more about the SPD SWG). Annual meetings were convened to develop a research agenda for SPD. This interdisciplinary group includes well-established researchers with expertise in genetics, psychophysiology, twin and familial studies, epidemiology, basic science, treatment outcomes research and assessment development. Most SPD Scientific Work Group members added the study of sensory processing to their already funded NIH grants, collaborating with one another where possible, primarily using existing paradigms, but developing new paradigms as needed to explore issues related to SPD.

The SPD Scientific Work Group formulated a research plan for validating SPD as a new syndrome using Pennington's model of syndrome validation (Pennington, 1991; 2002) as a blueprint for study development.

The model of syndrome validation adopted describes the following essential components:

1. Define and describe the disorder and subtypes (signs and symptoms)
2. Investigate the underlying mechanisms or neuropathology
3. Evaluate the etiology (or etiologies) of the disorder
4. Conduct population-based epidemiologic studies to evaluate prevalence and overlap with existing disorders.
5. Examine the developmental course of the disorder
6. Evaluate the treatment effectiveness, especially as it relates to hypothesized disordered processes
7. Research the rate of comorbidity between the new disorder and existing disorders

Investigators agreed that initial efforts should be devoted to understanding one subtype of SPD, Sensory Over-Responsivity. Following the first five years of research the SPD Scientific Work Group decided to expand the study of SPD to include both Sensory Over-Responsivity and Sensory Under-Responsivity.

With guidance from the SPD Scientific Work Group, two primary streams of research evolved at the SPD Foundation: a study of multisensory integration at the cortical level and the development of an examiner administered performance assessment of Sensory Over-Responsivity, Sensory Under-Responsivity and Sensory Seeking/Craving.

Research on multisensory integration ([Click here](#) to read the entire article) in children uses EEG (event related potentials (ERPs) to investigate Dr. A. Jean Ayres' original hypothesis that individuals with Sensory Processing Disorder (SPD) have impaired multisensory integration. Therefore, an EEG/ERP paradigm was developed to study auditory and tactile integration at the cortical level in children with Sensory Processing Disorder (SPD). Our work builds on multi-sensory integration research in the field of neuroscience using animal and adult human models. Our first step was to determine if multisensory integration could be reliably measured in typically developing children. Results indicated that typically developing children have patterns of auditory-tactile multisensory interactions similar to adults. Consistent with previous adult research, our study also demonstrated that multisensory integration in typically developing children reflects enhanced processing of multisensory compared to single sensory stimulation, e.g., the amplitude of multisensory responses in typically developing children is larger than responses to a single sensory stimulus, either auditory alone or tactile alone. The first study of multisensory integration in children with Sensory Processing Disorder is soon to be published. Twenty children with the sensory over-responsive subtype of SPD participated in this study of auditory-tactile unisensory vs. multisensory interactions. These preliminary results suggest that multisensory integration is less organized in children with Sensory Over-Responsivity as compared to typically developing children. Children with SOR appear to process multisensory stimuli differently than typically developing children, particularly over fronto-central scalp regions. Even the processing of a single domain stimulus e.g., auditory stimulus or a tactile alone appears different in children with Sensory Over-Responsivity.

The development of a reliable and valid scale for identifying subtypes of sensory processing disorder is proceeding. The Sensory Processing (SP) Scales ([Click here](#) to read the entire article), sensory over-responsivity, sensory under-responsivity and sensory seeking/craving, are measured by a performance assessment as well as a parent/caregiver report inventory. The SP Scales are theoretically linked to the current diagnostic classification system proposed by Miller and colleagues and are designed to identify the specific subtype of SPD that a child has for clarity in moving forward with treatment as well as for identifying homogenous samples for clinical research.

The first subtype on the scale was the Sensory Over-Responsivity (SOR) Scale which consists of a self or caregiver rating form (Inventory) and an objective measure of direct assessment by a therapist (Assessment). Both measures reflect sensory activities or components of daily life activities that both individuals in each of the sensory domains. The assessment attempts to capture typical behaviors that are seen in a child's life in the specific test items administered while the inventory, similar to other

parent/caregiver report measures, requires the respondent to indicate which of many specific sensory experiences bother their child. The pilot and research editions of the SOR scale had moderately strong internal reliability, demonstrating that the items and subtests were measuring the same construct. In addition, the assessment had moderately strong inter-rater reliability. Both measures discriminated between groups with and without sensory over-responsivity. We are now expanding the scale in order to include items that measure both sensory under-responsivity and sensory seeking/craving. Data on over 185 children with SPD and 102 typically developing children have been collected and we are currently directing our efforts towards refinement of the measures through examination of reliability and validity of the items.

The culmination of research efforts at the SPD Foundation, the Sensory Integration Research Collaborative and the SPD Scientific Work Group were summarized for the recent submission in 2007, 2008, and 2009 of reports to the DSM ([Click here](#) to read the latest on our DSM-V initiative) committee and an application to consider SPD as a unique diagnostic category. Over the 30 years of research, many questions have been addressed; but with each study more questions emerge than are answered by the study. The field has expanded dramatically in terms of the number of researchers studying SPD and the disciplines of the researchers involved. Collaboration is the key to answering the many questions remaining about SPD.

We predict that in the next thirty years, the solid groundwork that we and our colleagues have laid will expand exponentially and in time researchers will discover the genetic underpinning of and effective treatments for children with SPD. The secret is persistence and taking rigorous baby steps that build upon each other. The program of research begun at the Foundation will spread to scientists in many fields before final answers to the many questions about SPD can be answered. As we like to say at the Foundation, "it takes a village to do a research project."

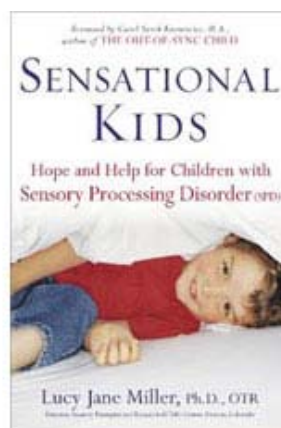


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By Lucy Jane Miller, PhD, OTR
Founder and Executive Director

I first learned about Dr. A. Jean Ayres when I was recovering from a serious eye disorder as a college student. The occupational therapist who gave me endless kindnesses and understood my personal needs during that difficult period inspired me to become an OT. (You'll find the whole story in the introduction to *Sensational Kids*). In 1972, I started graduate school in occupational therapy at Boston University just as Dr. Ayres' latest book was published. Sharon Cermak was teaching a course on Ayres work, and I enrolled.

Well, fast-forward to the summer after my first year of graduate school. I desperately wanted to study with Dr. Ayres at her clinic in Torrance, California. So I called her. She said she didn't have a student training or shadowing program. I replied that I didn't need one, I was happy to be a fly on the wall; I wouldn't even open my mouth. She said she'd "talk to her board," which I knew meant no.



After four or five weeks, I called her back and said, "Dr. Ayres! I've found an educational grant that will pay you \$100 a week if you work with me!" She said, "Oh, well, hmmm. I am working on this test, and \$100 a week would help.... I'll talk to my board and call you back." This time talking to her board meant yes. There was only one problem: I had no educational grant.

I called my parents. I hadn't even talked to them about any of this, and now I had this golden opportunity and no money. When I told my parents about the situation, they immediately said they would be my "educational grant." "But how will I ever pay you back?" I asked my dad. "You don't have to," he said. "You have to pass it on."

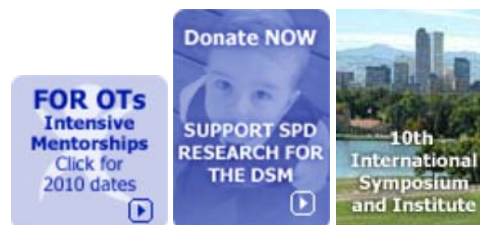
And that's how I came to be mentored by Dr. Ayres.

There's a postscript to this story. After my summer with Dr. Ayres, I finished grad school and moved back to my hometown of Denver. I finished writing the MAP manual and incorporated the Foundation to pass on my parents' gift through its work on behalf of children with sensory issues. Eventually, I needed to make some money to pay back all the loans I'd taken to develop the MAP, and I began teaching workshops on the MAP nationwide. Since I was pretty young at the time, I thought that having a series of videotapes featuring my mentors would be an excellent adjunct to my lectures.

So, in 1981, I produced a series of 13 video tapes to show during the MAP training seminars and, of course, one featured Dr. Ayres. I flew to Hollywood, hired a professional Hollywood film crew, and went to her clinic where we made broadcast-quality full-color videotapes of Dr. Ayres treating children and discussing her theories. At the time (and possibly now?) there were no professional films of her at work - nothing but home videos in black and white. So we made this amazing video of Dr. Ayres that I showed at all my seminars and sold for a period of time, using the funds to support Dr. Ayres' research on the SIPT and mine on my subsequent tests. After about a decade I put it away and moved on to other projects.

Now, nearly 30 years later, because of that long-ago project, the Sensory Processing Disorder Foundation is able to bring the groundbreaking work Dr. Ayres did in her clinic back to life for a whole new generation of therapists, parents, students, and others. It has been remastered along with relevant research and clinical practice information from today's world. Take a look at the [e-Learning class](#) we just opened to take you "into the clinic with Dr. A. Jean Ayres." I was in the clinic with her, and it changed my life; other leaders in OT were also there later and it changed theirs, too. Thanks to her, we're still changing the lives of sensational kids and families everywhere.

Lucy



Lucy Jane Miller, PhD, OTR
Founder and Executive Director



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Education Program Manager*

What do we mean when we say we are "teaching the world about Sensory Processing Disorder"?

In part, we mean we have a long record of educating people about SPD. We started in the early 1980s, when Dr. Lucy Jane Miller was teaching two-day workshops where professionals learned to administer the Miller Assessment for Preschoolers (MAP). These seminars were incredibly well-attended, which Lucy attributes to telling participants: "We don't know what we're doing! We have got to start doing more research!"

"We explained that we needed to know if what we were doing was working, and that standardized assessments were one way to begin measuring what we do," Lucy says now. She had learned in being mentored by Dr. A. Jean Ayres – the pioneer of sensory processing research and treatment – that "education is more about the questions you ask than what you do." The MAP workshops were the Foundation's first attempt to apply that philosophy to a large-scale education program.

So, at first, the Foundation just covered the map with the MAP, doing workshops in 20 or 30 cities coast to coast. Eventually, that proved so demanding that Lucy and the Foundation began educating other therapists to teach the MAP and the whole philosophy about the need for research in occupational therapy. "We trained five trainers - Wendy Coster, Ric Carasco, Diane Parham, Linda McClain, and Mary Schneider – who were then available to teach the MAP around the country. By the time the next standardized scale was done, a "train-the-trainers" model was in place, and we had 25 OTs who could teach others to administer, score, and interpret the First STEP" (now also available in Spanish as Primo Paso).

For subsequent tests that we developed, clinicians involved in standardization came to Colorado for training in large workshops where we also engaged in fun activities such as white water rafting to encourage team spirit. "In all, I now have developed nine standardized scales, so that's a lot of teaching," Lucy says. "I never could have done all that research alone. It takes a village to develop a standardized scale."

At the same time she was working on the scales, Lucy was teaching in university programs. Especially significant was her appointment in the departments of Pediatrics and Rehabilitation Medicine at the medical school of the University of Colorado. "At the med school, I showed medical students and residents what Sensory Processing Disorder looks like, what occupational therapy really is (e.g., not "just playing"), and discussed how doctors could use this information in their practices someday," she says. "To this day, there's a population of young physicians in Colorado who are strikingly better-informed about SPD than others because they went through the CU program during this period."

As crucial as all these early efforts were, the Foundation's vision was always to teach more professionals. In 2004, the Foundation produced its first large-scale Colorado conference for professionals and parents. The two-day program was attended by 550 people hungry to learn more about Sensory Processing Disorder and strategies for treating and living with it. Nine conferences later, we're just a few weeks away from our 10th major program, now called the International Symposium, and the one-day Pre-Conference Institute we've added to the schedule.

In 2008, still another educational program was added to the Foundation line-up: [Intensive Mentorships](#), a small-group experience where clinicians learn advanced methods and clinical reasoning the way Lucy learned them as a graduate student mentored by Dr. Ayres. In 2009, every one of our entry-level mentorships (Level 1) sold out, and we held our first Level 2 hands-on treatment program for those who had graduated from our mentorship Level 1 courses. Our dream is to someday run mentorships year-round.



As a new decade dawns, we are continuing the educational programs of the 2000s but embracing new educational technologies at the same time. E-Learning programs like our new ["In the Clinic with Dr. A. Jean Ayres"](#) allow people at computers anywhere in the world to experience our teaching without ever leaving home. "I'm especially excited about our new Ayres e-Learning module because it includes the rare historical footage we were able to tape in 1981 of Dr. Ayres demonstrating her strategies and discussing key aspects of her approach," says Lucy, who narrates the one-hour online program for professionals and parents.

Next up on the education front: webinars in the digital classroom. We're also at work on a publishing program to provide professionals and parents with helpful instructional booklets for use in practice, in the schools, and at home.

You often receive mailings from us with the signature line "teaching the world about Sensory Processing Disorder." In one way or another, we've been teaching about SPD for 30 years. We've changed our content and our delivery methods as needs and technology have changed, but what was constant then and remains constant now is our conviction that knowledge is power and that by growing knowledge, we empower people to make the world a better place for "sensational kids" everywhere.



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BY Lynn Witzen

Director of Clinical Services at the STAR Center

I remember the "funny kids" in my school when I was growing up. These were the kids who couldn't sit still, didn't seem to listen or even be interested in school. They weren't "bad" kids, but they were frequently seated on a chair in the hallway because the teacher couldn't deal with them in the classroom. I remember feeling very sad for these kids because school seemed so fun to me. Looking back, I can only imagine how frustrating it was for each of these children as they struggled through every day in school.

The work of Dr. A. Jean Ayres ([Read more about Jean Ayres in Ask Dr. Lucy](#); appearing in this issue) began before I enrolled in my occupational therapy academic program. Until then, when an occupational therapist worked with a child, it was usually because of an obvious physical challenge such as cerebral palsy, spina bifida, coordination problems, or a developmental disability such as Down syndrome. There were specific treatments that could be done, and progress was documented through improvement in range of motion, strength, or coordination. However, the improvement in these measurements did not always translate to a child's ability to function in his life.

Dr. Ayres looked for the "why" behind what parents, teachers, and therapists saw in children everyday. She realized that the base of problems often involved a child's inability to accurately take in, make sense of, and appropriately respond to sensory information. She based her "why" on careful observations of the children, and it guided her treatment as well.

This new way of looking at some of the children's challenges required a new vocabulary as well. It was critical to have common terminology so everyone could understand exactly what was being described. For instance, it is easy to understand the concept of visual input or what can be seen. However, there are more complex terms such as "proprioceptive input." This reference to the feeling of muscles and their positions was a new concept with a complicated name! Even now, it is not a commonly understood concept.

As Dr. Ayres explored these concepts in more depth, she realized that children would over-respond, under-respond, or appropriately respond to sensory input. This occurred as the child took in the information. When the response was not appropriate, it was because the information could not accurately be processed or - in her terminology - "integrated" in the brain. We see these responses in, say, a child who cannot tolerate eating certain textures of food or certain fabrics in clothing or noisy environments. The under-responsivity is obvious if children don't perceive when they fall and injure themselves, can't hear their names being called if there is other background noise, and can't find items in visually cluttered backgrounds.

Dr. Ayres was the first person to understand and name many of these concepts. She used her clinical reasoning skills, which means her professional problem solving ability rather than a formula she had learned, as she understood, named what she observed, and then decided with a great deal of trial and error the best treatment for the children. Part of her mission was to help other occupational therapists understand these concepts and to help them develop good clinical reasoning skills for treatment. I remember her "blue book," (Sensory Integration and Learning Disorders, 1972) which was a small but dense textbook outlining her concepts and treatment recommendations. She developed a test to measure the underlying abilities that supported sensory "integration." This test was packed into a large suitcase-sized container, which the evaluating therapists had to lug from place to place as they administered the test. The therapists had to be trained extensively prior to administering the test. In addition, the testing itself took hours, and the scoring often took longer than administering the test!

Unfortunately, this brilliant woman died at a young age. It was impressive that she completed so much in a short life span, but her death was also a great loss because she had such great potential to increase understanding of and improve treatment of Sensory Processing Disorder (SPD). Many therapists understood some of these concepts, but there was concern about her work and research continuing. This is where Dr. Lucy Jane Miller stepped forward, committing herself to promoting understanding and treatment of SPD and founding [Sensory Processing Disorder Foundation](#) in the process.

Dr. Ayres was a pioneer in the field of sensory processing. After being mentored by her, Dr. Miller continues the search for greater understanding and determining optimal treatment of sensory challenges. Part of Dr.



Miller's search has included assembling a team of researchers and establishing a systematic research program to document what occurs inside the body when a processing disorder is present and to study the changes that occur with treatment. I know that many therapists out in the field do not view research as related to their practice. But, as a clinician at [STAR \(Sensory Research AND Therapies\) Center](#), I know that the research of the team at the SPD Foundation is critical to what I do with children every day. With greater understanding of what the activities we perform with the child actually do to the arousal of the brain, and the specific outcome of the child's responses to specific sensations (things that are currently being measured by the SPD Foundation researchers), we therapists at STAR are able to more accurately assess and treat our clients.

Occupational therapists worldwide acknowledge the wisdom and historic advances made by individuals like Dr. A. Jean Ayres. We value the present work of Dr. Miller and her research team as they continue to learn more about the specifics of Sensory Processing Disorder, and we are grateful to have their guidance which is based on empirical data, for our treatment at STAR Center every day. We look forward to the Sensory Processing Disorder Foundation completing more groundbreaking research and with it equipping the therapists at STAR and throughout the world to provide the best assessment and treatment possible for clients and their families.

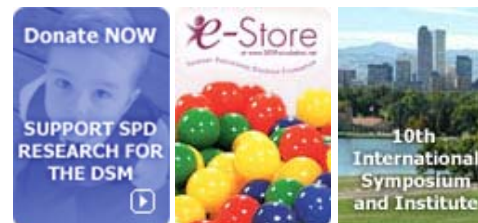
This creates the hope that, in the future, there won't be "funny kids" who end up sitting in school hallways separated from their peers but instead more kids who experience greater quality of life as they succeed academically and socially. We see it happening for many of the children we treat now and we want to see it happening for all children with Sensory Processing Disorders. We celebrate the progress the last 30 years have brought us toward this goal and anticipate with excitement the future research that will make this happen.



in this issue...[WELCOME](#)[FEATURE](#)[ASK DR. LUCY](#)[RESEARCH UPDATE](#)[EDUCATION](#)[STARLights TIPS](#)[SENSATIONAL FAMILIES](#)[HELP US HELP](#)[BOARD OF DIRECTORS](#)[Subscribe Now](#)[Visit Our Website](#)[Archives](#)[PDF Version](#)**The Parent Connections Journey: Past, Present and Future***BY Carrie Fannin**SPD-Parent Connections Host, Washington*

The moment when you first connect with other families raising a child with Sensory Processing Disorder (SPD) is life-changing. Your perspective changes immediately. You no longer feel you are "the only family" in your family/neighborhood/city struggling to understand your child's behavior. Almost immediately, your thinking changes from "isolation" to "community."

That "community" is what [SPD-Parent Connections](#) is all about. Here's the story.

**Past – Our Name!**

I remember vividly the day my husband and I were handed a diagnosis of "Dysfunction of Sensory Integration" for our daughter Hayley. I had never heard of it before - and neither had anyone else I knew. It was such a mouthful that I had to write it down on a piece of paper and carry it with me in my wallet so that I could tell people what she had been diagnosed with.

One of the most visible and welcome changes since my involvement began has been in our name. Originally named DSI (for Dysfunction of Sensory Integration) Parent Connections we then became Sensory Integration Dysfunction (SID) Parent Connections. That had its own problem (because SID was so close to SIDS, for Sudden Infant Death Syndrome). So many acronyms, so much confusion!

In 2005, the Foundation began to establish a new "nosology" (which I learned just meant classification scheme) for the condition we parents all knew regardless of what it was called. And finally the problem that our children had a new name: Sensory Processing Disorder (SPD). With that, our parent groups became known as SPD Parent Connections and FINALLY! We had a name I didn't have to carry around in my wallet to remember....

The Idea – Parents Helping Parents

Laurie Renke in Londonderry, New Hampshire first visualized a global support network for parents. She founded the original support group network and was literally a "connector," recruiting parents like me as hosts. She then served as the Foundation's national parent program coordinator from 2001-2005. A volunteer national committee was formed to provide support within the PC network and to share new ideas about how we could grow.

Another sensational mom, Raena Rawlinson, from Norman, Oklahoma, was our next national coordinator. All the while, Laurie, Michelle Morris in Florida, and I attended national conferences and events to introduce Parent Connections to professionals including occupational therapists, physicians, teachers, and others.

By 2008, the number of groups worldwide had grown to a point where the Foundation needed a dedicated resource in Denver to support our hosts and other parent volunteers. A challenge was issued to SPD-PC to raise enough money to help fund a part-time staff position for a year. The hosts stepped up with enthusiasm, and JoEllen Nikkel soon came on board as the Foundation's first in-house dedicated coordinator.

JoEllen now is the primary point of contact for all Parent Connections hosts, helping parents make the big shift from being a "parent of a child with SPD" to someone who connects with other parents and helps them connect with one another. JoEllen is also the mother of two "sensational kids" of her own and is a great resource for non-host parents who come to the Foundation with questions.

Our first national "host conference" was held in Manchester, New Hampshire, in November 2004. Pictured (back, l to r): Jean Manley and Tina Moyher of New Hampshire, Terri Linehan of Maine and Janet Wright, OTR/L; (front, l to r): Denise McKeon of Pennsylvania, Pam Cardin of Connecticut, author and SPD Foundation board member Carol Kranowitz, Laurie Renke of New Hampshire, and Carrie Fannin of Washington.



Present – Raising Awareness and Funds

One of the very first things created for Parent Connections support groups was a flyer we could use to explain our kids' behaviors. For the first time, parents had a handout that showed real-life examples of what SPD "looked like" in non-medical terms they could share with family, friends, and their child's school. Over the years, this simple flyer (entitled "Do You Know Me?") has become the trademark of the parent movement in raising awareness of Sensory Processing Disorder.

In the spring of 2005, original artwork was added to the flyer by Melissa Zacherl, a parent volunteer in Pennsylvania. Now, we have a Spanish version, too. Anyone who'd like a handy, vivid way to tell others about their child's sensory issues can download and print either flyer from the Foundation's wonderful website [Download a Flyer page](#), where all sorts of helpful downloadable materials are constantly being added. Today, you will find iterations of the foundation's "Do You Know Me?" awareness flyer all around the world.

Since JoEllen's arrival, SPD-Parent Connections has focused on fundraising in addition to sensory awareness and SPD support. In October 2009, the Foundation sponsored its first-ever international awareness event and fundraiser: SENSORY SHOWTIME, another milestone in SPD-PC history. Parent hosts and other volunteers raised more than \$35,000 worldwide to support SPD research, education, and advocacy - more than any other fundraiser has ever brought to the Foundation. Now plans for a 30th anniversary celebration event are in the works for next October. Stay tuned for news!

My Own Journey with SPD Parent Connections

Each year, I hear the inevitable: "Are you going to continue hosting now that Hayley is 15?" (Or 8, 11, 13 - fill in the blank!). Each time I hear that question, I am surprised because hosting is not something I actively think about. My SPD support group has become a part of my life; it isn't something that has an expiration date to it.

However, the question does remind me of those early years before we knew anything about Sensory Processing Disorder. Those were lonely years for our family - isolated and sad years as we struggled to find somebody to LISTEN and help us.

But the question also reminds me of my daughter, who teaches me every day about courage and determination. This child is the bravest person I have ever known in my life. She has struggled with an out-of-sync body, suffered through tough times at school that no child should have to endure, and at 12 stood up in front of more than 400 people at a fundraiser to share her story. She and I both believe that her story is worth sharing with every family who is walking down a similar road because it is a story of HOPE and SUCCESS.

I'm willing to share "our story" for as long as people want to hear it, and that includes remaining involved in SPD-Parent Connections. I share the Foundation's ongoing commitment to help families around the globe connect with one another.

The Future – Join us!

Do you have a child with Sensory Processing Disorder? Please consider joining the more than 80 other parents and professionals who host SPD-Parent Connections groups worldwide. Working together, we can usher in a new era of acceptance and understanding about this invisible disorder. To learn more, [view the Host Agreement](#) on our website.

We've made history! Come join us in making more.



NOTE: Carrie (pictured, left) is one of the Sensory Processing Disorder Foundation's original parent hosts. She has been involved with SPD-PC since its inception and was presented with our Sensational Parent Award in March 2008.



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