

## **Introduction**

Kaveh, 5, was referred to me by his parents as “a difficult and inflexible child,” who, if he didn’t have everything his way, he would have a meltdown. At first glance and based on his parents’ chief complaint, it seemed as though he was an uncooperative child with a difficult temperament and behavioral problems.

Detailed questionnaires and an interview with his parents, however, revealed much more. Getting Kaveh dressed in the mornings was a monumental task that more often than not involved several change of clothes. Kaveh often refused to wear weather-appropriate clothes, cried, complained that his clothes were uncomfortable, and refused to wear socks, certain shoes, gloves, hats, or jackets. His mother reported that she would take Kaveh shopping to buy whatever clothes he would agree to wear. Once they found something he liked, such as a pair of pants, she would buy several pairs of the same pants. However, that approach didn’t work all the time.

“What felt comfortable to him last week may not feel comfortable this week,” his mother said. This daily morning struggle would set the tone for the rest of the day, resulting in Kaveh being late to school and his mother late to work, feeling frustrated and upset.

In addition, Kaveh was a picky eater, needed a great deal of his parents’ help to fall asleep, and didn’t like personal hygiene activities such as clipping his nails, washing, and brushing his hair. He had weak muscles, tired easily, and was terrible at sports and physical activities, according to his parents.

Following the initial evaluation, Kaveh was diagnosed with sensory processing disorder (SPD).

## **What Sensory Processing Disorder Is**

Sensory processing disorder is, at the most basic level, an inefficiency in our central nervous system to process information, namely incoming stimuli. Our nervous system organizes the information we take in—the sights, smells, touches, tastes, and noises—and processes it for us to use in our day-to-day lives. Difficulties in the processing of this information can lead to numerous problems, such as disrupted motor coordination, sleeping, eating, paying attention, learning, and functioning socially and emotionally.

In Kaveh's case, he was referred to an occupational therapist for a sensory processing evaluation. This is a specific evaluation by a trained occupational therapist who will assess and determine the child's sensory profile, a list of the child's sensory issues and problems, and makes specific treatment recommendations. An example of such evaluation is provided in chapter 8.

Kaveh's parents received an individualized set of helpful activities and items, to use at home and school, including strengthening activities for his fine motor skills, practicing hand writing, manipulating small objects, developing a calming bedtime routine, and using a weighted (heavy) vest to help get the sensory input he seeks. In addition, Kaveh began occupational therapy twice a week.

Knowing the cause and reason behind Kaveh's behavior and having effective and practical tools for helping him reduced the family's stress tremendously, improved Kaveh's overall functioning, and prevented this problem from becoming a larger one in the future. This is, in part, how I hope to help parents of children with SPD in this book.

### **What it is like to have SPD**

Kaveh's case is one of many children with SPD who, on the surface, may seem like difficult, strong-willed, uncooperative, and temperamental kids whose behavior is simply confusing and does not make sense to their parents. How can Kaveh's parents, and others like them, understand their child's behaviors and what he/she may be experiencing? Consider the following analogy.

Imagine living in a home with an electrical system that is completely ineffective in processing the information sent to and from all the wiring in the house. Every time you turn on the television, the volume is on the loudest level. When you turn on any light in the house, it is either too bright, too dim, or flickers. The heating and cooling systems either force out air that is uncomfortably hot, painfully cold, or sometimes comes on and sometimes doesn't. The stove only works on either the highest level or it is barely warm. If all that isn't bad enough, there is a strong, noxious odor of burned wiring circulating in the air that you can't remove.

How would you feel living in that house? What would it be like for you? Would you be uncomfortable, frustrated, angry, disorganized, or lost? Your inability to control

the electrical system and equipment would probably lead you to behave differently than if everything worked according to your expectations. Your reactions to the extreme and unpredictable conditions may be out of your control—and loss of self-control is one of the scariest feelings to experience.

If you can think of the main electrical panel of the house as the human brain and the electrical wiring as the nervous system, the above analogy can help you to understand what it may feel like for your child to have sensory processing disorder.

### **What We Know about SPD**

Few people have heard of SPD and even those in the medical field seem to be unfamiliar with this diagnosis and how it may manifest in children.

Encouragingly, there has been great progress in the understanding, assessment, and treatment of sensory processing disorder since SPD pioneer A. Jean Ayers, PhD, OTR, published her first book on sensory integration in 1972. Ayers, an occupational therapist and psychologist, first identified sensory integration dysfunction, now known as sensory processing disorder, and was one of occupational therapy's foremost leaders.

Since then, the most important change has been increased awareness and information that parents, teachers, and service providers can use in helping children with SPD. However, compared to other disorders that have such a significant impact on an individual's functioning, such as Asperger's Syndrome, first described in 1944, we don't have nearly as much information and resources as we would like. Much work is ahead in this field, particularly, in the area of educating those who may be in the frontlines of providing care to children such as pediatricians, family physicians, and pediatric nurse practitioners.

I have worked with children with SPD since 1997 when I entered my post-doctoral fellowship at UCLA's Neuropsychiatric Institute and Hospital in the field of neurodevelopmental disabilities and related disorders. Initially, most of the children I saw had some degree of difficulty processing sensory information as part of their pervasive developmental disorder diagnosis, such as those with autism. However, more and more I began to see children who were referred to my private practice for diagnostic testing and

evaluation with behavioral problems, inattention, socialization difficulties, and such who turned out to be suffering from SPD.

Today, in my private practice office, I almost always include at least one questionnaire about the child's sensory functioning and profile as a screening tool as part of a comprehensive evaluation process. If there are indicators of significant problems in the area of functioning, I will perform additional testing, complete more specific questionnaires, and will observe the child during free and structured play followed by a recommendation for further evaluation by an occupational therapist who specializes in this area.

All the case examples presented in this book are of real children who either came to my practice to have a neuropsychological evaluation, a diagnostic consultation, or are children with whom I am familiar directly as an expert consultant or know their struggles and portraits, but have not myself treated them. Neither the children nor their families knew much about SPD at all. Their journey, their child's problems, the findings of the evaluation, and the treatment recommendations can help shed light on this process for any family that has a child with SPD. These families graciously agreed to share their stories with you so that you could benefit from their experiences (their identifying information has been deleted and/or changed to protect their identity and respect confidentiality).

In addition, as the director of McLean Hospital's Center for Neurodevelopmental Services in Belmont, MA, I oversee all the services provided to children and adolescents with autism spectrum disorders who attend our year-round school or summer camp. Most of the children in these programs have some degree of sensory processing difficulty. We develop an individualized and specific sensory integration treatment program for each child.

### **Strategies to Help Parents**

In this book, I not only discuss what sensory processing disorder is, but also focus a great deal on understanding this disorder based on a stress model, which is essentially my way of helping parents understand SPD as a source of chronic stress for their child. I've tried

to help parents get a feel for what it's really like to have this disorder, as well as its effect on their children's learning, behavior, and self-esteem.

This book can help parents help their children because I've provided important, practical, and helpful methods and step-by-step techniques to support and improve your child's functioning at home, at school, and in the community. There are very specific recommendations for almost every conceivable circumstance, problem, scenario, and situation. These include strategies for helping your child get more organized for school, prepare for various social situations such as a birthday party, to how to get your child evaluated, to getting services, to helping your child be more comfortable at home. I also help walk you through several important and key processes such as identifying the problem, getting your child evaluated, getting a neuropsychological and occupational therapy evaluation, and talking with your child's school and teachers.

Case studies included throughout the book show how SPD is manifested in children, i.e., the behavioral manifestations of SPD, how it affects a child's life, how it may be present along with other psychiatric and/or developmental disorders, what the assessment process entails, how an evaluation report looks like and what it includes, as well as some typical and helpful sample recommendations.

By reading these case examples so much of the mystery of such issues as what a neuropsychological evaluation is or what does a typical report look like and include, or what to do if you suspect your child has SPD is solved and made clear in simple terms and language.

In addition, I've included thorough discussions of assessment, treatment, and resources.

At the end, however, all I would like you to know is that SPD is a real diagnosis and disorder that is neurobiologically-based and that children with it can be treated with impressive results. Treatments such as occupational therapy, more specifically, sensory integration therapy and the use of an individualized set of helpful activities called a sensory diet, can make a world of difference in improving the life of a child with SPD. An effective treatment program can help the child with SPD to better organize and modulate their senses and responses to various stimuli from the environment around

them. More importantly, it can help the child to identify and reach for objects and activities that can help them to be more comfortable in any given situation.

Many children with SPD appear with behavioral problems and are misunderstood and mislabeled as behaviorally challenging kids. However, if the reason for that behavior is an ongoing sensation of discomfort, or sensory processing disorder, then focusing on the behavior alone does not make sense. Encouragingly, a very high number of children respond favorably to the specific treatments, such as sensory integration therapy, currently available for SPD. Therefore, the correct diagnosis and treatment make all the difference in the prognosis of this disorder.

Although SPD is a rather newer and still a fairly unfamiliar disorder to most, there is an impressive amount of information available on this topic that has been gathered in a very short period of time. Hopefully this book sheds new light on this fascinating disorder, and helps families by providing general information on this topic, relevant research findings, various ways of understanding this disorder, such as looking at it as a stressor on the child's body, case examples, sample neuropsychological and occupational therapy reports, and more importantly, step-by-step strategies and practical suggestions for parents on helping their child.