



## Sensory Integration: The Hidden Disorder

By Elizabeth Anderson, MA and Pauline Emmons, BS, BA - Printed in Sensory Integration Quarterly Fall/Winter 1995 P. 8-9

*SII is grateful to Elizabeth Anderson and Pauline Emmons for sharing their experiences of living with sensory integrative disorders. One of the most frustrating and challenging aspects of dealing with sensory integration problems is that there are so many manifestations of these disorders and no two children show exactly the same symptoms. While Ellie and Dylan both have signs of sensory defensiveness, other children may have primary problems in areas such as body awareness, balance and movement, motor planning or visual motor integration. SII welcomes other families to share their experiences of leaning about and coping with sensory integration disorders.*

“Look Mommy, we’re Super Heroes!” shouts my 5 year old from his swing. I’m Batman and Ellie is Batwoman.” My eyes filled with tears. “You ARE both super...” a lump in my throat prevents me from finishing the sentence with what is in my heart.

Dylan and Ellie are swinging from a suspended apparatus in the Rehabilitation Department of the local hospital. The woman supervising their “play” is an occupational therapist who specializes in pediatric sensory integration.

Although many people are familiar with the senses involved in taste, smell, sight and sound,

most do not realize that the nervous system also senses touch, movement, force of gravity and body position. Each of these senses is critical in your ability to function day to day.

When a child’s sensory systems do not respond appropriately to incoming sensations it is referred to as a sensory integration disorder. While this disorder affects an untold number of children, it is a relatively new concept in the child development field. Therefore, it is not well known to physicians, teachers or parents.

Although the mechanics of the underlying dysfunction are still not clear to the medical and scientific communities, the resultant behaviors can be catalogued and diagnosed. This is very important as early diagnosis and proper treatment greatly diminish the effects of a sensory integration disorder.

Because of the complex nature of sensory integration disorder, a poor self image, combined with emotional and behavioral problems, can result in both academic and social disasters. The risk is so great that now the time has come to bring sensory integration disorder to the forefront of behavioral problems and learning disabilities.

What are the main characteristics of a child with sensory integration disorder? What red flags should parents be aware

of, that might indicate that their child, or a child they know, may have a sensory integration problem?

Here are the stories of Dylan and Ellie, two children who suffer from a sensory integration disorder. By sharing their journeys of pain, courage, perseverance and hope, you can catch a glimpse into the life of a child for whom the world is a confusing, overwhelming and often frightening place. It is also about the struggle of two families who have been forced to create order from chaos and gain strength from weakness.

### **Dylan’s Story:**

As an infant, Dylan displayed many odd behaviors. From the beginning, Dylan found touch to be aversive. He wanted to have Mom and Dad in sight, but did not wish to be cuddled. Dylan was constantly wakeful, only taking 20 minute “power” naps throughout the day and night. In fact, only a layer of 100% cotton clothing and NO blanket resulted in his sleeping longer than 5 minutes. Strangely, Dylan never appeared to become agitated when he was physically cold; he enjoyed it. Baths were luke-warm at best, otherwise, he would scream as though he were boiling in oil. Similarly, if his bottle or food were even warm, they would be rejected.

It was upon reaching toddlerhood, that these odd behaviors became even more pronounced. No longer was Dylan just quirky. A “gut” feeling that something was wrong began to gnaw at me daily as I saw Dylan’s sensory problems become amplified. While Dylan continued to demand cold food, baths and sleeping conditions, now anything with an even remotely crunchy texture would be rejected. In addition, washing Dylan’s hair was akin to a world class wrestling event. Because it was such an ordeal, my husband flatly refused to bathe Dylan and avoided even feeding his son. I was appalled to realize that I no longer served hot meals! Dylan’s sensory integration disorder had come to rule our lives, and we had never even heard of the term.

By the time Dylan was two and a half years old, I began to seek help. I was not sure what was wrong, but I knew some form of intervention was needed. Thankfully, I had the support of my mother and a couple of close friends. The first two or three “professional” sources I sought out were less than helpful. The tacit inference was that I wanted a perfect child and was looking for something to be wrong.

Finally, my break came when a non-judgmental neighbor suggested that if I had concerns regarding a pre-school child, I should contact the local Early Childhood Direction Center. I did just that the next day and was relieved to find an informed and sympathetic ear. I was instructed to phone a local agency, and speak with someone about having Dylan evaluated by a developmental specialist and occupational therapist. Appointments for the evaluations were set up, and much to my surprise, they were performed at no cost to me.

At age three, Dylan began receiving occupational and physical therapy several times a week as a direct result of the evaluations he had undergone. Now a pre-schooler, his sensory integration problems became more defined and easier to pinpoint. Of course, it was also at this time that Dylan became one of the luckiest children in the world of therapy. His occupational therapist truly thinks he is special. Eileen loves him and in turn, Dylan absolutely adores her.

It was Eileen who assured me that I was not crazy when I described Dylan as being wired differently. In fact, I was shocked when Eileen would ask very pointed questions about Dylan’s behaviors, and then respond with a “that’s what I thought you would say.”

She knew that even though Dylan hated to be touched, loathed swings, and practically went unconscious when asked to ride on the sea-saw, that he would also seek out certain sensations in an almost obsessive way. This is a child who does not drink carbonated beverages, eat oreos [crunchy], or consume an ice cream cone [too crunchy]. Yet, the longer and faster the slide, the better. He loves the feel of the porcelain tub, and actually asks to sleep there. But, this same child also reacts to a rubber, texturized bath mat in his tub as if it were a bed of thorns.

### **Ellie’s Story:**

I was thrilled with the arrival of my second daughter, Ellie. It was a hot August and I envisioned picnics at the park and walks using the double stroller. Yet almost immediately I knew there was something very different about this baby.

I began realizing how strong this “gut” feeling was when

Ellie was about two months old. It was at this point I confided in a friend. “She cries all the time and never sleeps. She gets so frantic in her carseat she scratches her face until she bleeds. She has trouble nursing and takes an hour to drink a bottle.” I nodded in agreement that, yes, some babies are fussier than others, but inside was screaming “But, why can’t I comfort my own baby? Will I ever have quality time with her sister again?” I felt as if someone had turned my world upside-down.

So, I focused on the next developmental step to provide a turning point in our lives... maybe when she can crawl... maybe she can walk... but, instead of a clear turn in the road there were only rolling hills and deep valleys.

I knew from my first daughter that toddlers are unpredictable. But, nothing had prepared me for the emotional fragility and intense mood swings of Ellie; happy one minute; huddled in a corner hysterical the next. As a family we treaded lightly around Ellie knowing instinctively how weak the structure supporting her world was. Everything was a huge battle, washing and combing her hair, brushing her teeth, getting her dressed, eating a meal, sharing a toy. Only unlike her sister who had shown typical defiance, Ellie’s refusals were desperate attempts at avoidance and completely devoid of reason. A chasm was developing over which we could not reach.

At this time my third daughter was born and in the increasingly loud, hectic nature of our household, Ellie sunk into a state of despair. While everyone played games at her sister’s birthday party, Ellie would sob on my shoulder. If the baby cried, Ellie would cover her ears and hide. The bath water felt burning

hot, the tags in her clothing hurt her, she fell out of chairs and was terrified when the car turned a corner.

The birth of my son, coupled with Ellie beginning pre-school, finally gave me the means of comparison to validate years of concern. I stopped asking questions and began demanding answers.

While a fine motor and speech delay were obvious leads during Ellie's evaluations, the answer I'd been looking for came with a call from New Hampshire. A friend had heard about the trouble I was having with Ellie and wondered if she could ask me a few questions. After an hour on the phone I stood in disbelief when the sensory integration specialist said "Liz, I think she's one of my kids." Here was a woman who could accurately describe my child's behavior without ever having met her.

With this friend's guidance, I was able to locate an occupational therapist, with training in sensory integration, in my area. The success of this therapy has completely changed our lives.

What about Dylan and Ellie now? They both continue to receive therapy several times a week. Does therapy continue to make a difference in their lives? It certainly does. Dylan and Ellie are no longer just children struggling to be normal—they're Super Heroes, who enjoy sharing a swing!

What about their families? They take each day as it comes and have learned to appreciate the children not for what they can or cannot do, but for who they are and the joy they bring.

## **About Occupational Therapy for Sensory Integration**

Because a child with a sensory integration disorder cannot efficiently process the sensation associated with "play", therapy using a sensory integration approach creates an environment specifically designed to allow this to occur. Therefore, the primary focus of therapy becomes providing and controlling the sensory input for the child. To accomplish this, therapy entails using the whole body and all of the senses, so that the entire brain is involved.

While it may appear as though the child is "playing" on a platform trapeze, bolster swing or other apparatus, in reality the child is organizing his nervous system. Organizing the sensations coming from the body and then being able to respond to these sensations appropriately is the goal of therapy.

When therapy is successful, the child is able to almost automatically process sensory information more efficiently. This can usually be seen in improved motor skills, social interactions and language development. A child may seem more "put together" and much easier to live with. These positive results then vary forth from the home into the classroom.