

CASE STUDY DILLON'S STORY

As an Occupational Therapist, I have worked with my little clients most often to help them “catch up” with their development. While we cannot predict with certainty to what extent each child will have a successful outcome we do have a formula that we employ to help maximize their potential. Working with Dillon (and his village) over the many years that we worked together allowed me the rare professional privilege to develop and validate a successful clinical approach. For this, and for the fortune of working with an amazing boy and his extraordinary family, I am eternally grateful.

I first met Dillon at his home in August 2005. For the most part, Dillon sat in the corner of his dining room, engaged with a toy and barely making any eye contact. At the time, he was 29 months old. His test scores fell within the 18-month-old age equivalency. Shortly after beginning his treatment sessions with Sande Rutstein, OTR/L, his parents requested that Dillon be seen for occupational therapy in the clinic setting. This would allow for more access to the varied sensory motor modalities, which would address and help to improve a wide range of his developmental skills. A pediatric occupational therapy clinic, if equipped properly, consists of specialized equipment used to work on improving balance, gross motor, upper limb coordination/ speed and dexterity, perceptual and fine motor skills. Every activity provided at New Directions for Kids is purposeful. Since play is their work, a child can make significant gains and catch up readily with their cognitive, developmental, and social skills. We create structured activities in a safe, sensory-rich environment that result in children's ability to learn, grow, attend and behave.

Children take in information from their environments via their senses (hearing, smell, taste, vision, feeling through touch, and the muscles and joints), which translate through neural pathways sending information to the brain. Sometimes the information does not remain direct on the pathways and the messages actually become like a traffic jam causing dramatic responses and emotional dysregulation. This information can be easily misinterpreted as misbehavior causing strong reactions, which can be either over or under reactions that others commonly misperceive as behavioral issues. In fact, these children aren't misbehaving; they are challenged with Sensory Integration Disorder.

Much of my work with children and their families, caregivers and other concerned professionals centers on understanding Sensory Integration and Sensory Integration Disorder.

Sensory Integration is the neurological process of the central nervous system, which interprets, organizes and directs the sensory information coming in from the environment. It is as if there is a traffic policeman who locates, sorts and orders the sensations. For some this develops efficiently and the responses are normal. When the system does not develop efficiently the signals do not get organized and creates that traffic jam in the nervous system as mentioned above. The result is problems with arousal, attention and organizing behavior. These children are “Out of Sync” emotionally, socially, and behaviorally resulting in Sensory Processing Disorder when the sensations don’t communicate adequately with the brain. All of the seven (7) senses have to work together to have a normal response. As mentioned previously, the seven areas include sensory information coming in through sight, sound, smell, touch, taste, our sense of gravity with balance through the Vestibular system, and the Proprioceptive System via sensing information through the joints and muscles.

Dillon’s nervous system was compromised and he easily reacted in a “flight/fright” mode. Children who struggle with Sensory Processing Disorder have a difficult time finding a balance with the incoming sensory information, which causes them to be either overresponsive or underresponsive. As was the case with Dillon, he overreacted to incoming sensory input, especially with auditory, touch, balance, and smell senses. Although he was resistant and fearful to engage in many items throughout the environment he would benefit from a Sensory Integration approach to treatment on a consistent basis. Allowing him to have exposure to the appropriate sensory input, right amount of frequency, and quantity would allow children to slowly adapt. Like most children, routine and structure were also key for Dillon. Transitions and changes have always been difficult for him and this difficulty is common for many children with Sensory Processing Disorder.

Occupational therapists need to understand Neurology and receive extensive, additional training to work with children who display Sensory Processing Disorder. The rapid pace of change, technology, birth trauma, environmental factors, chemicals, sensory deprivation all contribute to many children impacted with sensory processing irregularities today. It has become a specialty for Occupational Therapists working in Pediatrics.

During his Occupational Therapy sessions, Dillon was introduced to a variety of therapeutic activities such as music, movement with sensory motor equipment to improve his motor skills, art for his fine motor skills, ball games for eye hand coordination, puzzles to improve visual perceptual skills and tactile activities to decrease his sensitivity to touch, also known as Tactile Defensiveness.

Initially, Dillon was not receptive to many of the activities provided to him. Due to delays with his vestibular system it was very scary for Dillon to crawl through tunnels, spin on spinners, sit in a tent, and/or climb up or down a ramp or across balance beams. He was apprehensive and it took months for him to be willing to try such activities. Dillon could easily move into a flight/fight state. He was easily fearful of sounds, movement activities, and defensive with tactile activities. He was easily triggered and became over stimulated by what was considered to be a normal amount of sensory input for another child of his age. He had difficulty filtering out the incoming information, became overloaded and/or strongly reactive and then at times could quickly move into a full-blown tantrum. We would have to cease our sessions or initiate more calming activities. Naturally, this was very stressful for his parents and could easily upset the family dynamic. Having the Occupational Therapist educate and set up a strong home program is vital to a successful program outcome. Creating a team approach where the parents can carry over the therapeutic activities at home is significant not only for progress in reaching goals but also to empower the parents to be more responsive and at times, even effective in the home environment. Although Dillon attended Occupational Therapy two sessions per week it was still necessary to have him receive appropriate sensory input on a regular basis on the other 5 days. This will be discussed further when the concept of a Sensory Diet is explained.

On several occasions, his mother would arrive and by chance there was a sound of a truck, ambulance or car driving by, Dillon would become triggered into a state of emotional dysregulation. Sometimes it would take the majority of the session to calm or distract him. I realized it was going to take time for Dillon to build trust and connection with this therapist. It took Dillon almost 2 months to feel comfortable to move towards and join this therapist independently. I capitalized on the 3 things he most enjoyed: music, ball games (his area of strength), and reading books. Since his language skills were delayed, language was emphasized. For example, with target ball games he would always be praised and his responses described out loud as to what he did, such as, "you did it", "you threw 3 balls", "you missed it." As he became more successful with these activities, his trust developed for his therapist, Sande Rutstein.

He barely tolerated movement given on swings, hammocks, climbing structures, and balance beams. He displayed tactile defensiveness by his inability to touch textures such as clay, play dough, gook etc... He would often retract his hand, refuse or cry or whine a lot. When he had this strong reaction and/or would cover his ears, especially to the sounds of trucks or cars, it was obvious that he had auditory defensiveness. He cried uncontrollably and at times clung to his mom making it difficult for her to leave and naturally straining for her.

Around the 8-month mark upon entering his regular session at New Directions for Kids, Dillon turned to his mother and pushed her towards the door and said bye-bye. That was a turning point. He also demonstrated his first positive response to tactile input by placing his hands in a bin of beans. Children need to touch a variety of textures and play with them to develop normal tactile processing. After Dillon was able to tolerate the beans, he was able to also tolerate having his hand on clay and putty with plastic wrap over the item.

Although Dillon had minimal verbal skills his receptive language was stronger so he was able to start to follow the verbal directions. Since ball games were his area of strength, it was usually a great way to start his Occupational Therapy and set a positive tone for the session. He never tired playing ball games.

We also set up joint sessions with his speech therapist who implemented communication sheets with photos of his family and of the chosen activities. He began to respond positively to the song, "Down on Grandpa's Farm" by Raffie and I too integrated that into the structure of each session with the same CD. His comfort level and emotional regulation steadily improved. This was very effective and as time moved on he became more secure which allowed us to branch out and slowly implement other activities such as songs, playing musical instruments and role-play animal sounds.

It was about the 7th month of working with Dillon that he was willing and able to tolerate wearing the headset for the Therapeutic Listening Program to reduce his sensitivity to sounds and improve his emotional regulation.

Around the 9th month, at the end of one of our sessions, Dillon became resistant to leave when his parents returned to pick him up. At that point, I knew we were on our way to success. This was also the time that Dillon began to understand and use some sign language.

Dillon was very attached to his Dad. At the times that Dad would bring him, it took him a longer time to accept when it was time for his dad to leave and again we had to continue to work on easing transitions to avoid becoming dysregulated.

It took about 9 months for Dillon to have built trust, confidence, and for us to start to see a reduction of his gravitational insecurity. He began to take a risk to jump off a 5-foot high platform into a pool filled with foam. We were now able to let go of the structure at the beginning of his sessions by implementing the music and balls. He was slowly beginning to enjoy swinging.

Dillon's ability to touch textures improved after about 1-½ years, but he was not always fond of touching texture, so his tolerance fluctuated greatly.

About the age of 4 ½ Dillon started to exhibit more independence by choosing activities of interest for his warm ups. His fine motor skills began to show delays. He would use a pencil with both hands together, which began to be integrated in his sessions. It was at this age that Dillon's mother reported that he was starting to exhibit difficulty with social and behavioral responses, which was a concern. At that point we discussed bringing on a behaviorist to support his parents and decrease stress it was causing his family.

Around the age of 5 when Dillon's language began to evolve. One day, as he was throwing balls overhand into a container, he yelled out, "you did it, you got 3, and "you missed it." I was stunned as he was copying my earlier responses imparted to him. From then on his language skills developed rapidly and it seemed that he quickly learned how to express himself. He also began to display a sense of humor by subtle teasing even at times non-verbally, such as hiding and attempting to scare me.

At about the age of 6 ½ Dillon was given a chance to try out in a sensory-motor group as a way to continue to improve his developmental skills but to begin to integrate social skills. Activities chosen were to emphasize self-expression, cognition in playing games and understanding others' emotions, increase social awareness and learn skills to interact appropriately and make friends.

His mother and I were not sure that this was the right time for Dillon to join a group and maybe he did not have the maturity and communication skills necessary to be successful. However, we were quite surprised as to how well he handled himself during the groups that he initially attended at New Directions for Kids.

During one particular session, as each of the children were checking in about the events of their week Dillon thought that they had completed the activity and yelled out, "Hey you left me out." That signified that he was cognitively ready to participate in the group on a regular basis.

For the next few years Dillon attended groups, which fluctuated with the children due to schedule changes, etc. Around this time, he began to show an edge of being competitive and did whatever he could to win, which included cheating when playing games at times. Even if he lost he would claim that he won. The children would argue and try to convince him that he did not win and yet he still believed he did. He showed no remorse for his strong responses, which were worked on for a good couple years.

Occupational therapists are required to have acute observation skills. As time went on it became more evident that Dillon was taking sensory information in from his environment primarily through his visual and his olfactory sensory sense, by smelling almost every item that he came in contact with. He also frequently, noticed new items around the clinic, by always tracking around the room and would make comments about the changes that he noticed.

His mother and I began to have concerns that as he gets older and other kids notice Dillon's habit of smelling would deter other children from wanting to play with him. And then one day, what was feared took place with a peer. There was a period of time when Dillon was paired up with another boy, who was much more socially exposed than Dillon, who was very innocent. One day Dillon smelled several items during part of the activities in which he was engaged. This other boy took notice of Dillon's sensory seeking behaviors and loudly commented, "Hey dude, why do you smell everything?" Although Dillon was stunned, he denied smelling anything. During a different session when alone with Dillon, I addressed the inappropriateness of his sensory seeking behaviors in the presence of others, especially other peers, his response was to minimize the severity of this habit, while engaged in other groups. A couple of years later, when Dillon was again observed smelling new pencils and other items given to him in varied groups, I broached the subject again. I discussed honestly how children could tease and make fun of him. At that point, he turned and looked at me with the following response, "Ms. Sande I have a lot of friends and my friends like me for whom I am. They won't leave me." With that response, I knew at that time that Dillon had built a strong sense of self and had self-confidence as he identified himself in a positive light.

Dillon's parents were very pro-active about creating a team of disciplines to not only work with him individually but they took the initiative and made provisions so that all of the team players coordinate and communicate their concerns, plans, and goals with one another. Each new school year I would meet with the others so we could share our plans for the year. Similarly, at the end of the year, we would try to make sure that we met our goals and were on track for the following year. Although, there may be some overlap, it does take a village in helping our children. A good portion of Dillon's success has to do with his parents' involvement, commitment, and follow through, which helped to enhance the positive result and success in his meeting goals successfully.

It was also around the time that Dillon was in 2nd grade that his language skills evolved which allowed him to be part of a school play. His early music skills paid off. His dance/singing skills began to blossom. His dad shared the video of Dillon's play. He was truly engaged and the most animated of any

child in the performance. I recall sharing in the excitement of Dillon's success. It was an emotional moment for both his dad and me. At that moment his Dad asked me, "Do you think we were going down the road of Autism?" I speculated and complimented him on being supportive, pro-active, and consistent, which has allowed Dillon to stay involved in his life and not check out "into his own hotel room." This is a piece of advice that Temple Grandin offers parents.

Sensory Diets are usually developed for individuals who need a large amount of input throughout the day. Just as your body needs food evenly spaced out throughout the day, so does the body need activities to keep its arousal level optimal. It is the job of the Occupational Therapist to figure out the amount, type, and frequency of activities one needs to function at their optimal level. During the times when children have difficulty attending to a task for longer periods of time or they are resistant, or just wiggly, squiggly, we offer them oral motor input, which consists usually of choices of textures for sucking, chewing, biting, or licking as input to alert their sensory system which helps them maintain their focus. This is a very effective technique with tabletop activities and/or handwriting tasks. We have implemented using a Sensory Diet Box with a variety of options. These include some of the following ideas, such as, licorice, beef jerky, pretzels, raisins, pieces of fruit, varied gum to chew, sour balls, ice chips, their own cup with a straw for sucking, It is important to keep in mind to sustain a variety of sensory textures to suck, chew, bite. Dillon loved chewing bubble gum, which helped him with his concentration... There was a period of time that Dillon began sneaking more than one piece of gum, sometimes up to four pieces, thinking we would not notice. His parents and I worked through this issue not only with consequences being implemented, but allowing him to request his needs for oral motor input. If he needed to have 4 pieces of gum and was allowed to have them during a task it seemed to help him overcome this habit.

As mentioned above, Dillon struggled with his hand skills. It took extended time for him to have a preferred hand, use both hands simultaneously, and lacked a mature tripod grasp. Many children with Sensory Processing Disorder have handwriting challenges. Their writing is often messy, challenging, illegible and there is inconsistency with pressure applied and children complain about hand pain. Children with SPD find handwriting laborious, tend to avoid the task, and exhibit awkward and inefficient grasps with both writing tools and eating utensils.

As Dillon's skills developed and he began to make progress, his academics excelled and we all began to notice that his handwriting improved. By the time Dillon was entering 4th grade, he began to approach activities in a very mature, serious, and mindful way. Simultaneously, his grasp improved and by the

time he was in 5th grade he wrote with an efficient mature grasp. Similar with math, Dillon used to struggle with his visual motor skills and lining up numbers, but around the same time his math skills began to emerge.

In the summer of 2014, Dillon's parents and I decided that after attending therapy for about 8 1/2 years and making such significant gains, Dillon was ready to be discharged from OT. Prior to doing so, he was given a full battery of tests to objectively track his progress and provide specific activities that his parents would continue to implement in his home program. As we spent these last few sessions together he asked me questions about what he was like as a younger child and wanted to know some of the details of his responses to sensory input. At times he laughed and other times he made comments such as "Really, that is weird!" He also reminisced about many of his experiences at New Directions for Kids, the other children he had met in groups and how he developed friendships and social skills. He brought up experiences that I had forgotten. We laughed a lot together. After the last assessment Dillon was given a diploma and he was so proud of his accomplishments and success.

Most of the test results ended with Dillon making gains with a few areas to improve developmentally. He still expresses mild gravitational insecurity by being cautious, and mild cognitive and social delays. Later his mother and I reviewed the results of these final tests and at the same time were able to also reminisce and feel joy for the progress that Dillon had shown over the last eight years. Dillon is a success story. Early intervention, consistent family support, a unified team approach by the professionals and following Dillon as a whole child are the key ingredients that maximized Dillon's potential for success.

Dillon has grown into a unique and wonderful young man, who was able to overcome many of his sensory irregularities that were interfering with his functional abilities and showed steady progress with his developmental skills, which could have held him back in life. We shared in a special connection that grew over the years. He was very comfortable imparting his quick sense of humor and wit from a very young age and other times was able to stand up for himself and in spite of having language delays, he learned to express himself clearly. He provided me with a gift to grow professionally by having so many years working together with both him and his parents. It has been an extremely rewarding professional experience to work with Dillon and to witness his growth and academic success. He will always have a special place in my heart.

~ Sande Rutstein, OTR/L