



A Mother's Story:

How Occupational Therapy Helped My Daughter

By

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I want to tell the story of how my daughter's life changed in just two years.

My daughter, Amy, suffered from sensory integration problems until the age of ten when we finally found the right therapists to diagnose her problems and set a successful therapy programme.

While I had my suspicions that Amy's development had been slow, it wasn't until the nursery teacher told me she was concerned about Amy's progress that I started to get concerned myself. Amy disliked mess on her hands, was not mixing with other children and seemed quiet and immature. I was not sure what I should do or who I should go and see.

We were living in Malaysia at that time; my husband was on a construction contract with his company based in the UK. Life was relatively comfortable, with all the benefits of the expat lifestyle for my family but lifestyle didn't appear to be enough. I needed to get some professional help for Amy. What I didn't realize was that finding a true professional, who knew what they were talking about, was going to take years.

In Amy's first year of school, I went to see a speech therapist. She suggested that Amy had a mild case of dyspraxia. Amy had no concept of spatial relations: She could not understand over, under, beside and below. She could not find her way around her school, or even our house. Someone had to help her find her way around all the time. But telling me that Amy had a 'mild case of dyspraxia' didn't help me understand Amy's difficulties.

Needing more help to understand Amy's problems and to seek a way to help her, I went to see a paediatrician who said that I had caused Amy brain damage at birth as there had been problems with the placenta. I was distraught. I didn't know if there was anything else I could now do to help my child. Was she always going to have problems?

The news of Amy's "brain damage" had a dramatic affect upon my family and particularly with my relationship with my husband. I was riddled with guilt. It was

somehow my fault that Amy had "brain damage". I felt it, and my husband felt it. Our relationship became strained. We decided that it might be best for the children and I to return to the UK.

Compared to the expat life where most of the children in an international school had parents in professional occupations, school in the UK seemed more 'normal' as the children had a wider range of abilities and Amy didn't appear to be so out of place.

Having settled in the UK, I then sought the help of an educational psychologist. In his report, the psychologist said that Amy had no sensory problems and again said she only had a mild case of dyspraxia. This report only made things worse for me and I remained confused and still unable to know what to do for Amy.

At school, I found Amy had an excellent teacher who understood Amy's needs and gave her lots of support in class. She recommended that I go and see an occupational therapist.

The occupational therapist I went to see worked for the NHS. Her assessment stated that Amy did not qualify for occupational therapy support as her score was one point higher than the mark set for such support. I was livid. As I was to discover later, the OT had no knowledge of sensory integration and did not know how to assess her in order to identify the nature of Amy's problem. I didn't know what to do next other than to get involved in Amy's schooling myself.

I volunteered at the school as the dinner lady to help the children during lunch. I was able to pay particular attention to Amy who, even at the age of 6, was a messy eater and other children would not sit beside her during lunch. She would have food all around her mouth and I would get her to wipe it away when she finished eating. While she did not seem to even feel that she had food around her mouth, at other times she was over sensitive to touch and did not like people to touch her, or even for me to cuddle her. Which, of course, tended to hurt me.

But Amy still didn't make friends. She was socially isolated. She couldn't play sports well so the other children wouldn't pick her for teams. Amy was missing out on the social aspect of growing up with her friends. This was a main concern for her Dad. She would spend a lot of time in her room reading her books. Even if we took her to birthday parties, Amy would sit with the adults rather than play with the other children.

In 2002 we moved to Dubai. Schooling for both Amy and myself has been a nightmare. Each year I had to explain all over again to each new teacher the difficulties Amy faced.

Some teachers didn't believe me and they'd roll their eyes in skepticism. But the children were no better: Girls in the netball team would throw the ball harder at her as they knew she couldn't catch the ball. A boy in her class told her she was 'thick'. I wasn't able to help, and I was fed up with all the assessments and being told different things. It was exhausting.

Friends urged me for a year to go and see Sheena Reynolds, an Occupational Therapist, at the British Institute for Learning Development (BILD) where they used sensory integration therapy. Finally I agreed to go and see her. My husband was not convinced it would do any good but he came with me. By the end of the consultation my husband could understand the concept of sensory integration and how it related to Amy's difficulties.

I bought the book 'The Out-of-Sync Child' which explains sensory integration dysfunction and I was amazed how well it explained Amy's problems.

A full assessment was done.

In response, and firstly, I was told Amy doesn't have 'brain damage". Second, I was told that she did not have a mild dyspraxia, but in fact it was quite severe. And third, it was explained to me that Amy was experiencing sensory integration dysfunction of her vestibular and proprioceptive systems which was affecting all of her motor skills, spatial

awareness of self and other objects/symbols/letters/numbers. Because of the poor processing of these sensory systems it was affecting how she processed sound and touch.

I came to understand that Amy, suffered from tactile insensitivity. Her skin was not sensitive and she could not even feel the food around her mouth. She could also be sensitive to touch getting angry when someone came up behind her and she was fussy about her clothes. Noise also bothered her. Amy's motor skills were delayed, she couldn't hop or jump a rope on the ground. All of this was affecting her ability to play sports, make friends and do well in school.

Amy has been doing therapy with BILD once a week for 2 years. Now, instead of being the usual last in class, she is top of her English class. Homework that would previously take 2 hours now takes 1/2 hour. Her father is glad that she now has friends and is no longer missing out socially. But the most enjoyable change for me has been the hugs and cuddles that Amy and I now share.

If I had only found an organisation like BILD with occupational therapists experienced in sensory integration when my daughter was four we would not have endured seven years of stress and heartache. We have coped as a family by being open and honest and her brothers and sisters have learned to be understanding and supportive. They now understand when they see another child who has difficulties in school, that it is similar to what their sister experienced.

Much of my anguish has been that my daughter had to go through all this - critical teachers, no friends, failing at school - because there was no one to understand her or help her.

I am very angry that I have put my trust in 'so-called' professionals who were not able to give me the right information or help my daughter.

Finding a professional who actually knows what they are talking about and knows what to do in therapy to make a real difference.

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