

Family Story – Living with Developmental Co-ordination Difficulties (DCD)

Noticing the first signs

I think I knew that there was something different from birth really. He was meeting all of his developmental milestones, but he always seemed to be so demanding. People would say '*oh yes my child is just the same*', but I knew it was different. I was constantly worrying about him. I had my second baby when my son was 18 months old, I started to notice the differences between them which made me think that there was definitely something there. My eldest son started nursery 2 days a week so that I had some 1:1 time with my youngest. Whilst at nursery the workers started to ask questions about his hearing as he often didn't respond to them. We got his ears tested, but I knew that wasn't it, as I could be at the bottom of the garden, whisper chocolate and he would come running! When he left nursery I remember them telling me that they felt he might struggle at school, but I think I just buried it.

Referral to community health services

When we attended his first school parent's evening, his teacher told us that he needed constant supervision. He was also very impulsive and didn't have much self-restraint, although he wasn't naughty as such, he just couldn't stop himself sometimes. We decided at this stage that we would take a two pronged approach, so we went to our GP with our concerns and the school brought in the Educational Psychologist. They did observations of him at school and he did tests as part of their assessments, but he seemed to be just below the threshold for Autistic Spectrum Disorder or ADHD. It was all still a bit vague really. I think they said that he had general co-ordination difficulties and mild developmental delay in some areas. The good thing that came out of all of it for us was that we had an open referral for the Community Paediatrician. This meant that we had access to expert advice if we needed it, which made us feel a bit more in control.

Further involvement

By this stage we were tearing our hair out with his behaviour. As it was all quite low level and not naughty we were still really unsure what to do. At a year 4 parent's evening his teacher said to us '*something is not right*'. That was quite an important moment for us. She had been using strategies within school to manage his behaviour, but he was still not processing information or completing tasks, he had problems with writing and concentration difficulties. We contacted the Paediatrician and reopened the referral. The Paediatrician referred my son to the Occupational Therapy (OT) service. They made us aware that there was a long waiting list and it may take a long time. I have to say I wasn't very optimistic, I thought it would be the same as everything else up until now.

We finally got a letter inviting us for an assessment to see if they could help him. We met with 2 OT's at the first appointment. They chatted to both us and our son, he loved that! There was loads of exciting equipment to use and he really enjoyed all of the attention. They felt they could help him and offered us 10 sessions working on his core muscles and helping with writing. They also talked to him about what he would like to focus on and he said that he would really like to be able to ride a bike.

What happened next?

My son really enjoyed his weekly sessions and his OT was brilliant. Although the sessions were therapist lead she always gave him choices like which equipment he wanted to use. He was always allowed to express preferences and have an input. The OT quickly picked up on my son's interest in technology and suggested that I filmed some of the sessions on my phone to document his progress and play it back to him. For one of his sessions we met the OT at Blaise Castle so that she could go through some tips to help him with riding his bike. She also gave us a step by step programme to work on with him. After a couple of weeks he had mastered it! We filmed it and he took it in to show his OT, he was bursting with pride!

We are optimistic for his future. The transition to senior school has gone well. It feels that the gap between him and others has lessened and he is getting much more out of life now. Of all of the professionals the one that I felt the least relevant has been the most beneficial to him. I am full of admiration that she has been able to bring the best out in him.

Story details taken 13/10/14