

A Mother's Story

My story begins in 1996. We had already been blessed with two beautiful daughters, Nikita 7 and Sophie 5 years. Having suffered two miscarriages, you cannot imagine our joy when our son Lucien arrived on 25th July. This also meant that Nikita would not be leaving home to go and live with her Nana, something she had threatened to do if she were to have another sister!

It had been a very worrying and stressful nine months with my previous history, but the moment I held Lucien in my arms, all my worries were over and forgotten. At least I thought they were. When we brought him home, it seemed everyone was besotted by him including my daughters' friends. He was and still remains an idol among the girls. I suppose we should have realised from the beginning that Lucien had something extra special that was going to change all our lives.

He went on to reach all his milestones, crawling, walking etc ... everything he was supposed to do. By two years old he didn't have an enormous amount of language, but that could have been due to having two doting older sisters anticipating his every need. Although he sang simple nursery rhymes and would shout his Daddy by his Christian name at the bottom of the stairs to wake him up, something he had seen me do on many occasions!

However, he had a couple of ear infections and a case of impetigo, all of which had been treated with antibiotics. It was at an 18 month check up by the health visitor in October '98 (when Lucien was 27 months), that I was asked if I had any worries. I mentioned that Lu didn't have a lot of language and that I wasn't sure whether I should be worried or not. She assured me that there was absolutely nothing wrong with him and that his sisters were doing all the talking for him, but if I wanted to see a speech therapist for peace of mind that she could arrange that for me. I said that I thought that this was a good idea. I have never seen or heard from that health visitor since that day.

It was Christmas '98 when I believe Lu had a serious ear infection. He was very poorly and this was when the little boy I had given birth to was snatched from me. In the new year, 1999, all that was left was a shell. Suddenly, there was a deadly silence, no eye contact, no emotion, no recognition of anything or anybody. What had happened? When had it happened? Why had it happened? After I had voiced my concerns to a few friends and family members, someone mentioned that they had worried that their son may have been autistic when he was younger, but had developed fine. I had never really known what autism was and I wanted to find out more. To my horror, everything I read described Lucien. For days my husband and I watched him, speechless as he lined things up before our eyes.

We had booked an appointment with a paediatrician because of our concern with his ears. It was at this appointment that I first asked if my son may be autistic. He told me that I shouldn't read into things.

After months of appointments, tests and assessments, the bombshell came in July 1999 from a specialist paediatrician. What do I do now? That was my response to the news. To which the specialist replied: "I don't know, I haven't got a crystal ball!"

With the help of my best friend we came across an article in a Sunday supplement about Ivor Lovaas and that's where our journey into ABA (Applied Behaviour Analysis) began. Our first ABA workshop was 3rd December 1999 and the moment our consultant walked in the door, I knew that this is what I had been waiting for. She was actually able to get a response from Lucien straight away, she just knew how to approach him and he was like putty in her hands.

For the first time I felt that someone could help and knew what to do with my child. That was all a very long time ago and since then he has had many setbacks. The biggest being when the Local Education Authority took over his programme from the ABA consultant for a year in 2001. It was a disaster and after battling with the LEA, we managed to get Lucien back on to an ABA programme in 2002. Lucien has always struggled with language but with the consistency of the programme and dedication from our ABA team we constantly see glimmers of Lu entering back into our world.

One of the most special memories was in April 2003, I was in labour with my fourth child and preparing to leave for the hospital. It was bedtime for Lu and I kissed him and told him that I loved him. He said: "I love you Mummy," burst into laughter and then said "Baby!" No-one had ever explained to him what was going on, but he already knew. This is why we believe ABA is so important. Our children are capable of so much more that they are given credit for and ABA consultants recognise this and strive for our children to achieve their full potential. Make no mistake, it is not easy running a programme. It is very invasive on your life and family. We had to battle with our local LEA to get funding for what we believed was the right education programme for our child and we went through a very costly tribunal just as many other families do. The funding was withdrawn and we were forced to take him out of mainstream school to home educate as we believe that for the moment Lucien needs to be taught on a one to one basis. He cannot talk well and he cannot learn in the same way that other children in mainstream school can. He and many like him, need specialist education to help maximise their learning potential. Giving them this specialist education now will hopefully work towards these children becoming more independent, and them being able to integrate into mainstream schools and society.

I never imagined Lucien would be able to go to sleep alone in his room without me beside him, or that he would sleep through the night or even be dry at night, but he is. He bakes blueberry muffins, he reads the recipe for each stage and whilst stirring the mixture has exclaimed: "A birthday surprise!" What an achievement. Our determination to provide an ABA school for children in the same position as Lucien is stronger than ever and we will never give up our fight.

Regina Coulon, mother to Lucien and trustee of Wishing Well House.