

Finding the right education for

By Fiona Wilson

In 2002, our second child, entered this world in a hurry, with a big story to tell and many lessons to teach, most notably to me, his mother. Patience, fighting for what you believe in and honesty are all traits that my 9 year old son, Charles has taught me.

After his birth, I was traumatised and in shock. I coped by throwing myself into everything I could to try and understand him. I would sit in Makaton classes when he was 6 weeks old looking for answers. The joy I felt when he signed back to me at 18 months was overwhelming.

As a mum, I feel we all have expectations for our children. I have expected no different for Charles. I discovered an inner tiger that I didn't know existed when I had to start challenging the "system". As the years went on, I learnt when to put the tiger in the box and when to bring it out to fight his corner, something I've had to do as we discovered it was not just down syndrome we were dealing with.

By the age of 3, he started to walk, albeit it a bit wonky to say the least. He struggled with crawling, walking seemed to pain him and he was by then a big boy for his age, tall and stocky. He was falling over a lot, something my mother and I would argue and argue with the "professionals" about for 2 years. Our voices fell on deaf ears.

After inviting local children with down syndrome to his 6th birthday party, I realised I was not over-reacting.

Although all the children had different characteristics, they were riding bikes and scooters, something Charles has never been able to do, even to this day. The next day I asked for an MRI of his brain. A video assessment was then made of him. I was told that my 6 year old son had a form of cerebral palsy, a hemiplegia. I was told he had either had a starvation of oxygen at birth or a stroke during birth. Nobody has ever been able to confirm this one way or another.

I'll be honest at this stage, I collapsed with exhaustion as the realisation that he was now going to be considered severely disabled was very upsetting. I then found a wonderful place called Brainwave, a charity who help children up to the age of 12 with brain disorders and also Down's syndrome. The 2 days we spent with them in assessment were what saved us as a family. They put him on a 20 minute per day programme of exercises designed to tap into his sensory needs. They alerted me to the sensory integration issues he had, which they classed as being pretty severe. To this day I tell the staff there, who helped us that if it hadn't been for them, I would have been forced into fostering my child as the stress the behaviours were placing on us as a family were too much for us to cope with.

I then asked for a complete assessment for him, to find a solution to his educational needs. This included a full assessment for autism, not as easy as it sounds because again the "professionals" deemed him too "sociable" to be on the spectrum. Quite what that means is beyond me as I often wonder is it sociable to smear things, to steal off others plates, to scream and throw yourself on the floor, to refuse to move for hours morning and night... the list goes on and on.

The results of the assessment did not surprise me. I felt weirdly only a sense of relief when I was told he was on the autistic spectrum. It would explain the behaviours, the constant sensory seeking activities he would engage in from smearing everything in sight, to flapping his toy monkey, to flapping the telephone backwards and forwards, to refusing to have his nails cut, his hair cut, his constant need to control everything and everyone in the house. It also explained to me why I felt powerless with my own child.

By this stage, I felt that Charles's life was falling apart and as a family we were at breaking point. I spent the next year videoing his worsening and challenging behaviour as part of the

a child with dual diagnosis

next move I was to make with his education. His infant school head was an amazing woman to us as a family and to Charles in the three and a half years he spent in mainstream school. The children were also wonderful as were the other parents. The Head was often called in to coax him out from under tables at school, he would refuse to leave the taxi in the mornings to go into school and it would take 3 LSA's, all amazing people, as well as the head on occasions to encourage him into school. He started pulling children's ears so hard, they bled. He would lie on the floor at home refusing to get into the taxi, all the while I was videoing away, in the pouring rain he would lie on the floor of our driveway refusing to move. I was hoping that the behaviours I videoed would be black and white evidence that he needed specialist help.

The decision had to be made to send him to the junior school of his school or the local special school. The LA seemed to have his life mapped out but it just didn't fit in with who Charles was. I felt that what they were offering could not meet his needs. This was to form the basis of my argument with the LA, as I decided the only way to help my son was to fight for a 24/7 living learning environment, at an independent residential school. I was warned that I would not win and that places were not given to children his age. I shelved that thought, given that these same "professionals" denied he had any further life long disabilities to me for years. Never before has that tiger had to come out of the box in such a ferocious manner.

A 2 year preparation battle then

commenced, gaining momentum each week.

Two years passed and 6 weeks pregnant with my twins, I found myself having to fight like I've never done before for my child through a gruelling 2 day tribunal. Initially my first choice of school was rejected but the panel agreed he needed the 24/7 lifestyle that only a residential school could provide.

The day I found out we had won the case I was admitted to hospital, pregnant with twins, and very nearly died after being diagnosed with severe pneumonia. Fortunately I fought through this (the babies are 13 months now so all was well in the end). I was given 2 months to find an alternative school. I trawled up and down the country, looking at schools, none were suitable. Miraculously the LA came up trumps for us. They knew I was keen on the Steiner principles and philosophy and they offered us The Sheiling school, Ringwood. We all visited the school and I was blown away by the therapeutic ways of the school, 6 children in a class and a real home from home environment. I was delighted when they wrote the school's name into Part 4 of his statement.

The holistic setting, the 50 acres of grounds, the methods of teaching, the camping trips, the learning in a real environment and the freedom to learn self help skills and sociable skills have all started to come together for Charles.

He has been at the school for over a year now, coming home at half term and holidays. He loves the school, has proper friends for the first time

in his life and is engaging properly with both adults and children. His mischievous character and his amazing sense of humour has not been lost and he literally falls over himself (in the best way possible) to get into the car to go back to school. His speech has improved, he can cook some basic dishes with help, his swimming is first class, his horse riding skills have improved. One of his tasks this term in house is to lay the table and dry up – he makes an amazing helper in the kitchen now at home and anytime there's vacuuming or gardening to be done, he's first in the line asking to help. All that and he's just 9 years old.

I know that our battle isn't over, we are just in a period where we don't have to fight the LA, where we can sit back and let someone else take charge. He's still a very important part of our family unit and always will be. I know there will be battles ahead, that's the nature of this journey we are on. For now though thankfully the tiger is resting easily in his box.

