

# Alfie's home

## education programme

*I wasn't sure where to start this but I think I will start right at the beginning so as to give readers a full picture of who my little man is.*



Alfie was born on 29th April 2005. He was born with Down's syndrome which I had prepared myself for as it was suspected during my pregnancy. I was much more worried about the fact that he had been diagnosed with a large AVSD heart defect when I was 20 weeks pregnant and I knew that he would definitely need open heart surgery in the first few months of his life. Those first months until he had his very successful surgery in Guys Hospital were fraught with worry, hospitals, medications, scans and the terrifying thought that he may not make it. I love him so much and he was very much wanted by me, although sadly his father didn't hang around to support me through this difficult time.

Thankfully Alfie is a fighter and he was back home just 6 days after his surgery. After that it was all about physio, as he has exceptionally low muscle tone and super flexible joints, as well as attending our local child development centre here in Brighton. Alfie responded well in a class of four children with Down's syndrome and everyone commented on how alert he was and what good eye contact he had. He enjoyed social situations and was generally a laid back kind of guy who charmed everyone who met him.

No one had any concerns about his development at that point because he had such a shakey start to his life, he was expected to be a bit behind the other children in his class who had no significant health problems. Because of his low muscle tone he wasn't expected to be able to pick up signing like the other children but had just started to begin to hold his thumb in an attempt to sign his name during singing time and this felt like such an achievement for him.

At around 17 months old things started to change, Alfie started to become unhappy in group situations and this was put down to possible hearing problems or just general ill health due to colds. He seemed to lose interest in communicating with me in any form and his eye contact became poor. In fact it became clear that full eye contact with people was uncomfortable to him. He began picking up small soft toys and twirling them by their labels and seemed engrossed in this repetitive activity. Alfie was so unhappy in his classes and support groups that his Speech and Language Teacher, Sue Crane, suggested that he might benefit from being removed from these groups while she did some one to one sessions with him.

The phrase "social communication difficulties" began to be used and after some research on the internet I realised that Alfie may have autism. I was so scared as I didn't know anything about autism and I was afraid of losing my beautiful boy with Down's syndrome who was so precious, to this unknown condition. I became depressed and eventually ended up at a support group for parents of children with various special needs called Sweetpeas where I met other parents of children with autism. At that time I felt I no longer belonged to the world of Down's syndrome and felt I fitted in much better in a group like this. Meeting these parents and children helped me to understand what autism is and how it would affect Alfie and prepared me for his eventual official diagnosis of autism in conjunction with Down's syndrome, which happened just after his 2nd birthday.





It was clear by then that Alfie's learning style was very different to a child with downs syndrome alone. He does not copy or imitate, he found it difficult to be around anyone other than myself and seemed to see any sort of playing as hard work. Even Sue Crane our S&LT who is one of the most experienced and capable professionals I have come into contact with, was finding it almost impossible to get Alfie to engage in anything other than twirling soft toys.

However, at home I was having some success with the help of our portage service at getting him to engage with me when I sang a song, using makaton signs and built that into a game. It became clear that the only place he was learning was in his own home environment and that he needed daily, small step, repetitive sessions. Obviously, this was quite hard on me, I was already nurse, ot, physio, speech & language teacher to Alfie and yearned for some time to just be his mummy.

Through talking to the parents at Sweetpeas about how they had helped their children with autism to grow and develop despite their unique learning styles, I found out about ABA Therapy (Applied Behavioural Analysis) and I became very focused that this was what Alfie needed. I managed to get all the professionals involved to write letters to our Local Education Authority stating that Alfie was unable to access a nursery environment due to his sensitivity of noise and sensory processing difficulties and that he was finding it hard to engage with adults outside of his home environment. We built a very good case together and to be honest everyone thought it was a done deal that the LEA would help me to fund an ABA programme in order to help him develop with the view to getting him ready for special needs nursery.

Well, the LEA turned us down flat and said that they would only fund 1:1 support in a mainstream nursery for 12 hours



per week. I was devastated, I knew that this was not the right support for Alfie and that he would not learn anything in that environment whether he had 1:1 support or not.

Unfortunately at that point, funds were tight in the LEA and there was a distinct backlash against ABA programmes mainly because of the cost of the therapists and supervisors but also because these programmes were seen to be quite rigid and therefore not suitable for all children with autism, especially if they have a dual diagnosis.

This was such a blow but I picked myself up, regrouped and started to think about how I could change the LEA's mind. It all seemed very political at the time because although all the professionals were supporting me in my quest for home education for Alfie, they were only allowed to express their support for some type of home education programme but were not allowed to show direct support for an ABA programme as it was a conflict of interests. At the end of the day these professionals were all tied into the LEA and I could not expect them to put their jobs at risk even though some of them supported me passionately.

I then requested that instead of the 12 hours funding (at £6 per hour, ABA therapists charge between £12-£20 depending on their experience and supervision costs a lot more) being in a nursery environment, that those hours be used for supporting Alfie at home. I had two ABA trained therapists lined up but I knew that I could not pay them £6 per hour when they actually charge £15 so I asked them if they would initially work for £10 per hour with myself making up the difference from Alfie's DLA money. The LEA conceded that this was a good compromise and thankfully the therapists agreed to work for less money as it was hoped that once we had proved to the LEA that this programme was making a significant difference to Alfie's quality of life that they would increase the funding and we would be creating a totally new programme that was individually tailored to Alfie's unique learning style but that could also be adapted to other children with significant learning difficulties. To be honest, looking back, I am glad that this is the route we took rather than a straight ABA programme. An ABA programme is run by an ABA provider

and therefore strict guidelines are adhered to, this way the programme evolved around Alfie and I am pleased to say he has made great strides in his progress.

I managed to get the Head of our Autistic Services and our wonderful Speech and Language Teacher (who was the main supervisor) to come to our home once every two months to help the therapists set targets for Alfie and talk through activities that he was finding difficult. One of the therapists was very experienced and she has been amazing with Alfie.

Because he is now being treated as an autistic child who has Down's syndrome, rather than the other way round, he is responding to certain activities and has developed into a much more sociable little chap because these things have been encouraged at his own pace and in his own style. By the time he was ready to go to special needs nursery, he was holding his own bottle to have a drink, walking, looking at books, smiling reciprocally at adults (not so sociable with other children as yet) as well as joining in hand actions for wheels on the bus. All things I really thought I would never see.

He has now successfully made the transition to Special School in their autistic unit and is developing into a confident, independent minded, charming little boy who is able to interact with adults and tolerates them helping him to learn activities which he has an interest in. Above all he is my little Alfie and he is happy! **By Suzanne Knight**

