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## **Clearing the path to school**

*“If you're walking down the right path and you're willing to keep walking, eventually you'll make progress.” – Barack Obama*

As the early years passed we started to think more about school. In our society education is a fundamental right of passage. Most children start school at four or five, progress through to senior school, then at 16 either continue, enter college or start work. Nearly 50% go on to some form of further education. The path is very well worn and very well known.

In contrast, our path didn't look well worn and clear at all. In the distance we could see lots of children like Freddie happily going to their local schools and playing with other children their age, but between them and us was a baffling landscape. On the face of it, there seemed to be a few quite good routes, but along most of them, it seemed that there were teams of officials hastily planting brambles, creating diversions and building the sort of swamps you could get stuck in for a life time. There was a guide, but where it said there should have been clear paths, they were either non existent or choked with such well tended undergrowth that they were virtually impassable. We started daunted, but pressed on never the less.

For any child, there are decisions about what school to go to, but with Freddie the decision was complex. It seemed that before we even started looking at individual schools we had to choose what sort of education he would have. Thanks to changes in the Education Act and encouragement from members of the DSUK newsgroup, it seemed that we could ask to send him to the local school, send him to a specialist school where all the other children would have learning difficulties or disabilities of some sort; or we could choose to educate him at home. In short, mainstream school, special school or home schooling.

We dismissed the last option without really considering it. It may work for some people, but I knew I wouldn't have the patience or dedication to education him at home. As much as I love my children, I do like a break from them and needed some liberty. We also wanted his education to be far broader than simply learning the 3 Rs. We thought that a school with other children would help him learn how to get along with other people and to make friends and socialise.

We made the special school/mainstream school choice almost by accident. When he was about two years old, I was offered a place at a special needs nursery called the "Frome Opportunity Group". We lived about 25 miles from Frome and I didn't fancy the idea of a long journey there and back each time he went. Ironically, years later I discovered that the Frome Opportunity Group wasn't in Frome at all; it was in Yate, about a mile from our house.

There were no other special needs nurseries nearby, so he stayed at the nursery he'd started going to two days a week when he was a baby. The nursery worked very hard to include him, and at their expense, virtually assigned one of the play leaders to help him. She kept in touch with his portage worker and together they made sure that he fitted in well and was happy. The nursery children lived over a wide area and only a few of them would be going to the local school. We thought that it would be good if he could make some friends with more children who would be going to the school. The obvious solution was to enrol him in the playgroup.

This is where the problems started. There was a path for children like Freddie to go to mainstream school, but it was the one most obstructed by brambles, bogs and rabbit holes; Alice from Alice in Wonderland would feel quite at home. There was a superb map in the form of a government publication called the Special Educational Needs (SEN) Code of Practice. This guide told us exactly where the path was and how to get onto it. It was extremely good except for one major failing; none of the people responsible for looking after the path seemed to have read it.

The playgroup was very keen to have him. Understandably they wanted some advice as they'd never had a child still in nappies and who couldn't walk or talk in the group before. They thought that Freddie would probably need quite a lot of extra attention and didn't think they'd have enough staff to do it without help. They phoned the Local Education Authority.

The Education Authority phoned me up and asked if we'd like to send him to the Frome Opportunity Group! We declined again. If we'd resolved the misunderstanding that the group was in fact just around the corner, that's probably where he would have gone, and I wonder how different the rest of Freddie and our lives would have been. However I still mistakenly thought it was miles away and wasn't interested. Undaunted, they eagerly told us that they had three other nurseries in Bristol which were prepared to accept children with additional needs and that we could have a place at one of those instead. We explained that while we were sure the nurseries were lovely, what we wanted was for Freddie to go to playgroup with the children he knew locally, who he'd be growing up with and who he would be going on to school with. The LEA went very quiet. Had we looked at Warmley Park? That was an excellent special needs school. Again, we patiently explained that we were sure it was but that we wanted him to be in a school with his friends.

It became clear that going to a mainstream playgroup was a problem for them. I worried that maybe I was being unrealistic, so I went back to the DSUK newsgroup and asked other people what they'd done. The group seemed to be split between those who'd gone down the special school path and those who'd gone down the mainstream path and it seemed that the paths were very different. However, lots of people replied with encouraging messages to say that their children were in mainstream schools and playgroups, seemed to be getting on very happily and that we should be able to get support in playgroup. The children we could see in the distance happily going to their local schools playing with

friends weren't in our imagination, they were real. The DSUK people said that what we needed was a Statement of Special Educational Needs.

I'd never heard of a Statement before, but it was going to be a word that was going to pop up with tedious regularity and a system that was going to virtually take over our lives. Statements were introduced in the 1981 Education Act and are documents used to describe what extra help a child needs in school and how the help is going to be provided. By the time we were beginning to think seriously about formal education, Freddie was three years old and the UK was supposed to be operating under the 2001 Education Act. When the Act was passed, the Government went to the trouble of publishing a smart glossy document to go with it, called the SEN code of practice, to tell the authorities exactly what they were supposed to do.

It seemed that far from being pushed in the direction of a special school, Freddie now had all sorts of rights to go to a mainstream school, with lots of extra help; which was handy as that's exactly what we wanted to do. Unfortunately LEAs seem to operate in their own time frame. Where as I was used to working in an environment where decisions have to be made in hours, if not minutes, our LEA seemed to make decisions in months, if not years. I guess that all the beautiful new shiny documents produced by the Government had barely made their way into anyone's in tray, let alone been read.

We went back to the DSUK newsgroup again and were advised to go up a gear and get some professional advice. Someone suggested an organisation called the Independent Panel for Special Educational Advice (IPSEA). We telephoned their helpline and were given an advisor. It seemed that to get extra help, Freddie needed a Statement and that to get a Statement, we needed a Special Educational Needs Assessment.

We went back to the LEA – “We need a special educational needs assessment”. We were told that the playgroup would have to apply for one. Clever catch 22 number 1 – they couldn't apply for one, he wasn't there yet! We went back to our IPSEA advisor. No, he assured us, we could ask for one, and in his opinion it was much better if parents made the application then they became the main point of contact (rather than the school) and got to see all the documentation.

Back to the LEA again. This time we were told that there was no point in them carrying out an assessment as we were very unlikely to be granted a Statement as they were only carried out for children with complex difficulties. I was really pleased to hear that Freddie's needs weren't complex enough to need a Statement, obviously all the early intervention work we had done was paying off. I wrote to the DSUK news group to break the good news. The members had seen it all before and let me down gently. They pointed out that Freddie was three years old, had Downs Syndrome, couldn't talk, could barely walk, was doubly incontinent and obviously found it very difficult to learn new things. It was difficult to see how much more complex it could get. Without question he needed more help than children his age, and as such needed a Statement. In their opinion we'd met our first example of official avoidance tactics; authorities have a nasty habit of avoiding having to carry out their legal obligations to protect and help needy and vulnerable people by simply reclassifying them as not needy and vulnerable enough. Problem solved.

When I phoned my LEA education officer again, I was upset and felt that I'd been misled. I pointed out that a week before they'd been trying to put him in a special school and that

they couldn't have it both ways. It was like trying to cut through the brambles with a pair of nail scissors; I got nowhere. I went back to IPSEA who told us to send a complaint to the Director of Education. I was very thankful that I had worked at a senior level and was not in the least intimidated by the thought of writing to a Director. The letter worked and a week later the application form for an Assessment of Special Educational Needs appeared.

Freddie was duly assessed and a further expert joined the ever expanding "Freddie support team". He was an Educational Psychologist who concluded that, yes, he had Downs Syndrome and was going to need lots of help – in fairness, he actually wrote an excellent report which was to prove very useful. The LEA to our surprise finally agreed that all the bureaucratic demands had been satisfied and they would issue a Statement of Special Educational needs.

Reports were requested from the psychologist, speech therapist, portage worker, paediatrician, nursery, pre-school, social worker and ourselves. The report from the social worker always interested me as I don't recall ever meeting her. We went back to DSUK again to ask if anyone had a good format for the report we'd need to write – they did.

All the paperwork was issued and digested by the LEA machine, which spat out a Proposed Statement which bore no resemblance what so ever to the reports that had gone in and seemingly tried to massage Freddie into the systems and resources they already had in place. We were not impressed; nor were IPSEA. We asked for a meeting to appeal the Statement and headed into one of the most bizarre meetings I've ever been to. Richard works as a Solicitor and as such is a bit of an expert in gamesmanship, but even he was completely outclassed. We went into the meeting on a very warm day and were shown to a tiny little room with a radiator running full blast. The room was completely bare with tables and chairs crammed in, there wasn't room to pick a cat up, let alone swing it. There was no water or any other refreshments. It looked exactly like an interrogation room in a B movie, all it needed was a bare light bulb. Come to think of it, I think there was a bare light bulb. Fortunately Richard recognised the situation for what it was; very intimidating and not in the least bit conducive to working in partnership. He took charge, insisted we moved rooms, counter gamesman-shipped all the seating arrangements, organised some water and took over the meeting. The LEA contingent quietly sat looking rather dejected. It quickly became clear there was no room for negotiating as no one in the room had authority to make any decisions and the meeting was a complete waste of time. It was just a tick in a box. You can just imagine the LEA procedure. "Have you given the parents an opportunity to question the statement"? Answer "Yes". Tick.

Clever catch 22 number 2. You can't appeal a Statement until you've got one. We had already spent nine months getting the Statement to this point and I was concerned that it was all taking so long that he'd have left playgroup before we had it finished. In order to take the appeal to the next stage, we had to ask the LEA to finalise their Proposed Statement, warts and all. This was psychologically very difficult to do and I can imagine hundreds of Statements and children up and down the land, languishing in limbo for years while parents sensibly refuse to agree a rubbish Statement not realising that while they do so, the LEA can happily sit and do nothing. We took a leap of faith, asked the LEA to finalise the Statement and applied for a Special Educational Needs and Disability Tribunal (SENDiST) to put what we saw as it's failings to an independent panel.

The good thing about finalising the Statement was that from that point the LEA had to provide some support in playgroup. Not as much as we thought he needed, but enough so that he could go. He loved playgroup. Even though he wasn't really walking, he crawled around happily and no one fell over him. Even though he was still in nappies, the playgroup staff coped fine and he wasn't bothered at all. He quickly learnt the routines and sat happily to listen to stories and we all noticed that he closely followed what the other children were doing. Without support, he tended to sit back and just watch what the other children were doing. He found everything a bit more difficult and was happy to just sit and observe.

Surprise, surprise, once we had made the official appeal and legal proceedings were looming, the LEA suddenly agreed to a number of changes and we managed to get most of the important bits of the document re-written with specific details about what they were going to provide. We were left with two sticking points, providing support in both his pre-school and nursery and most importantly, a commitment to the number of hours of support he was going to get. In our LEA, there was a practice of leaving the Statement as vague as possible. The LEA claimed that this was so that they could be flexible and responsive in providing what the children needed, but friends with children further into the school system told us that in practice, it simply provided them with an excuse to provide as little as they could possibly get away with. Everyone told us that it was vitally important to quantify exactly how many hours of support he was going to get.

I spent weeks putting together our arguments and all the evidence – the people who would hear our case didn't know Freddie and would need evidence that he needed what we claimed, so everything we were asking for had to be backed up by independent reports. IPSEA told us what paper work we needed to prepare, I then put it all together and emailed everything to them for their comments, and then we forwarded the whole lot to the Tribunal.

The Tribunal hearing was in Bristol on 2<sup>nd</sup> May. Over a year had passed since we first started trying to get Freddie a Statement, life had moved on and I was 8 months pregnant! I waddled my way into the room and we were surprised to see that the LEA hadn't brought any legal representation. It was apparent that rather than defending their position, they were simply using the Tribunal as a way to get someone else to make decisions for them. The hearing was relatively quick and we rapidly agreed the things that had been obvious all along; that Freddie needed a substantial amount of support, 8 hours out of 10, leaving two hours when the rest of the class would be doing normal play activities which he was quite capable of doing without too much close supervision. We were happy with that as we felt at the time that too much supervision was going to stifle him. With hindsight, we should be gone for full time cover as you could guarantee that the time he'd have a toileting accident or get in a muddle would be just after his support had gone home, but you live and learn and at the time we were very happy with the outcome.

The question over two nurseries was more tricky and complicated by the fact that one of them was in another LEA. We hadn't realised that the time, but LEAs are very parochial – even the head of the Tribunal started to use the phrase “check point Freddie” to describe the point at which he left one LEA area and entered the other and magically ceased to have any learning difficulties. Like most parents we didn't have a clue which Education Authority we lived in until it came to school applications, and it all seemed very silly, but seemed legally to be very important, even if no one really knew why. After much deliberation the Tribunal said they didn't know and they'd get back to us.

A few weeks later and a year and three months after we started, we got the final report. We'd got the increased hours of support and the LEA had been instructed to specify the hours of support he needed and put a figure on all the support he'd need. However, the Tribunal had concluded that they still didn't know whether he should be supported at both nursery and playgroup and concluded that as it was now June it was too late to make any difference anyway so they officially sat on the fence. He only had four weeks of term left before he was going to leave playgroup and start school. I wonder how many people die of old age while waiting to resolve these sort of disputes and whether in fact, the system is deliberately designed to be long winded for just that reason?

As soon as the Tribunal's decisions had been incorporated into the Statement we had to write to ask the LEA to change the number of hours to reflect the fact that he was going to move up to the Infant school and would have increased hours, and after all that effort, get them to change the name of the school in his Statement. Needless to say, they even managed to get that wrong and the document sent back had managed to lose all the changes insisted on by the Tribunal. We were beginning to lose the will to live and I can honestly say I'd never had to deal with such hopeless administration before in my life. This document was supposed to be a critical foundation for Freddie's future years in Education, but I am sure the LEA only ever saw it as a box to be ticked and issued with the bare minimum amount of effort and cost. Despite the years of thinking and planning by some very clever, very experienced senior people in central government, to them it was just something that got in the way of letting them do what they wanted to do.

In the middle of all this our third son was born. He must have realised that things were a bit tricky as he managed to be conveniently early, appeared at the weekend and with as little fuss as possible. I mentioned after breakfast that I thought he was on his way, so we took George and Freddie next door as arranged, then went to the hospital. An hour later Richard was back. "Oh" said the neighbour "don't worry, I'll look after them for as long as you need". "That's OK" said Richard, "I've come to get them to take them down to the hospital to meet their new brother". We were home a day later and I only stayed overnight so I could get a good night's sleep.

Juggling Statement re-writes and a new baby, we were left with virtually no time to do any preparation for his transfer into school, but luckily both the infant school and preschool fell over backwards to help us and arranged for him to visit his new school and for his teacher to see him at the playgroup. He had a lovely morning visiting the school. They took lots of photos of the classroom, teachers, dinner ladies and Headmaster and put them all in a little red book for him to take home so we could look at it together over the holidays. His class teacher was a very experienced teacher and although she hadn't had a child with his level of need before, she was very enthusiastic and keen to have him in the class. I already knew her as she had taught Freddie's brother George a few years before and she knew Freddie from the times we'd been in to school to drop off and pick up George. I remember having a meeting with her when she asked all about Freddie and where she could find out more about teaching children with Downs Syndrome and if I had any books she could read. I passed lots of things on to her and at a later meeting she told me about how she thought she was going to include him in the class and what she planned to do. She then said "of course that's only the plan, all plans fall at the first hurdle, then we'll think up a new plan"! Needless to say, his first year at school was an outstanding success.

We'd finally hacked our way to the far side of the brambles and Freddie was about to join the children happily playing with their school mates. The source of all the fuss, the Statement was safely tucked away in an envelope. After all the obstructions that we'd negotiated, battles we'd fought and problems we'd faced the Statement was a bit of an anticlimax. After all that, it's only 4 pages long! But it's unquestionably been the most valuable 4 pieces of paper I've ever owned.

