

Starting School

A Parent's Perspective

Joseph was our first son and he was born with his hand missing, a fixed elbow and shortened forearm. It was a big shock to my husband Stuart and me when he was born, and whilst Stuart came to terms with it very quickly, I did not. I continually worried about everything. At six months I worried about him getting married, then I worried about him riding a bike, driving a car, playing sports, but most of all, I worried about him growing older and attending school.

Joseph started nursery at the age of three and I chose his nursery by my first impressions. I casually brought up the fact that Joseph was born without a hand and left it at that, to gauge their response. The nursery I chose was the one that explained that Joseph's hand was not a problem and that they would love to meet him. I never returned to the nurseries that suggested we needed to sit down and discuss Joseph's arm and requirements before they had even met him.

My husband works for a bank and came home one day saying that he had been offered a post in Dorset. Joseph was four that month. I was devastated. How could I start all over again explaining Joseph's arm to new people, starting new nurseries and a new pre-school? I also had a one-year-old - Dan - at the time.

Well, we moved and Joseph started a new nursery and a new pre-school. Why was I worrying? I only had to explain to the children once about Joseph's arm and they accepted it. I worried about them singing and dancing in circles, holding hands. Why was I worrying again? The children did not seem to have a problem with him.

Pre-school and nursery came to an end and school was about to begin. I had no worries about him starting school (although I had always anticipated that I would) and his new reception teacher also seemed to think he would have no problems. Everything was fine until Stuart came home, once again, and said that he had been offered another promotion in Devon. Again I was distraught and by now we had our third son, Jacob who was only three months old.

I could not believe that we would have to move again to another county and Joseph would have to start yet another school. Even though it was the right move for us, the timing seemed awful. Stuart went down to the village school where we were intending to move and explained to Joseph's new reception teacher, Mrs Bond, that we were moving to the village and that Joseph had only one hand. She was amazing! She was so energetic about helping him and making him feel welcome in the school. She did not think that his arm was going to stop him from doing things. We had a lot of faith in her. Just talking to her made us realise that this was the school that we wanted Joseph to attend. We haven't looked back.

Joseph did go through a time when he continually asked us why he had been born with one hand, saying that he wanted to have two hands like his brothers. He used to tell us that he wanted to sellotape his counting arm (his cosmetic arm) to him so that he would look the same, and we found this really difficult to deal with. After talking with a paediatric counsellor, and with Sue Stokes, we realised this was normal and that he was probably

finding his feet and was upset to have left all his friends behind in Dorset. Joseph is six now and is doing well at school. He goes to Beavers, plays football on a Saturday and rides his bike wonderfully without stabilisers.

Sometimes things come up that he has a problem with, but it is very rare. When it came to counting on fingers, he used his cosmetic arm and called it his 'counting arm'. When it was said that he was slow changing his clothes, we practised it at home. When he had difficulties with paper cutting, again, we practised at home. I think you just have to be one step ahead all the time, which is hard sometimes.

Joseph hasn't really had a problem with name-calling or bullying. If someone asks him why he hasn't got a hand, he usually tells them he was born like it and that was how he was in his Mummy's tummy, and if

he feels mischievous he tells them that a shark ate it!

There was only one occasion when we had a problem with another child, and that was after Joseph had been in the school for quite a while. One of the new children would not go anywhere near Joseph without screaming and telling Joseph to go away. It really upset Stuart and I because for the first time ever we felt it was out of our control. The staff at the school were deeply saddened at the episodes as this had never happened before at their school. After a while it was sorted out with the help of the child's parents, and not long afterwards Joseph was invited to this boy's birthday party. What seemed upsetting at the time turned out to be a mere hiccup. Why did I worry so much?

One of my favourite songs has the words 'life is a rollercoaster, you just gotta ride it'. There are ups and downs, even if only a few, there's no going back. We have to go forward – and that's what the Brooks family is doing. Two years on, when I began to write this, it was surprisingly difficult to remember the feelings we went through. This was due in the main to the predominantly positive experiences we have had. Anyway, here are just a few learning points we'd like to share:

- First and foremost, try not to get too concerned about other children's reactions. In hindsight, we shouldn't have.
- Agree the 'ground rules' for raising issues before your child enters the school.



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- On the rare occasion that a problem occurs, deal with it promptly and directly with the teacher.
- Remember there is now increased and shared support/responsibility to deal with any issues – it's not just down to you again!
- Always get the teacher to seek your child's opinion first – just like **you** would usually do.
- Some other practical steps to consider:- Let the teacher know if your child needs any extra support, equally, make it clear that they should not *assume* extra support is necessary.
- Make sure the teacher knows how to refer to your child's limb and prosthesis.
- Don't be afraid to be inquisitive about their progress in gym.
- Potential adverse reactions tended to be more frequent in the summer because of lighter school-wear/swimwear, so be ready for this.
- In summary, our experiences early on were somewhat mixed, but as time went on, things settled down. The key factor was our relationship with Joseph's teacher, which grew into a positive and supportive partnership.

Our confident and fun-loving (yet frustratingly talkative) little Joseph is a result of this partnership, where his natural personality has been allowed to come through. SIÂN BROOKS

A Teacher's Perspective

Joseph transferred to our school in his Reception year, and had therefore already started school once before. The first time he had gone to school alongside all his friends from playgroup. Now, he and his family were moving house to a new area where he was unknown.

Joseph's parents told us about his limb deficiency on their first contact to enroll him at school. Joseph's father Stuart then came to school and spoke at length with me and my classroom assistant. This was an important meeting, where Dad could tell us not only about Joseph's limb, but also share with us such things as his favourite toys, his character traits, and some family background information. At this meeting we also talked about the things that Joseph could do easily for himself, and those he may need support with, what he called his limb and his prosthetic arm, when he used this, where we should keep it, how best I should prepare the other children in my class etc. Dad left me the Reach video, which I circulated among all the staff, as I felt it was important for all of us to know the information, not just those adults who would be working directly with Joseph. I also wrote a memo sheet for all staff, so that we all had the same information and would be using the same terminology.

We talk a lot at school about everyone being different, all being individual and all being special. Previously, I had taught a child with two prosthetic legs, and there had never been a problem for other children to accept her. So it was easy in one of our circle time sessions to talk about the new little boy who would be joining our class. I told them about my special grandmother who had no little fingers, and about all the clever things she could do, like knitting and sewing. We talked about Esther who had 'special' legs. Amazingly, one child then told us about his grandfather who had only one arm. I had not know this previously. This obviously led easily into our talking about Joseph. At another session, I

read a story called *I'm Special*, which included children with many different disabilities and a teacher with one arm. Mum also lent me the Reach story book, *Ben's Spider*.

When Joseph visited school for the first time, the children were looking forward to seeing him just as they would any other new child. They chatted and played with him and immediately accepted him for who he was. I had never experienced any other reaction and had no reason to expect anything different. When Joseph started school properly, he was pleased to show all the children his special arms, and they would often find his prosthetic arm for him if he needed it. It was, just as his father had told me, as common a thing in the classroom as the toys and was often left among them or in the dressing-up clothes.

After Joseph had been with me a few weeks, I became aware of some things that I felt he needed support with. Joseph found using scissors difficult, not because he couldn't use the scissors, but because he needed to be able to keep the paper taut. He did not find the prosthetic arm helpful for this. It had not presented itself as a specific need at home, probably because Joseph had not been working alongside children cutting at a much faster rate than he was. This did not worry Joseph, but I wanted to give him equal access to the curriculum, and felt he was entitled to support with this. So, we experimented with ideas such as blu-tacking the sheet to the table in places and holding the sheet in a page-up computer holder. I bought different types of scissors: easy-glide, one-handed, battery operated, and a cutting blade and mat. Joseph was keen to experiment and so were all the other children. They often used his scissors too. They became an alternative class tool for all.

As time went on and Joseph began to write more, I also felt he found this a tiresome task. An angled writing board with a non-slip surface proved to be the answer. This kept the paper still, and Joseph's writing and colouring improved immediately. Again, other children used it, and liked it, and I invested in several non-slip mats for anyone to use.

Joseph could access most of the curriculum as easily as any other child. It was however always important to be sensitive to his needs, and there were a few areas where it was essential that I thought ahead carefully. One of these was in country dancing, where children usually need to hold hands, and where Joseph participated well, when positioned carefully on the 'right' side of his partner. Another was in PE when the children were about to begin early tennis skills, and needed to throw a ball up with one hand before hitting it with a bat in the other hand. We would always plan ahead the way we expected Joseph to do it, and he often experimented with different ways himself, and increasingly became able to decide the best way for himself.

Joseph really enriched the experiences and awareness of the other children in the class. His Mum suggested we invite Frank Letch into a whole-school assembly, and this was a wonderful experience for us all. We chose Reach as one of our charities to support that term and it was a proud moment for us when Joseph presented Frank with the cheque, which just about covered the cost of a one-handed Reach recorder.

Because things had gone so smoothly when Joseph joined the school, I suppose I was shocked when a child who started school

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a few terms later reacted strongly when he saw Joseph. Unfortunately he screamed when he saw Joseph's little arm. I needed to do a lot of work, talking with the child and his parents to redress this. I feel sure this was an unusual reaction, but feel I should mention it, to warn others to be prepared for it. I had thought a lot about preparing the children in my class before Joseph joined us, but obviously had not thought enough about preparing each new set of children as they entered in subsequent terms.

It was important to talk with Joseph's parents throughout. Joseph's Mum was a great support not only in helping Joseph to practise some of the little physical tasks he found difficult to do, but also in giving me access to support via the telephone from members of Reach, particularly Frank Letch, if ever I had a concern.

One thing that could have been made easier for me, and therefore for Joseph, was access to information relating to educational aids available. I had to do my own research on scissors, angled writing boards etc. Even the Education Show did not have immediate answers for names of suppliers. Maybe this is an area Reach could consider. It would have been great for Joseph to arrive in school accompanied by a list of resources and suppliers that may be of benefit to him.

Joseph moved on from my class after one year, and is thriving well as he moves up the school. When watching Joseph with all the other children, playing football, painting, folding paper and cooking, it is difficult to believe that he is any different from them. His successes are mostly due to his sheer determination, something I feel sure being a member of Reach has inspired.

CAROLE BOND

The Reach Guide to Starting School

The following information stems from a meeting of Reach parents and other members at the Annual General Meeting in 2003. The views came from parents and limb-deficient people between the ages of 16 and 60 (well, 59 to be precise). The thing to stress is that there is no one solution or approach because we as individuals vary so much. We offer a reasoned variety of approaches and hope that you will find this of help.

The Early Years

As soon as your child is born you should have a small network of support around you. This will include your GP, your Health Visitor and an Occupational Therapist linked to your local Limb Centre (and other Reach members if you need them). It is important to familiarise yourself with the education system as soon as possible. Find out about pre-school facilities and enroll your child well in advance to avoid disappointment, as places can be very limited, especially if you require specific days or times to accommodate work commitments. Visit as many pre-school settings as you can and talk to the staff so that you can get a feel for the place. Ask about their attitude/approach toward children with disabilities; you may not think of your own child as disabled but their responses to these questions can be very telling. Look for people who will be sensitive but positive, and avoid those who seem either patronising or dismissive of your child's limb deficiency.

Go along to the playgroup/nursery with your OT if possible and discuss with the staff what needs your child has. Most OTs attached to a Limb Centre are willing to visit your child's pre-school or school. Early years education focuses on improving manual skills such as pencil control and fine motor skills, as well as things like attaining independence in dressing, toileting and eating. This is one of the key times where advice from a specialist OT can impact positively on your child's development by showing the adults caring for your child how best to encourage and support with special techniques or equipment. Your pre-school is unlikely to have had previous experience of children with upper limb deficiencies, so your input and that of your OT is going to be very important.

Take your child along to the group before they start so that they



are aware of their fellow playmates and so that the other children have a chance to look at them. Unlike a group of older children, very young children may not notice your child's limb deficiency straight away, it may take a while for some children to realise that your child is 'different' and their reactions can range from total indifference to grabbing hold to get a good look, and even, rarely, fear and revulsion.

Primary School

If your child's nursery or pre-school is a feeder to your own local primary school then your child will have the advantage of going up to their new school with a few familiar friends. While this is helpful, if it is not possible try not to place too much importance on this because your child will probably come home on the very first day with a new friend. Again, it is difficult to generalise here because some children feel much more nervous than others when trying to join in with children they don't know. Your child's key worker at their pre-school setting should be able to advise you because they will have seen how your child has reacted in the past when you are not with them.

Remember that you have the right to request an assessment for a Statement of Special Educational Needs for your child (which may help secure admission to the school of your choice). This should be done well in advance of starting school as it takes around 26 weeks to complete; some pre-schools will be able to help you get this under way. You should contact your local

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Education Department and they will arrange for an assessment.

Contact A Family (telephone **0808 808 3555**) have an excellent guide, *Education and Disability – A Parents' Guide to Rights from Nursery to University*, which includes detailed advice on seeking an assessment for a child with disabilities.

If your child receives a Statement saying that s/he needs support then a Learning Support Assistant will be assigned to him/her for a part or all of the day. There is no stigma attached to having a LSA as most primary schools have several. The schools welcome them as not only does your child's Statement bring with it additional funding, but also the LSA will facilitate the learning of your child and is another useful resource in the classroom.

Preparation

This proved to be a 'walking on eggshells' topic. When asked whether the pupils of the school should be told that they were going to have in their midst a pupil with a missing limb or not, most thought that explaining to the pupils in appropriate language was a good idea, but others thought that this might be unnecessarily attracting attention. Before you decide which approach to take, have a talk to your child's future class teacher and remember that you know your child better than anyone else. Remember that you can always let the staff look at or use the Reach video. The teacher could talk about various disabilities and maybe challenge the class to open a bag of crisps with one hand. Your child is bound to be asked about their limb deficiency, so prepare them by teaching them a simple explanation. Most children find 'that's how I was born' quite easy to say, but you may have to think of something else. Staff will also need to know what your child calls their deficient limb (their 'small arm', 'stump' or as one member declared: 'George') and prosthesis.

It is important that your child is not hidden away or made to seem different; it can be useful if they win a prize or awards and have to go up on stage but the staff must be aware how your child will take hold of the award etc, so that there will not be an awkward moment on stage.

Parents must take the lead in telling the staff what their child can reasonably be expected to do so that your child cannot use their limb deficiency to 'skive off' unpopular pursuits. This is particularly true of PE where your child may not complete a challenging task simply because they just don't want to, they lack the motivation and won't be alone in that. You might suggest that they could help or support others with activities they find difficult; co-operation is a wonderful team builder.

You might suggest that the school has a disability awareness assembly and you might even offer to take part and explain about the work of Reach. If you don't feel up to doing this yourself there may well be a Reach member in your area who is willing to help.

One Jump Ahead

It is a good idea to find out what future challenges the curriculum holds. These days all teachers plan their lessons in great detail and well in advance, so should be able to discuss this with you if you arrange to meet. Remember that your child's teacher is unlikely to have taught a child with a limb deficiency before and may not recognise a potential problem until it is highlighted by you. Discuss in detail with the staff what lies ahead in the weeks, months or terms to come so that your child, their teacher and learning support staff can work out a plan of attack if necessary. This will be more important in secondary school with such subjects as science, craft, sports and technology. Here again, there may well be a Reach member who has been there before you and is willing to advise. Look on the Reach web site bulletin board or contact Sue Stokes if you come up against something difficult. Devising ad hoc solutions as you go along can be nerve-racking so try and stay at least one jump ahead.

FRANK LETCH & LIZ BLEACH

If you would like to comment, or have advice to share with Reach members in future Reach Guides, please contact the editor.