

# Adam (Y2) 'He belongs in our school'

## One school's determination

### 1. Introduction

Adam lives approximately 150 yards from his local mainstream school where he started with his friends in the nursery aged 3 years. At the end of that year Adam went abroad with his parents and older sister for a family holiday. During the holiday he had an accident that resulted in a high spinal chord injury.



Adam was immediately admitted to hospital. When he came home he was taken into a specialist hospital for people with spinal chord injuries. During this time he was visited by school staff and friends from school and their parents.

Adam was in hospital for 16 months and missed all of his reception year. When it was time for his discharge medical staff / doctors said that he would have to go to a special school as he was paralysed from the neck down and needed ventilating to support his breathing. Initially he needed 24 hour health care both at school and at home.

Although Adam's educational needs in terms of accessing a mainstream curriculum had not changed Adam's parents were offered a special school place for Adam by the LEA due to his medical needs.

### 2. Adam's choice

Initially medical people at the hospital told Adam's parents that he would need to go to a special school in order to have his medical needs met.

Choice of school was not an easy decision for parents and they consulted Adam and the head teacher of Adam's mainstream school. They were not sure how Adam would feel if he chose to return to mainstream, being different from his friends and they were not sure whether the school would feel able to meet Adam's needs.

Adam was clear that he wanted to return to his school and to be back with his friends. The head teacher, Mr. T said that they would do their best. They had already had the school wheelchair assessed with the Occupational Therapy Service and he said that Adam could have a place in school until the end of year 6 if that was what he wanted.

Just as Adam's parents had not faced this situation before, neither had school staff. As soon as it was agreed that Adam should return the head teacher began to make preparations. Parents say that this really made a difference to them. Education is the only area where they felt that they didn't have to fight. The school wanted Adam back and the staff went out of their way to prepare.

### **3. School's preparation for Adam's return.**

As soon as it was decided that Adam would return to his mainstream school staff, pupils and their parents were very clear that this was not only what Adam wanted, but it was also what they wanted. When visiting Adam in hospital they regularly asked the question, "When are you coming back?" This made a significant difference to how Adam and his parents felt about the return, knowing that staff, pupils and parents wanted Adam to return and wanted to support in any way they could.

I will describe here the preparation school and the LEA made for Adam's return. Medical support will be described in a later section.

It cannot be understated that one of the most significant preparations was to let Adam and his parents know that Adam was wanted in school by giving the clear, significant and genuine message that:

**Adam belongs in this school**



Adam's mum said:

*"The decision to let Adam go back to mainstream school was not an easy one. It was made easier knowing that they all wanted Adam there –not because they had to accept him. There is a big difference."*

Within school a variety of preparations needed to be made. Physically the school was modified to ensure that there was wheelchair access for Adam. Adam was assessed for equipment and things like a high table, computer, etc. were bought. Some equipment was funded by the school and LEA and some equipment was bought using the trust fund that had been set up for Adam.



School staff felt concerned about how they would respond to Adam's health needs. Both teachers and Adam's learning support assistant attended the hospital for training about Adam's healthcare needs although they **knew that they would not be directly responsible**. They volunteered to have training in both life support and managing his tracheotomy so that they would be able to understand their role and the role of the healthcare professionals if there were an issue or emergency.

One of the learning support assistants in school, Lisa, was asked to extend her hours and become Adam's learning support person. She was keen to do this but realized that it would be a challenge and that she had much to learn. Lisa attended the hospital for training around such things as moving and handling. She worked very closely with Adam's mum and dad to ensure that Adam had confidence in her. Initially Adam visited school and both his mum and Lisa were around. It did not take long before his mum was able to take a back seat and then go home, feeling confident that Lisa was able to support his needs in school.

It wasn't only the school physical environment that needed to be well prepared, but also the school staff and pupils. Adam's teacher spent some time at the hospital learning about Adam's condition and how she might ensure that he would be safely included in the class. Pupils also needed to be prepared so that they could understand how to continue their friendship with Adam and work alongside him in a way that would support him and be positive for them. The head teacher gave talks in assembly, using role play and wearing some of the equipment himself to help the children understand Adam's condition and to see that although he was in a wheelchair and used a variety of equipment, that he was the same person underneath.

#### **4. The effect of Adam on staff and pupils**

The teacher who had year 6 when school was preparing for Adam's return commented on the behaviour of a particular pupil who liked to think of himself as strong and 'hard'. This pupil had some behaviour difficulties and tried to show that he didn't care about all these preparations. When Adam returned for an initial visit to school this boy was one of the first to go to Adam, take hold of and shake his hand saying, "Good to see you back mate". The year 6 teacher said that she felt at that time – "This is absolutely right for Adam, the staff, and all our children – we have to make it work".

After reading this paragraph Adam's parent's said;  
*"After reading this, I know we made the right decision."*

#### **5. Adam's CAP assessment, independence and Assistive Technology for Learning.**

**Learning together: it's not all 'plain sailing' but we'll get there together.**

Including Adam within his class group was relatively straightforward. Although he had missed 12 months of school he is bright, articulate and popular and he was soon fitting back into his group in class and making good progress.

Adam has both an electric and manual wheelchair and it was possible to fit switches into the headrest that enable Adam to move about independently. It was also possible through CAP to assess Adam for Assistive Technology for Learning (ATL) that would enable him to record his work independently. Adam therefore has a computer that he can use to record his own work using switches in his headrest. He has one laptop but two larger screens, one for home and one for school, provided by CAP, so that he is able to complete work at home comfortably.



Unfortunately when Adam was initially using his electric wheelchair around the house to practice using the switching mechanisms he had a frightening experience. He pressed one of the switches, the chair flipped and Adam was thrown into a bent position. Although this did not hurt him, the experience really frightened him and he would not go into the electric wheelchair for some months. This also meant that he could not use his ATL.

This has affected Adam's independence, both in his social activity with friends and in his learning. He has been dependant on Lisa in school to move him round in his manual wheelchair and to record for him. More recently Adam has agreed to go back into his electric wheelchair with support from his mum and colleagues at school – both education and health professionals. Although he can now build up the use of his ATL to engage with the curriculum it is likely that it will take some time for him to become sufficiently comfortable and confident to be more independent in getting about to engage more independently with his friends.

## 6. Adam's medical needs and provision.

Adam uses his wheelchair and it is hoped that this will enable him to be independently mobile in time. The challenge to schools and the LEA is to ensure that he is able to access physically barrier free school environments, have access to appropriate ATL so that he can record his work independently, and access a support person when appropriate to carry out necessary activities, under his direction, that he cannot carry out for himself.

Adam is ventilated 24 hours a day. This is done in different ways. Adam has a tracheotomy and uses a ventilator to manage his breathing during the night. During the day Adam has 'pacers' that work to stimulate his diaphragm regularly so that he breathes more naturally. The machinery needed to do this is mounted on the back of his wheelchair. Because Adam uses life support machinery he has medical support while he is at school. This support comes from the Children's Airways Support Team (CAST) which is provided by the local NHS Trust. Colleagues from this team are available to look after Adam's personal care needs in school and to deal with any medical issues / emergencies.



Colleagues in CAST have a variety of backgrounds, from nurses to people who have worked in children's nurseries. It is as important that people in this team are able to interact positively with the children and their families as it is to have the specialist training that they all receive.

Adam's teacher and support assistant received training about Adam's condition so that they are able to support colleagues from CAST in the event of an emergency. They are trained to know what to expect, how to behave around Adam and what to do with the class. Their training will be updated regularly by the NHS Trust. This planning is in place, but hopefully will never be needed. The Senco is presently negotiating training for the whole staff because they all want the same knowledge.

Adam also needs Physiotherapy but this is provided twice a week, at home after school. Adam's mum carries out exercises with Adam between visits. Adam also needs to be in a standing frame for some of the day. Adam has a frame in school and he uses it at appropriate times, such as P.E. Adam is then able to get the physical experiences he needs while engaging with the activities of the other children, as the class teacher always ensures that Adam has a role in the lesson.



Here Adam is working with his teacher, giving instructions to the children about what to do with the ball.

There have been times when Adam has not been able to go to school but has been well enough to complete educational activities. At such times his learning support assistant from school works with Adam at home so that he doesn't get behind.

## 7. What Adam's inclusion means to him

Adam loves to go to school and does not like to be off. He has a real sense of humour and loves to be with his friends. He is now used to having the attention of adults as he has been the focus of a media attention several time. He tries to pretend that he feels 'cool' about it all.

He has the usual 'banter' with his friends, experienced by children of this age. His mum talks about the 'issues' for parents as children of this age try out for example, appropriate language to see what effect they can have on adults, and in this respect Adam is no different. Although Adam is unable to do many of the physical things his classmates can do he is going through many of the usual childhood stages. He has also achieved level 2 in his SATs this year, even though he has missed over 16 months of schooling.

If Inclusion is defined in terms of Presence, Participation and Achievement then Adam is included and everyone is working together to ensure this continues by anticipating and removing any barriers that may occur in the future.



(As Adam cannot put up his hand to answer questions he opens his mouth to show that he wants to offer an answer.)