

THE  TIMES

Our son had autism: no one believed us



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For years doctors dismissed Clare Lawrence's fears. Now the condition may be diagnosed by a 15-minute scan

How does it feel to be told, "Your son has autism"?

We were told just that the week before Christmas 2003 and what we felt was relief. At last we knew why Sam was different.

Researchers at King's College London have recently had success using MRI scans to detect differences in the brains of people with autism. Although this research is at an early stage, it is exciting because it brings with it the prospect of speeding the whole process of diagnosis for Autism Spectrum Disorder, or ASD. The MRI scan takes approximately 15 minutes. Diagnosis of ASD at the moment is only given after lengthy observation of behaviour, carried out by a team of experts, including paediatricians,

psychologists and speech and language specialists. Waiting times for these assessments are, understandably, long. The assessments are expensive and gaining access to them can be difficult.

For us, it took nearly five years of hard battling to reach a team who could help us. Sam was born happy and healthy, but his behaviour almost from birth made us uneasy. He seemed detached from us. He breast-fed as if he were drinking from a feeding machine. There was no connection. Was it me? Was I failing to bond with our second child? Why did I feel that his undemanding behaviour was too easy?

We first raised our concerns with the health visitor when Sam was eight weeks old. We were told he was fine. We persisted. We had his eyesight checked (“Is that why he doesn’t look at us?”), we had his hearing checked (“Is that why he doesn’t respond to our voices?”).

Again and again we were told that there was no problem. When we persisted, the health profession pointed the finger of suspicion towards me. Was I rejecting my child? Was I suffering from postnatal depression? Even friends became restless. Why was I making so much fuss? When medical staff did eventually take us seriously, suspicion was directed towards both parents. The symptoms we were describing (and health professionals were finally beginning to observe themselves) were of withdrawal, of a child who pulled away from an embrace, who didn’t ask for anything, who didn’t turn to parents for reassurance and protection. They were similar behaviours to those of a neglected or abused child.

In the end one GP, who was younger and perhaps more on the ball, referred us to the Social Communication Disorders Clinic at Great Ormond Street Hospital. This wonderful service specialises in the diagnosis of ASD in children with average or above average intelligence. The experts there didn’t think we were mad because we were so concerned. Finally we were asked relevant questions and our anxieties were taken seriously. The relief was immense.

For example, one day we had found Sam toddling around with a pin stuck in his foot. We realised only when we saw him limping. Why hadn’t he cried, or come to us for help? We didn’t know, then, that inability to process pain can often be one of the signs of ASD. Sam’s assessment at Great Ormond Street was intelligent, comprehensive and definite, but we got there only because we kept on making a fuss.

It is impossible to imagine the difference it would have made if we could have had that answer after a painless 15-minute scan rather than waiting five years. It is impossible to assess the impact it would have had on our family if health professionals had been more knowledgeable and if that relatively quick and inexpensive option for diagnosis had been available.

But there is more to it than speed. Yes, if we could have obtained a quicker diagnosis we wouldn’t have wasted precious time that we could have spent working with Sam during those all-important early years. We wouldn’t have had to obsess about it, observe him all the time, scour the internet for clues or fight to get on to waiting lists. We wouldn’t have had to send him to school without a diagnosis, so that he was immediately labelled “naughty”. I wouldn’t have spent so much time weeping in sheer frustration, with a curious Sam observing that I “had water coming out of my eyes”. However, that is not the

only, nor even the main point.

A scan which shows that Sam's brain is different from that of a "neurotypical" child is tangible, irrefutable evidence that he is different. There is no one definitive pointer to his autism because there are no specific symptoms of autism.

His various behaviours were observed in different contexts; we were asked about his development in early infancy, and told to record him at play, test his responses to stimuli. His interaction with doctors was assessed — all to determine whether his behaviour was caused by autism rather than, presumably, the way we were bringing him up or by another medical condition. It did give us an answer. But it doesn't tell us why. We still don't know why Sam, now 11, can remember things so vividly. Nor why he can hear sounds that are beyond most people's range, why he can read with phenomenal concentration yet cannot write his own name. We don't understand, really, why he finds some things so frightening, why he becomes anxious when routines change, why he has such intense and focused interests, or why he struggles to recognise members of his close family. Most importantly, neither does he. We know each reaction is because of his autism, but no one can tell us what that really means. This scan highlights which areas of Sam's brain are different from that of a neurotypical person. And with this may come understanding.

For years people told us that there was nothing wrong with Sam. I totally agree. There is nothing wrong with Sam because there is nothing wrong with having autism; but it is a difference. There used to be a great emphasis on "normalising" the behaviour of people with autism, as if, by making people act the same, they would become the same. Perhaps one of the gifts that these scans will bring is the acceptance that being different is perfectly OK.

Explaining Autism Spectrum Disorder, by Clare Lawrence, is published by Emerald Publishing, £9.99