

Mum's battle to raise awareness of autism in children

WHEN Clare Lawrence's son was diagnosed with autism, she set out to learn all she could about the condition. She has now written four books about her experiences in a bid to help other parents with an autistic child. **JENNY CORNISH** finds out more.

WHEN Clare Lawrence's second child was born, she soon realised there was something different about him – but it took nearly five years to find out what.

After a long battle her son Sam was finally diagnosed with autism shortly before his fifth birthday.

Clare then set out to learn as much about autism as she could – and now writes books which explain the condition.

Her new book, *Explaining Autism Spectrum Disorder*, sets out to debunk some of the commonly held beliefs about the condition and give practical help to parents and others.

Clare, 46, who lives with her family in Longthorpe, says it was a huge struggle to get Sam, now 11, diagnosed.

"When Sam was born he was perfectly healthy," she said. "But I noticed almost straight away that there was a difference in the way he interacted with us.

"Because he appeared to be a happy, healthy lad, it was difficult for us to get anyone to take us seriously that there was anything wrong.

"They tested his eyesight to see if that's why he wasn't looking at us, and tested his hearing to see if that was why he wasn't responding, but they kept saying there was nothing wrong – and we were very pleased to hear that there was nothing wrong.

"But we knew there was something different about this kid."

Clare says doctors even started suspecting that she might have post-natal depression, because she kept bringing this apparently healthy child back to them.

There were also a series of problems with waiting lists and paperwork which held up the diagnosis.

"Everything I'd read said that the early years are the most important time, but we couldn't get anyone to give us a proper assessment," said Clare. "It took an incredible amount of time getting him diagnosed.

"We finally bullied our GP into sending us to the Great Ormond Street social communication centre, and they were fantastic."

Sam's parents were finally given a full assessment of their son, including tests which



SPREADING THE WORD: Clare Lawrence with the books she has written on autism.

showed that he had a very high IQ.

"We didn't just get a diagnosis of autism, it was much more positive than that, which was hugely important," said Clare.

She remains angry about the delays and this is one of the reasons she has been inspired to write about the condition.

"He had started school without a diagnosis – he couldn't follow instructions, he must have been very confused, and that was an unnecessary thing to put him through," she said.

This also made things difficult for their first child, Elizabeth, who is now 13. As a young child she had to stand up for Sam at school and try to explain his behaviour to people.

"When she was young it was quite difficult for her because we were so caught up in trying to get a diagnosis," said Clare.

"Part of the point of the book

really is that if people are much more aware of autism then they will be more equipped to recognise autism."

It is estimated that one in 100 people of all ages in the UK have disorders in the autistic spectrum, but the condition is still widely misunderstood.

Clare herself was a secondary school teacher but says she knew nothing about autism before Sam was diagnosed.

"I'm a teacher and autism wasn't mentioned in the training," she said. "I knew nothing about it at all.

"After Sam was diagnosed I did lots and lots of different courses. The more information you have the more empowered you are."

She now has post-graduate certificates in the study of autism and Asperger's syndrome, a high-functioning form of autism. Sam attends school part-time, and Clare also teaches him at

home.

This is the fourth book she has written and it aims to bridge the gaps between parents, teachers and doctors.

"I was aware that health professionals know a huge amount but possibly too much, and parents know absolutely nothing," she said.

"There wasn't much of a bridge between the two points. There wasn't much proper information given out.

"My other interest is teaching and the same is true in schools – teachers are teachers, but they're not necessarily specialists in autism. There are lots of experts, but no way of linking them up. The child with autism was falling between these three points."

Clare says things are improving for children with autism, but it is even harder for adults with the condition.

"If one in 100 children has autism, then one in 100 adults has autism," she said. "There needs to be much greater awareness among the police, hairdressers, opticians, dentists, shopkeepers – all the people who deal with the public need to be much more wised up about autism. I think it's slow in coming – it's getting better for children but it's still quite poor out there for adults.

"People need to be made aware that autism isn't necessarily a problem. It's really interesting to be around people with autism, they are usually people with really dedicated interests, they're often very funny.

"I think that a more positive attitude towards people would make a huge difference. It's all doom and gloom and it can be more positive."

Clare says often people misunderstand the actions of someone with autism and assume they are being rude.

She gives the example of someone pushing into a queue – everyone gets tense and angry, but if that person has autism, they might not even have noticed the queue is there.

People are also often wary of someone if they know they are autistic, says Clare. "Most people's reaction is to leave them alone, and not talk to them," she said. "This is leading to an awful lot of social isolation."

One of the difficulties is that there is a very wide autistic

spectrum ranging from mild to severe – people with Asperger's syndrome are usually of average or above average intelligence, but have difficulties with social interaction and communication, while those with more classic autism may have learning disabilities and more specialist needs.

Recently scientists have announced they have developed a brain scan that detects autism in adults, which could mean easier diagnosis of the condition.

Clare says this could be a major breakthrough. "If we can finally have a scan, then people can be diagnosed very quickly," she said. "It is tremendously exciting."

After her family's early battles to get a diagnosis she now has high hopes that Sam will be able to lead a happy and successful life.

"I hope he will go on to somewhere like Cambridge University," she said. "I think if we can avoid the pitfalls, if you can avoid the child thinking he's a failure because he doesn't fit in as well and celebrate the positive stuff, there's no reason why he can't go on to be something truly great. I hope that his Asperger's will never hold him back.

"Our task has always been to allow him to be happy. A lot of children with Asperger's are very anxious. I don't see why he should have to have this anxiety and worry. Things like team sports are very difficult for children with autistic spectrum disorder. So he's doing a lot of individual sports instead."

Clare herself has already started writing a fifth book, aimed at teachers. "Originally I thought I'd just write one book but they're now coming thick and fast," she said. "I hadn't thought of this becoming my new career but it's great."

She says Sam's autism has changed their lives – but in a positive way. "It's been an interesting change in my life," she said. "When we first found out we were fairly stunned.

"But we wouldn't change Sam for the world - he's great just as he is and it's been an interesting change of direction for us all."

■ Explaining Autism Spectrum Disorder, by Clare Lawrence, is published by Emerald Publishing.

