

A MOTHER'S COURAGE

An uplifting story of strength, perseverance and the love between mother and child. Emdad Rahman explores how a person with disabilities can thrive if given adequate support

Ibrahim Hamzah Rahman was born on 19th December 1990 in Cambridge. He was a normal, healthy boy and weighed 5lb 15oz. From the age of about two, Ibrahim was an extremely boisterous child who suffered from a speech and language disorder called Semantic Pragmatic Language Disorder.

He had difficulties in expressive language which affected every aspect of his life. Ibrahim also had difficulties with his gross and motor skills. Semantic-Pragmatic Language Disorder (SPLD) was originally defined in Literature on Language Disorder in 1983, by Rapin and Allen, although at that time it was classified as a syndrome. Many people who definitely are autistic have this kind of language disorder, Dustin Hoffman's character Raymond in the film 'Rainman' being a typical example.

Ibrahim's problems had a huge impact on the family, but mostly on his mother, Shahidun Rahman. She was only 22 years old when it was discovered that Ibrahim had difficulties. There were bad days when she would think, "Why can't he be normal? Why did it happen to my family?" On a good day, it didn't seem to matter so much and the family coped well. She soon realised that she had to learn to be patient the hard way. "I would forget that the mistakes Ibrahim made were because of his problems and that it was not his fault, and everything become an enormous strain. The pressure caused me to feel quite depressed at times and I became quite tearful. The prospect of having to struggle everyday in this way was demoralising and I wasn't sure I could cope. I used to lie awake late at night trying to find answers to my questions and I had a good cry at times. At times, I felt isolated and alone".

Shahidun was born in Cambridge as a twin. Her parents are from Fenchugonj, Sylhet. She married at the age of 18 in Bangladesh. Ibrahim's father was not able to gain UK entry clearance until October 1991 so he did not see his son until he was 10 months old.

When Ibrahim attended nursery, his mother worked at the Cambridge Citizens' Advice Bureau as a volunteer. "I had previously trained for six months prior to Ibrahim starting school when I sent him to a day nursery once a week. He had trouble settling in and it was difficult to leave him. He screamed and clung to me as if he thought he would never see me again. His young mind just couldn't understand why I wanted to leave him there. I was virtually in tears when I walked out of the nursery, and



Ibrahim Rahman

felt as if I was being incredibly cruel to him. Ibrahim had lunch there but did not eat a thing, although the nursery assistants tried very hard to encourage him. I even considered leaving the training course because of Ibrahim.

Shahidun was concerned about Ibrahim's poor eating habits so she would usually take him home for lunch, but even then she couldn't persuade him to eat much. When she took him back to school each day, she was invariably feeling angry and frustrated and continued to worry about his diet. He had developed many bad habits and would only eat small amounts if he had his toys with him or was watching television. Although Shahidun knew this was not the best way to deal with the situation, she gave

butter on the bread.

I was so pleased that a new food had been incorporated into his diet. This may seem insignificant to most mothers, but this small breakthrough in his diet meant so much to me".

Ibrahim's journey from birth to his teenage years was fraught with problems as he struggled through school. However, with grit and determination, he made excellent progress at the secondary school he attends now. "He is a clever boy with talents. He is a computer wizard, he actually knows more than me!" beams Shahidun. "Ibrahim can write really good poetry and stories. He read the whole of Qur'an at the age of seven by watching Qur'an recitations on video despite having severe language difficulties.

"I remember one occasion when I shouted at him all the way to school because he had refused to eat any lunch. As he went into the classroom he saw a friend and sat next to him and told him tearfully, 'My mum went mad!' When I heard this I felt like a complete monster and his words and pitiful expression haunted me all the way home. By the time I reached my front door, all my pent-up emotion was released and I broke down and cried"

in to Ibrahim's demands because she was desperate to see him eat. She reflects on one particular occasion: "I remember one occasion when I shouted at him all the way to school because he had refused to eat any lunch. As he went into the classroom he saw a friend and sat next to him and told him tearfully, 'My mum went mad!' When I heard this I felt like a complete monster and his words and pitiful expression haunted me all the way home. By the time I reached my front door, all my pent-up emotion was released and I broke down and cried. I was totally obsessed with the idea of getting Ibrahim to eat and this had caused me to become unbalanced so that I began to take all my frustrations out on him. His poor eating was seriously affecting me and all I could think about was ways to improve it. I felt hurt and guilty and desperately needed to know where I was going wrong".

Shahidun's patience finally paid off. On one occasion at school during his speech and language group, Ibrahim made sandwiches. When he came home from school, he ate them! He had not eaten them before and this was the first ever sandwich he had eaten at home. Shahidun recollects the events of that day; "Ibrahim told me he preferred to eat grated cheese sandwiches with

He learnt Arabic with little effort.

He also managed to memorise verses from the Qur'an with little effort. Arabic is the only language he 'bonded with'. English and Bengali, he always found difficult. His Arabic accent is excellent" gushes Shahidun. In the Islamic school he attends, he is chosen regularly to call the Adhan.

In May 1998, it was decided that Ibrahim should take the SATS at Key Stage One. He achieved Level 2 for English in reading, writing and comprehension tests and Level 1 in speaking and listening, which was not a surprise as most of his difficulties were in these areas. Ibrahim's spelling was excellent and he achieved Level 3 in the spelling test. In Mathematics, he gained Level 2, and was assessed as Level 1 in Science. Shahidun was happy with the situation; "Ibrahim had always worked hard, despite being under a great deal of pressure with the added problems of his disability.

It was good to see that all the hard work and dedication the teachers had put in to help Ibrahim had paid off. They were very patient and understanding".

Ibrahim's vocabulary is excellent for his age and well above average. At the age of seven years and two months, Ibrahim had a spelling age of ten. He was keen to learn

new vocabulary from a young age and his parents provided him with a dictionary - The Oxford Primary School Dictionary and Thesaurus; "He spent many hours looking up new words and always liked to tell me about them, many of which I had never heard of".

Ibrahim still needs to be guided in most things he does. He is still vulnerable which can be a worry. His learning disorder will remain with him for the rest of his life and it is sad that it can sometimes be mistaken for his character. Shahidun hopes that people in future will judge Ibrahim by his character and not his disorder because as she puts it in her own words; "I know he is a sensible and bright boy".

Shahidun had to work very hard to make her own family understand about Ibrahim's learning disorder and to explain it to anyone. She does feel she could have done more to help Ibrahim in the early stages of diagnosis, if only she had known then what she knows now. She believes that more and more Bangladeshi children will have this disorder and hopefully it will be recognised and accepted in the future. "We have been fortunate to receive much help from the various agencies in this country. If Ibrahim had lived in Bangladesh, then this type of help would not have been available. His behavioural difficulties would have been blamed on Ibrahim being possessed by evil spirits and people would have said that this was the work of the devil because sadly, in our community, this conclusion is not uncommon".

Shahidun has written a heartwarming account of her struggle "Ibrahim - Where in the Spectrum Does He Belong?" This is an autobiographical account of her struggle to bring up Ibrahim. It tells the story of Ibrahim, and his struggle. As readers follow Ibrahim's journey, from birth through to his early teenage years, they can observe how his struggle to overcome his difficulties have impacted on so many other aspects of his development. Narrated by Ibrahim's mother, ultimately this is an inspiring tale, which provides hope and encouragement for those undergoing similar circumstances. Shahidun has her own website: www.spldinfo.com.

The book "Ibrahim - where in the spectrum does he belong" is available to download on www.lulu.com, www.deunantbooks.com, and www.publishyours.com. Deunant books actually selected this excellent book for their site as an e-book. A publishing company, writers world will print the book within days of this interview. "Ibrahim" will be available at every major internet bookshop, including Amazon, Bol, Waterstones, WHSmith, Ottakar's, Hammicks, Blackwells, Thins, Methvens, etc., on Websites throughout Europe, the Far East, Australia, America and over 12,500 retail booksellers.

Shahidun is forever grateful for all the people who have given Ibrahim help and support over the years. Without their help, Ibrahim would not be where he is today.

She has advice for parents with children who have similar difficulties, "Never say never! Children can progress in ways you never expect them too. I am grateful every day for the progress Ibrahim has made. And despite all the difficulties, I wouldn't change him for the world".

"I am grateful to Almighty Allah for the progress he has made. This is why I wrote my book. I am sure there are other children like him. I hope to give them hope and encouragement through my book".

IBRAHIM

WHERE IN THE SPECTRUM DOES HE BELONG?

Shahidun's book is a must read