

"Not everyone is an Einstein," Merry Barua said to herself as she watched her three-year-old son. While the other kids in school enjoyed crayon work and pasting, Neeraj's exercise book lay empty. When she tried to get him to hold a pencil, his fingers were limp. "I knew there was something the matter but I hadn't a clue what it was. I'd read a *Reader's Digest* article way back and recalled the word autism - but I knew nothing more," says Merry, casting her mind back to twenty years ago. Neeraj had no speech but her husband's family propped her up with the assurance that he himself spoke late. By age 3½, however, the anxious mother was looking for a diagnosis.

Diagnosis-shopping, Merry and her spouse ran through a long list of paediatricians and psychologists in Calcutta.

Driven by the need to understand autism Merry wrote to a doctor friend in the UK who supplied her with a copy of *A Parent's Guide To Autism* that she devoured with a rare hunger (Autism is a lifelong developmental disability primarily affecting a person's social and communication abilities). With zero training, Merry persevered, guided only by a mother's instinct, and taught Neeraj to read 3-letter words, his number

implementation. "I pulled him out of school, locked us up in a room and worked for a year-and-a-half. The change in behaviour was incredible, and his learning sped up." Meanwhile she had also networked with 30 families across India, contributed articles, and started a magazine to spread awareness. "I used to visit video parlours, ask for cassettes of *Rainman* and paste information on autism on them." Seeing the change in Neeraj, other mothers approached Merry with the request to work with their kids.

Those were the humble beginnings of *Action For Autism*, the national organisation for autism in India. Parent-directed and parent-supported AFA works with autistic cases of all ages and their families. AFA's goal is to create an environment that maximises opportunities for the autistic to lead independent, meaningful,



Sevan Shou

Merry Makes a Difference

From a reassuring but inaccurate 'Nothing wrong with him' - to a callous 'Obviously you don't hit him hard enough' - to explain his spitting

and colour concepts. When the family eventually moved to Delhi she enrolled him in a Special Needs school where he spent the next five years.

and productive lives. The centre offers assessment, referral and counselling services and teacher training methods, besides conducting practical and

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and other irregular behaviours, to being asked inappropriate questions about marital conflict, the parents went through the gamut of confusing opinions. When a firm diagnosis did arrive it was from a Canada-based psychiatrist experienced in dealing with autistic cases.

"I was very upset. For almost a month I sat and stared at the walls, lonely and immobilised," confesses Merry, a proactive person by nature. "But there was nothing in India. Not a book, not a bookstore, not a library, not a person who could give me any information. And what I got from the doctors was

"It was a good place but they were clueless about autism." By age ten, Neeraj's behaviour had become severely challenging - defecating, shouting, hitting. "I cannot even begin to describe it. My family life had become desperate."

As Merry's knowledge broadened it dawned on her that autism was not the same as mental retardation and the school's handling was completely inappropriate for Neeraj. "I had to move on." It was the advanced work done in the US that brought a ray into her world of despair. When she trained in the US and returned a year later

interactive workshops all over India. It was a Chennai workshop organised by WE CAN, a Resource Centre, where *Madrasplus* caught up with Merry who, true to her name, is sheer effervescence.

Neeraj is 22 and able to take care of his needs today. "He's learning something every day," says Merry who takes immense pride in every new mountain he climbs.

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