THE BLESSINGS OF MOTHER MERRY

BY THE SIDE OF MANY AUTISTIC CHILDREN

MERRY BARUA STANDS LIKE...

Help at hand

WENTY-three-year-old Neeraj looks across the table at his mother with an expression most people would not understand. Is he gazing at her fondly? Or is he vaguely amused?

It doesn't really matter what onlookers may wonder, because mum knows. Merry Barua has spent the past two decades, figuring out how to figure out what Neeraj thinks, needs and wants. "Now I can help other parents with autistic children because of my own personal experiences," she says. Barua has been running the Delhi-based NGO Action for Autism (AFA) for 12 years now. In 1994, she founded Open Door, a school specifically for children with this disorder.

Today, at least autism is part of the vocabulary of cine-goers who've seen that early 1990s film Rain Man, starring Dustin Hoffman and Tom Cruise. Hoffman won an Oscar for his performance as Cruise's autistic brother with a genius for unexpected things. Four years back, largely due to lobbying by organisations like AFA, the Indian Parliament passed The National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act. But when a doctor in Kolkata in the early 1980s first told Barua that her four-and-a-half-year-old child was autistic, she had no National Trust for support, and no Rain Man for ready reference.

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"I remember going to British Council where I found a book on psychology that mentioned autism," she recalls. "It seemed to suggest that I as the mother was to blame for Neeraj's problem." There were other pointed fingers beyond the text. Now of course, Barua knows that her son's condition is not her fault. Autism is a life-long developmental disorder that severely hampers a person's social and communication skills, and often results in repetitive behaviour. Autistic people inhabit a mysteriously structured and closed world. The biggest problem parents of such children face is ignorance about the disorder in India.

Neeraj, for instance, went through several schools in Kolkata and Delhi, some of them well-meaning but ill-informed, one that would even tie him to his chair or punish him for 'misbehaviour' by shutting him alone in a room. "By the time he was 11, it had become very difficult," says Barua. "He would scream and shout all the time, even hit me." She looks at her strapping son affectionately and asks, "Isn't that true? You would hit me?" "Hit," Neeraj repeats the word, gently rocking his head back and forth.

They can smile about it now. Back then though, Barua remembers even buying a how-to-commit-suicide book. But this is not a woman who gives up easily.

Frustrated but convinced that her son was not a hopeless case, Barua took Neeraj out of school when he was 11 and spent an entire year at home with him, training him to adopt socially acceptable behaviour, teaching him the rudiments of mathematics, geography and history. "That's when I discovered this bright little mind in my severely autistic son," she says. "Medicines can't cure autism, but you can correct certain behaviour patterns and take a child from level 5 to level 8 with early intervention." Today Neeraj busies himself with various chores at AFA's office in Chiragh Gaon.

As for his mother, at 51, she continues to be one of the most untiring voices for parents of autistic children in the country. Barua and her son live alone together in Delhi. How will Neeraj cope after she is gone? Well, she is working towards setting up a residence where persons with autism can stay away from the family, under a social worker's supervision. Beyond that, "I don't worry about things I can do nothing about," she says simply.