

# "I LEARNED TO SAY 'I LOVE YOU' TO MY SON..."

...SAYS MERRY BARUA, DELIGHTED WHEN SHE COULD COMMUNICATE WITH HER AUTISTIC CHILD. PURABI SHRIDHAR MEETS A WOMAN WHO HAS OFFERED HOPE TO OTHER MOTHERS LOCKED IN SILENT COMBAT WITH A COMPLEX DISORDER

**'MERRY'** is a difficult name to live up to — since one's joys and sorrows visit us, unbidden. Merry Barua, so christened because of her sunny nature as a child, radiates a rare vitality. For the last 25 years or so, she has been committed to the needs of the autistic child after she found out her own child was one. Founder of Action for Autism (AFA), Open Doors, a school for autism-afflicted children, and now the National Centre for Autism, she betrays no signs of any of the wear and tear of such relentless care giving. We meet at Café Turtle, a charming, spacious, European-style café in the Greater Kailash area of South Delhi, where customers want to linger languorously over their cappuccinos even as Merry and I talk about how life-changing problems impelled her on her crusade to help the autistic child.

PHOTOGRAPH: ASHWANI NAIGPAL

## SIGNS THAT WENT IGNORED

It was when he turned five that Merry was given the chilling diagnosis that Neeraj, her only child, was autistic. The signs were there from the beginning, only she could not recognise them. She did a futile round of paediatricians and psychiatrists, who completely missed the condition — autism was not widely heard of in India in the late '70s — and thought her son's problem was to do with a lack of discipline. "We were waiting in the lobby of a leading paediatrician's clinic in Kolkata," she recounts, "and Neeraj was running around like a charged particle, banging the door of the paediatrician's chamber with his body. When the doctor came out and I apologised, he wanted to know why I didn't slap the child more. I never went back to him."

There was no dearth of those



tacitly implying that Merry's parenting skills were inadequate. "Neeraj had no speech for a long time and everyone said 'never mind, you were a late talker'. He never played with other children, nor slept enough, barely three hours at night and no nap in the day. He would not eat; take hours to have a bottle of milk. It was much later that I realised he had sensory problems." There are things in the house that bear the ravages of mishandling, such as the battered phone or crockery regularly sailing out of the windows of the ground floor flat.

"I needed to do something," says Merry, remembering how desperate she was for information upon learning of the diagnosis. "To be faced with a total vacuum was disconcerting. I spent a month in a haze." She began educating herself feverishly after a doctor friend from abroad sent her a book by Lorna

Wing, a parent with an autistic child. "Do you know most autistic services in the world have been started by parents?" The book was a basis on which to begin understanding the complexity of the disorder rather than have guilt induced by well-meaning, but ignorant, friends, or completely misguided teachers. A home tutor sent to her by a special school was actually thrashing her child when she was not around.

Finally, her painstaking fact-finding led her to the school for children with mental retardation, run by the Christian Medical College, Vellore. "I was clutching at straws," she says, "but when they said I would have to stay there with Neeraj, I agreed." It was an 8 x 9-foot, frugally appointed room, with an iron bed, a kerosene stove, a folding chair and table. Merry stayed for six months "because they were truly wonderful people", and she was able to focus completely on her son. The obsessiveness with which she worked bore fruit for he learnt reading, was able to identify the entire colour palette, and so much else. "I think mothers, very often, through intuition, do the right thing," she concludes.

### LIKE 'RAIN MAN'

When the Baruas moved to Delhi thereafter — and another 'regular school' — Neeraj, 11 by then, was becoming unmanageable and home life increasingly difficult. As a journalist, Merry was writing in newspapers to create awareness about autism, while the movie, 'Rain Man', was popular on the video circuit. She pasted stickers on the videotape, giving information about her son and seeking companionship for him, and put up posters. She was already counseling families.

All the while, Merry had been reading widely, corresponding with schools abroad where autistic children were being taught very differently. She decided to go to a school called Options, in

### BEENA PRITHVIRAJ, SPECIAL EDUCATOR, AUTISM THERAPIST, CHENNAI

"My 11-year-old son is autistic. He was three when diagnosed. I saw Merry on TV and got in touch with her. Upon her suggestion, I went to NIMHANS, Bangalore. We tried out a school for multiple disabilities, but it didn't seem to be doing him any good. I decided to take him to Delhi and train at AFA. Since 2003, I have been working at my son's special school here. Merry has single-handedly worked not just for her son, but for others' too. She has so much energy; she's amazing. It's difficult for me to put in words what I feel about her. Today, we consider AFA our family and my son is doing quite well."

### THE OTHERS SAY

Shubhangi Vaidya, academician and parent of nine-year-old autistic boy, New Delhi

"My son was diagnosed with autism when he was two-and-a-half years old and I was referred to AFA, which was of great benefit to me. The most important thing I learned is that autism is not a huge disaster. It is a development disorder, and that ultimately, the child is a child, and autism comes later. I lost my husband three years ago, and through it all, the AFA community gave me immense support. The AFA is meant not just for rehabilitation, but offers extended family support, missing in today's urban context. The reason could be because AFA is a family-directed organisation, primarily run by people who are parents, and all of us belong to it."

Massachusetts, USA, where the teaching programmes were based on behavioural principles. Upon her return, for one-and-a-half years, she worked exclusively with Neeraj. It involved staying awake nights, transcribing the tapes she had from Options, reading and researching. Her efforts were hugely successful.

"It was as if I had rediscovered my son," she says. "I learnt to say 'I love you' to him again, and let him know

how much I valued him. If you love someone you have to let them know, and that applies to all relationships. After a year and a half, he was absorbing everything like a sponge."

It was then that Merry, who was already bringing out a magazine, opened her school, Open Doors, at Vasant Kunj, beginning with two students, Neeraj and a girl. She found it was also essential to share appropriate ways of teaching, and that's how Action for Autism (AFA) was founded. Today, Open Doors has 60 children in a day-programme and 40 in the outreach. Since 2000, Merry has had enormous success with her Mother-Child programme, where a mother is trained to work with her child and others' children too. "Our aim is to empower the families and give them the required tools to cope," Merry explains. And that's how the national centre came about too. "We realised that people needed a place to go to. We want to work as a nodal agency," says Merry, who holds workshops all over the country, and notes with pride that her programme has been replicated in Mumbai, Goa and Madhya Pradesh.

### UNCONDITIONAL LOVE

Even as she ensured that other autistic children and their families had a place to turn to, she learnt to accept that Neeraj would not be able to keep up. "When you work intensively with such kids, you realise that they learn from the environment, and then have to be given opportunities to move into the mainstream," she points out. Neeraj could not do this because he started late. "He is mildly autistic and works at our vocational centre." What has seen her through it all is her abiding faith. "If I had to live my life all over again," says Merry, "it would be with Neeraj. He is the child I know and love. He is also not the easiest young man to live with, but you can choose what to make of life and I've learnt some of life's best lessons from him." 