

Rudy Baylor in John Grisham's novel was the only hope of an elderly couple whose insurance company denied payment for an operation that could save their son's life. Merry Barua is the hope of thousands of autists and their parents in India. She is working incessantly to light up their lives. **Anindita Chattopadhyay** catches up with the mother who's driven to make a difference.



# THE RAINMAN

**W**hen I first met Merry Barua, the founder of the NGO Action for Autism, what attracted me was her smile. It lights up her face. And the smile has never waned in all these years - not even when she found out that her only son, Neeraj, was autistic.

No doubt her world had fallen apart when she found out her only child's special condition. "But I never took it as a tragic incident. I love my son, so I learnt to accept him the way he is," she said with a smile.

What spurred her to set up an NGO for autistic children is a gruelling experience she went through. When her child was nearly three years old, Merry noticed that Neeraj was unusually shy and hardly spoke. The playschool teachers complained that

he would roam around in the class and never pay attention. The drawing book showed that he repeatedly rubbed the pencil at one point instead of filling the picture with colour. She left her advertising job to be with him all the time. Finally, when Neeraj was diagnosed with autism, she felt like being plunged into an abyss. She had no one to approach for help - neither were there counsellors, nor awareness about the disease or schools for such children.

She started getting books from abroad to learn about the disease and how to deal with such children. Finally, she started home schooling Neeraj when she found he is not learning the way he should be. "A reputed special school in Delhi treated his aberrant behaviour by tying him to chairs,

locking him up and beating him. He became violent. They thought it was mental retardation. But autism is actually a disability of impaired communication and lack of abstract thinking. Kids become aggressive because they cannot communicate. That's when I started home schooling him. I went to the Options Institute in Massachusetts, US to train myself and took Neeraj with me."

It was in 1991. She structured Neeraj's day, laid down visual schedules for him and tried to explain the things around him. After a year, she could help him develop vocabulary and make sense of the world around him. As he learnt to communicate, his violent behaviour mellowed. Buoyed by her success, Merry started reaching out to others. A freelance journalist, she wrote articles in the media to create awareness about the disease and interacted with parents of such children. "I even went to video parlours and pasted a small strip on the cassettes of Rain Man, which read Rain Man Babbit has autism and a few lines dispelling the myth about the disease," she laughed.

Parents often approached her to train their children. Finally, she took in a child and home-schooled him along with Neeraj. When he started showing improvements in behaviour and communication, she got the calling of her life - setting up a school for autists and an NGO to help parents like her. In 1994, Action for Autism was born. An Open Door school was started with two children. Now it has 70 plus students. More importantly, Merry started training teachers, counselling parents, holding workshops across India and helping parents set up support groups. Hope for Autism at







# E R A I N M A K E R

ry Barua, NGO Act- at attract- 2. It lights er waned she found autistic. len apart l's special s a tragic to accept 11 e. NGO for perience hild was iced that lly spoke. ined that

he would roam around in the class and never pay attention. The drawing book showed that he repeatedly rubbed the pencil at one point instead of filling the picture with colour. She left her advertising job to be with him all the time. Finally, when Neeraj was diagnosed with autism, she felt like being plunged into an abyss. She had no one to approach for help - neither were there counsellors, nor awareness about the disease or schools for such children.

She started getting books from abroad to learn about the disease and how to deal with such children. Finally, she started home schooling Neeraj when she found he is not learning the way he should be. "A reputed special school in Delhi treated his aberrant behaviour by tying him to chairs,

locking him up and beating him. He became violent. They thought it was mental retardation. But autism is actually a disability of impaired communication and lack of abstract thinking. Kids become aggressive because they cannot communicate. That's when I started home schooling him. I went to the Options Institute in Massachusetts, US to train myself and took Neeraj with me."

It was in 1991. She structured Neeraj's day, laid down visual schedules for him and tried to explain the things around him. After a year, she could help him develop a vocabulary and make sense of the world around him. As he learnt to communicate, his violent behaviour mellowed. Buoyed by her success, Merry started reaching out to others. A freelance journalist, she wrote articles in the media to create awareness about the disease and interacted with parents of such children. "I even went to video parlours and pasted a small strip on the cassettes of Rain Man, which read Rain Man Babbit has autism and a few lines dispelling the myth about the disease," she laughed.

Parents often approached her to train their children. Finally, she took in a child and home-schooled him along with Neeraj. When he started showing improvements in behaviour and communication, she got the calling of her life - setting up a school for autists and an NGO to help parents like her. In 1994, Action for Autism was born. And Open Door school was started with two children. Now it has 70 plus students. Most importantly, Merry started training teachers, counselling parents, holding workshops across India and helping parents set up support groups. Hope for Autism and

quick to reply that she took it as her challenge. "They all gave me emotive support. But my husband was travelling a lot, so he really didn't have time. My parents and in-laws were not living in Delhi. Though my mother offered to come and stay here I didn't agree because I and our parents have done enough in bringing up their children and I shouldn't burden them any more," she said adding "But I have always been lucky with maids. They understood me and never complained."

Merry thinks the strong person that she is, was partly because of circumstances and partly her upbringing. "My parents always encouraged us to think and do things independently; to take responsibilities. I learned from them that life would not always be the way one wants it. I guess that helped making me strong." Today Merry feels confident when she sees 28-year-old Neeraj working with children at the work-space centre of the school. She sees herself as a driven person who wants to make a difference. "I could have safely immigrated to a developed country. But I thought about parents like me. If I had services at that point of time, the difference it would have made. So, I took it on me to help others. Moreover, I enjoy connecting to these children," she signs off with a smile.

### THEY ARE SPECIAL

- Be happy and teach your child to be happy
- Enjoy your child and accept the way he is
- Learn to be silly with your child
- See the glass half full - see what they can do and not what they cannot.

