

Opening the door on autism

Children with autism have special needs in terms of education and life skills. A mother's account of how she dealt with her situation, and now shares her experience with others

■ Merry Barua

When I got to know that my son was autistic, I was confused, as I had not known about autism before. I had guessed by then that Neeraj might be 'slow', since as an infant, he had no social smile, no deep interest in me. He could not differentiate between my breast and the bottle. He never expressed an interest in any of the adults who fussed over his crib.

Then I bumped into an old friend whose son had Down's syndrome, and who was also a trained special educator. She suggested I take Neeraj to a child psychiatrist. It was then, when he was nearly five, that he was diagnosed with autism. With no information on how to help him, I ordered books on autism from friends abroad. Then I started looking for special schools and teachers but found that there was really nothing available.

Neeraj attended various special schools for the mentally retarded for about six years. Sometimes schools used inappropriate techniques since there was little understanding in India at that time on how to teach autistic children. Despite that, I deeply appreciate the time we spent at Nambikkai Nilayam in Bagayan, Andhra Pradesh: I lived there with 15 other mothers with differently-abled kids and learnt to be non-judgemental and help others. At Bagayan too we sometimes used inappropriate methods, but the atmosphere was so wonderful and the people so caring that it all balanced out. But when I returned to Kolkata, my son once again

had to cope without a proper trainer.

Children with autism display difficult behaviours that may appear 'violent'. My son too passed through such a phase as a child. Not having anywhere to turn to, I began to feel helpless and unable to cope. It was then I realised I would have to train myself as his teacher. I underwent training for teaching autistic kids at the Options Institute in Massachussets, USA, in 1991. I started teaching Neeraj when he was 11, through a very focused home programme. I had learnt how to make his environment more positive, reinforcing, and inspiring. His behaviour gradually came under control. He grew from an angry, stressed out little boy into a happy young man.

Neeraj does not really have friends though he would dearly love to hang around with other young people. Nobody has the patience to be friends with an autistic young man. He does have some autistic friends whom he

is happy to be around. And of course, my colleagues at Action For Autism (which I founded) are his friends too. He loves being around them as well.

Neeraj now works in the vocational centre at Action For Autism. He helps me shop, lay the table for dinner, clear it afterwards, tidy the house. After work, we have tea together, go for a walk and watch TV.

Children with autism cannot express their affection easily. Now when Neeraj tells me: "Love



Martin Louis

Merry Barua with her son Neeraj

mamma," it might not seem such a big deal to most people. But to me that is cause for celebration. Also, most people in their 20s won't tell their mother that, so I consider myself privileged!

On discovering that autism was nearly unrecognised in India and hardly any doctors could diagnose it, I tried to create awareness through different means. Initially I wrote in the media. I got a label printed with information on autism, which I pasted on video cassettes of the Oscar-winning film Rainman (that told the story of an autistic person played by Dustin Hoffman) available at video parlours.

Something concrete needed to be done. I founded Action For Autism for raising awareness and social advocacy. In 1994, the Open Door school for autistic children was inaugurated in Delhi. Now there are plans to open a bigger school and expand our training of teachers to teach children with special needs.

Autism is a fascinating disorder. One can never

lose interest or 'get bored' of teaching or researching it. And of course it is lots of fun to teach the kids new skills and concepts. At Open Door, you can't but help notice the cheerful and energetic atmosphere. The children are happy and we try to help parents view their children positively.

We try and change the feeling that their life is a 'tragedy' because of their child. Action For Autism's focus is on empowering parents. We help parents accept their children as human beings who are different, and not as a 'problem'. Of course they cannot develop a positive attitude overnight. But they can work towards accepting their child with disability for who they are rather than wanting their child to be the way they would prefer them to be. ▀

—As told to Pallavi Bhattacharya

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