

## OFF-BEAT

# To win, despite the odds

These are special children — not just because they are autistic but because they still try to beat the odds. RUMU BANERJEE reports

“Hello, my name is Neeraj.” That’s the first greeting that I get when I reach Action for Autism, a non-government organisation. Looking at Neeraj, you wouldn’t say anything was amiss — you see a ‘normal’ young man of 20-odd, who also appears extremely friendly. It’s only when you shake hands and see him reach out towards you to tuck away your unevenly placed dupatta that you realise that Neeraj is not your normal 22-year old. Neeraj is autistic.

Very few people in India know about autism, which is a developmental disability, a result of a neurological disorder. In a country which finds it difficult to clothe, feed or provide employment to its abled citizens, it’s perhaps not surprising that people with disabilities are often overlooked. According to international statistics, one out of 500 people have Autistic Spectrum Disorder or autism. In India, says Merry Barua, there are about two

million autistic people. Barua runs Action for Autism (AFA), a specialised centre for autism in Delhi. She is also Neeraj’s mother.

Observes Barua, “No allowances are made for autistic children. This is because autism is not distinguished by physical impairment. What we have to keep in mind is that kids with autism have a social impairment.” Autism is distinguished by impairment of social and communicative skills. Says Alok Guha, Chairperson, National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities under the Ministry of Social Justice and Empowerment, GOI, “In autism, you see an uneven skill development, especially in a child’s communication skills. This development happens at age one while the cognitive skills develop at age three.” This could be manifested through communication problems, echolalia, repetitive behaviour etc. In lay



man’s terms, it means that the autistic child would display socially regressive behaviour like hand flapping, echoing of words/sentences without understanding the meaning, body rocking, extreme sensitivity to external stimuli like sound, smell or touch, or the inability to speak or express him-

### Fast facts

Most parents avoid too much exposure to computers as it reinforces the child’s isolation, says Guha. Barua adds that any profession that doesn’t involve too much social interaction is usually considered fine.

Incidentally, the government has set up the National Handicapped Finance and Development Corporation (NHFD) to provide loans at soft interest rates to persons with disabilities. There are also Special Employment Exchanges for disabled people.

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self. Autism, incidentally, is usually four times more prevalent in males than it is in females. At times, the affected person could also display anti-social or self-injurious behaviour, as well as be hyperactive, suffer from insomnia and an eating disorder.

"Autistic children often seem wilful, disobedient or spoilt to outsiders. Since they are socially impaired, they learn social skills almost by rote. It's like having to follow social scripts in order to be able to function as a social being. Imagine functioning on Mars after reading a manual on social rules. You have learnt the rules, but people

### Help channels

- Action for Autism, Delhi, 011-6416469/70
- Institute for Remedial Intervention Services (IRIS), Tamil Nadu, 044-2310968
- Academy for Severe Handicaps and Autism (ASHA), Bangalore, 080-3225279
- The Inspiration Centre/Prerana Special School, Delhi, 011-5611861, 5412463
- Tamanna, Delhi, 011-6883853
- Muskaan, Delhi, 011-6566766/6532608

don't always behave according to rules! Autistic children don't know when to 'bend' the rules of the manual to fit a changed situation," explains Barua. She cites the example of one of her co-workers, who would insist on wishing her every time he met her, irrespective of whether she was in the middle of a conversation. "It wasn't that he wanted to interrupt. He simply didn't imagine that he could wait for me to finish," says Barua and adds, "Yet this behaviour would not be acceptable in most work situations."

"Autism is a complex disorder — as Barua says, no two autistic children are the same — and is often referred to as a spectrum disorder, where symptoms can be present in a wide variety of combinations, ranging from

mild to severe. Neither is autism always accompanied by mental retardation. Says Guha, "In almost 50 per cent of the cases, autistic children don't have mental retardation. In fact, it's often been seen that they excel in maths, music or the arts." Does that mean that they can be gainfully employed? Says Guha, "Obviously, some employment assurance is needed. Some can, in fact, be more appropriately employed than others." Yet where can they be employed? "In sheltered workplaces that are dedicated to the differently abled, or in semi-sheltered environments such as an organisation that has a policy of employing some persons with disabilities. Some with very mild autism do work in an open environment as well," points out Barua. But the immediate need is to educate them, says Barua, before one can even think of giving them employment. As she says, "They don't all need special schools. Regular schools are the right place for some, provided teachers are sensitised and given training in dealing with children with autism."

As I walk away, I ask if Neeraj is also being trained for some vocation? Barua informs me that Neeraj, who used to be severely autistic, is now being trained in printing, which he has picked up quite well. It seems that hope has once again triumphed over adversity.

### Possible options

- Candle making
- Photo-copying
- DTP
- Food processing
- Masala/ agarbatti making
- Printing
- Agro-based work plus dairy farming
- Computer-based work
- Assembling, sorting

