



# Born different

**AUTISM:** Early diagnosis and intervention help

By RASHMI SAKSENA

Autism was just another word for Meena till six months ago when her son Siddhartha was diagnosed with the brain disorder. As the three-year-old sits with eyes downcast, seemingly unaware of the bright red toys around him at Open Door, the Delhi school for autistic children he attends, the only comfort for Meena is the knowledge that she is not alone. Around two million in India are autistic.

Described as neuro development spectrum disorder because symptoms range from mild learning and social disability to severe impairment with multiple problems, autism remains a low profile disability. The word autism was first used by Dr Leo Kanner, a

psychiatrist at Johns Hopkins University, to identify a group of children who were self-absorbed and had severe social, communication and behavioural problems. The Government of India recognised autism as a disability in 1999 by establishing The National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities, under the ministry of social justice and empowerment.

Parents still have to knock at many doors before they get an accurate answer to what makes their child different. "My son reached his milestones in time but did not speak till he was two," says Meena. "Some said he is a late speaker. Our paediatrician did not bother about it.

Only when we mentioned autism did he look at the possibility."

Says Merry Barua, credited with putting autism on India's map by founding Delhi-based Action For Autism (AFA): "Most autistic children are not diagnosed." Merry's 22-year-old son Neeraj is autistic. "I went to leading paediatricians because I felt there was something wrong with my baby. He did not speak or play and just walked around in his nursery school. Once I was late by three hours to pick him up and I was told that he had not once asked for his mother. But no doctor could diagnose."

When Neeraj was four and a half years old, Merry met a friend who was trained in the UK as a special educator for children with special needs. She advised Merry to see a psychologist

Autism is a disorder of the brain that makes it difficult for the child to make sense of the world and communicate and socialise. Since we do not know the cause yet, autism cannot be prevented or cured. But with appropriate intervention, people with autism can make remarkable progress and live a full life. So it is important to recognise the symptoms and act accordingly.

## How to detect autism

- ◆ The child has difficulty in playing with other children
- ◆ Uses gestures to indicate needs
- ◆ Laughs and giggles inappropriately
- ◆ Avoids eye contact
- ◆ Poor in social skills



- ◆ Echoes words and phrases
- ◆ Does not like change in routine
- ◆ Is hyperactive or is extremely passive
- ◆ Doesn't respond when called
- ◆ Doesn't understand real dangers
- ◆ Enjoys spinning or rotating object

- ◆ Doesn't respond to normal teaching methods
- ◆ Is inappropriately attached to objects
- ◆ Shows apparent insensitivity to pain
- ◆ Has crying tantrums and shows extreme distress
- ◆ Exhibits unusual body movements such as flapping of hands or rocking or jumping



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only model school for autistic children. AFA networks with six organisations in India and one in Nepal to train parents and professionals, and plans to set up a national centre for advocacy research and training for autism in Delhi.

◆ Shakeela, a teacher from Ladakh, took her 7-year-old daughter Asma all over India for a diagnosis. Asma does not establish eye contact,

flaps her hands and can barely communicate. A doctor in Chandigarh directed her to Merry.

◆ If Puja's neurologist uncle had not come visiting she would probably have not discovered why her son Rishabh at two and a half years did not speak and respond, though he had passed a hearing test. "My uncle told me to go to NIMHANS," says Puja. "They gave a diagnosis in two minutes."

◆ Priya was worried when her 6-year-old son Manish showed a "different behaviour". When no doctor in Jamshedpur, where they lived, could diagnose his condition she took him to Delhi.

Life for her has completely changed after the diagnosis, just as it has for Puja, Shakeela and Meena who moved to Delhi to train their children at Open Door. "Parents of normal children and teachers don't understand," says Priya. "Some tell children not to mix with the odd one. We mix only with each other because we understand each other's problems."

"Autistic children look normal, so people find it difficult to accept them as disabled," says Alok Guha, chairperson of the Trust, which

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### REACHING OUT FOR HELP: An autistic child at Open Door in Delhi

who worked in Kolkata and Canada. Neeraj was diagnosed as autistic "but there was little information about the disorder". To know more, she read books on the subject. She trained and worked in the US as a teacher for autistic children, and visited special schools in the UK, Denmark and the Philippines before setting up a classroom back home for her son. Another girl with the same disorder joined in.

Merry started AFA, a non-profit organisation, in 1994 and the demand for services has kept her busy ever since. AFA conducts training workshops for autistic children and their parents. Her Open Door is India's

**The Hug Machine** has a calming effect on the hypersensitive autistic person. Developed by Dr Temple Grandin who was diagnosed autistic at 2, the machine has cushioned sides hinged at the bottom to give a V shape, a headrest and hydraulic controls. The user lies down or squats inside the V and using the controls allows the side boards to apply steady pressure on the body. Grandin in her books, *Emergence Labeled Autistic and Thinking in Pictures*, describes how her discovery of pressure helped her reduce the effects of anxiety.