

## By Irene O'Brien

SHE is their mother, teacher and friend. She laughs with them, cries with them and is no less a child in their company. She is Merry Barua, the founder of Action for Autism (AFA) in New Delhi. Established in 1994, it networks with six organisations in India and one in Nepal.

Merry has the credit of starting India's first school for special children (1991)—'Open Door' which facilitates a barrier free environment—informational, attitudinal and physical—to create opportunities for education, employment and socialisation for persons with Autism Spectrum Disorders.

And how did it all start? Says Merry, "My son Neeraj was diagnosed with autism at the age of four and a half. Knowing little about this disability, I went to the US and got trained as a teacher for autistic children, and visited special schools in the UK Denmark and the Philippines. After I returned home, I had one-on-one sessions with my son, and was surprised to find him



PHOTO COURTESY OF AFA

improving. I then thought why not help out other autistic children. And thus started my school with the help of other parents."

AFA also conducts workshops for autistic children and their parents to empower families with autistic children. Says Barua, "Parents are our main target as they need to build an emotional bond with their children. For this purpose, we have experts coming from the US and other organisations to provide ample information on autism."

In order to create awareness, a website, library and an information service has also been provided.

Merry enjoys what she does. The bell rings. Merry is ready for her class. She must leave, she says. A modest Barua then stops, looks back and says, "I don't want to be known as a martyr who gave up her life for the cause of autistic children. "Autism is not a disease. What these children need is empathy and not sympathy. They need to be understood and loved rather than be made fun of and shown pity."

**SPIRIT OF ENTERPRISE  
COURAGE UNDER FIRE**

**Merry Barua**

# NGO's effort a ray of hope for autistic children

BY NEEMA PAIDAK  
*Correspondent*

**New Delhi :** There is a glimmer of hope for children suffering from autism. And it comes as a relief for their parents. Delhi Chief Minister Sheila Dikshit recently laid the foundation stone for the National Centre for Advocacy, Research, Rehabilitation and Training.

Located at Jasola, near Indraprastha Apollo Hospital in South Delhi, the four-floor centre would cater to hundreds of autistic children, and their parents, who find it excruciatingly difficult to come to terms with life.

## Pioneer

The facility is the brainchild of Merry Barua, founder, director of Action For Autism (AFA), a non-profit organisation that has pioneered the autism movement in South Asia.

A parents-driven group, AFA is involved in training teachers, counselling parents and campaigning for the rights of autistic children and adults.

About 22 years ago Merry's world had fallen apart when she realised that something was crucially amiss with her son. He was diagnosed as autistic. Merry did not know where to seek help as autism till then was a little understood disability in the country.

Autism is a complex, lifelong developmental disability, which appears during the first three years of a child's life. It impairs a person's social, communicative and abstract thinking skills. A number of autistic children do not ever develop speech, while others do but rarely use language to communicate. This means that an

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autistic person is trapped in a bubble-world, which has no relation to the world around.

As things turned out, Merry took her son to the Options Institute in Massachusetts, US. The course at the Options helped the child immensely. The mother worked hard with him and assisted him in developing a vocabulary and a sense of the world around him.

As the child learnt to communicate, Merry's zest to know more proved a turning point not only for her son, but also for several other children. She decided to reach out to others.

In 1991 she started AFA with two students including her own son. Today her centre caters to over 60 autistic children. But for lack of space, every month she has to turn away 10 to 12 parents with autistic children who call up at the centre that provides special education.

"I really feel sad for parents, but we have run out of space on our present premises. Given the demand for services, the place has become inadequate," Merry said.

### **Mission**

The centre is being run from the third floor of a building at Chiragh Delhi Gaon in south Delhi. Merry is hopeful that she will be able to take in many more children on moving to the new premises next year.

"There are very few schools in Delhi that provide special education exclusively to autistic children," Merry said. In fact, for a long time autism was not on either the federal government or the city government's health care list. The Persons with Disabilities Act passed in 1995 did not cover autism.

It is the third most common developmental disorder, more common than the Down's Syndrome. According

to estimates there are over two million people in India with Autism Spectrum Disorder. And 80 per cent affected by autism are boys.

It is not the staggering numbers alone that is worrisome for both parents and doctors. "The infrastructure to deliver special education for autistic children is woefully inadequate. Unlike in the US and some European countries, there are no studies in India that document the rise in autism," Merry said.

"Persons with autism have to learn normal patterns of communication and ways to relate to people," Merry explained.

"The symptoms range from a mild learning and social disability to a severe impairment. The disorder may occur alone or with accompanying problems such as mental retardation, cerebral palsy, or seizures," she added.

No single, specific cause of autism is known, though current research links autism to biological or neurological differences in the brain. But contrary to the general perception, autism is not a result of poor parenting. And with early, accurate diagnosis and appropriate and intensive intervention, people with autism can make significant progress and live productive lives.

The AFA's mission is to facilitate a barrier-free environment; to empower families of persons with autism; and to act as a catalyst for a change that will enable children with autism to talk, interact, play and learn.

The centre trains teachers, counsels parents and holds workshops. It looks forward to generous donations from people to extend its activities and help more people.

### **Reaching out**

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Research, Rehabilitation and Training at Jasola in south Delhi to cater to autistic children and their parents

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- Action For Autism (AFA), a non-profit organisation pioneered the autism movement in South Asia in 1991
- A parents-driven group, it is involved in training teachers, counseling parents and campaigning for the rights of autistic children and adults
- Persons with autism have to learn normal patterns of communication and ways to relate to people
- There are over two million people in India with Autism Spectrum Disorder. And 80 per cent affected by autism are boys.
- Very few schools in Delhi provide special education exclusively to autistic children.

## **Symptoms**

- Difficulty in expressing needs or wants verbally or non-verbally.
- Repeating words or phrases rather than responding to questions
- Making repeated movements such as rocking or hand flapping
- Not responding to questions by appearing not to hear
- Displaying emotions, pleasure or distress for no apparent reason