

## 'Action for Autism' in India

### A visit by Cath Hayes

Many of you will have experienced the late diagnosis of your child as having an autistic spectrum disorder after years of puzzling and soul-searching. Then following diagnosis, you will have experienced the anguish of the search for appropriate education and advice on how to help your child at home. But imagine how much harder your task would have been in a country in which the government does not recognise autism as a disability, and therefore provides no funding, where no educational psychologists are able to diagnose autism, and where children are educated either in mainstream schools, where classes can have as many as 65 pupils, or in special schools where many disabilities are grouped together. What would you do?

What Merry Barua did, when Neeraj was diagnosed at the age of 10 by health professionals, was travel with her husband and son from India to the Options Institute in Massachusetts, USA, for one week, following which she set aside a room in their house to work with him. After 18 months, and success in the areas of communication and sociability, she was faced with the problem of finding suitable education to enable Neeraj to move from the home into the community. What this dynamic woman then did was take herself to North Carolina, to see what the TEACCH programme had to offer. Returning to India, after having also visited Helen Allison and Storm House schools, she decided that her son's needs could best be met if she opened an autism-specific school. Thus the 'Open Door' school in New Delhi came into being. At the same time, Merry began to set up and organise 'Action for Autism', a parent support organisation similar to WMAS, to provide support and training for parents, except that her organisation covers India, Pakistan, Nepal and Bangladesh!

I was privileged to be able to contact this organisation and visit the school during my recent visit to India. Merry runs the whole organisation from one room in her apartment using her own telephone, due to the delay in India in getting an extra line installed. She works in the school each day, Tuesday -

Saturday, from 8.30 until 1.00 with the children, followed by a staff feedback session, after which she goes home and opens the 'office', helped by a friend and neighbour. In addition to running the school and society, she edits the regular newsletter, which is sent to members, and tries to raise funds to keep the whole thing going!

The school takes 11 pupils, including Neeraj now aged 17, aged from 4 to 18. There are two trained teachers and a number of volunteers to facilitate a ratio of 1:1. The children cover the whole autistic spectrum, several being non-verbal and others having what we would define as Asperger syndrome. They all live by necessity within the Delhi area, as parents have to bring them in daily, although one family have moved from Kashmir for two years to enable their son to go to the school. Needless to say, there is a long waiting list! Parents pay according to what they can afford, Merry having to pay an exorbitant rent for the three rooms, which the school occupies.

The school comprises two classes, 7 in the junior class, which is a large room at the top of two flights of stairs, and a senior class of 4 which occupies two smaller rooms on the ground floor. There is no outside play area, recreation being taken in one end of the large junior room. The children are able to work at non-distracting individual workstations according to TEACCH principles, and one adult works with a child at new skills, or with a group, whilst another adult records and observes, so that staff receive non-threatening feedback on their work daily as part of their on-going training. When not working, children play under guidance and supervision. Each child has a keyworker but all programmes are decided on jointly and with parents, and everyone working in the school is treated as an equal. The senior class concentrates on group projects, such as office skills to prepare them for possible outside employment, and also on social language situations. All the staff try to restrict their language when speaking to the children, although there is the additional difficulty for the students in that English is the teaching medium, as it has to be in a country of so many languages. Obviously, though, the