A glimpse into a different world

To create awareness, the United Nations General Assembly in New York has declared April 2, 2008, as the first World Autism Awareness Day. A glimpse into the world of people afflicted with this genetically caused brain disorder.

Dr. Antonia Rotgers

The film "Rain Man" starring Dustin Hoffman, 20 years ago, thrust into the limelight, a condition which most of us are still a mystery. Autism is believed to be a genetically caused brain disorder, which impairs social skills and communication. But not every autistic person is like the Rain Man; the autism disorder spectrum ranges from severe learning difficulties with complete lack of speech to highly intelligent and verbose but socially-odd behaviour as was the case with Albert Einstein. The physicist would smoke trashied cigarettes butts he fished off the streets, lecture his eight-year-old nephew on higher physics, and ride his sailboat on windless days.

"For very long, autism was seen as a disease affecting the West and we could get neither correct diagnosis nor therapeic assistance for autistic children in India," says Reeta Sabharwal, Director (Finance and Administration), Action For Autism (AFA), a parent-run self-help organisation.

Around 1894-95, when Sabharwal was desperately seeking answers to what was "wrong" with her daughter Ishqeta, then about 8 years old, she met Serry Banerjee, who was founding AFA to offer advice, support, and education for parents of autistic children. AFA officially started in 1991. A freelance interior designer at the time, Sabharwal later joined it as an active member.

Between then and now, AFA has developed into a small but efficient centre for training and schooling. Sabharwal's daughter, 24 — attending AFA's vocational school — has grown up into a young adult with many skills, such as block printing, envelope making, wind chime making — repetitive activities. How was the mother's experience in equipping Ishqeta with all this? "Initially it was very difficult because of her low concentration level. There were times when she would put water from a jug into a glass and then back into the jug. And, she would keep doing this for half an hour. But if I asked her to do something, she would do it for one minute and lose interest." Sabharwal says she would get her daughter to do what she wanted her to, for example threading a full string of beads — by what trainers term reinforcemement. In other words, offering an incentive that the child enjoys, such as chips.

AFA runs a three-month programme for mothers together with their children. "We have mothers coming from as far as Dubai and Pakistan for the three month training course," says Sabharwal. "During the course these mothers learn how to communicate well with their child," says Indu Chawal, Director Education, AFA, who has two autistic children herself. "In the first two weeks of the programme we have orientation classes to tell the mothers what autism is, what is different about their child so they can understand the child. Then we do an assessment of the child — what his or her interests are and how to modify the child's behaviour. Autistic children clap or rock repeatedly. The mothers feel very uncomfortable with this. We talk to them about it," she adds. Initially the mothers are advised to let the child do so and then an occupational therapist gets involved, says Chawal. "We train the mother to work one-on-one with her child by providing hands-on training."

The children are also given some communication therapy. According to Chawal, autistic children do show affection (provided you can perceive it). "They’ll touch your hair. They will want to hug you. Don’t want to be left because they are very touch. Sometimes very inappropriate if they meet you..."