

**T**he day Mary Barua learnt that her only child, Neeraj, was autistic, she headed straight for a library. She wanted information on his condition, which the doctors were at a loss to explain to her. When Shyama Chona's second child, Tamana, a pretty little girl whom people came for her 'very special dance,' was diagnosed with cerebral palsy, the world seemed to have come to an end for her.

Shanti Auluck's feelings were no different when she realised that her son, Puneet, now 21, was born with a chromosomal abnormality called Down's syndrome, which is accompanied by a mental handicap. Sanjit Sengupta had to cope with his daughter's suicide note when she killed herself after giving a bad paper. Her note read: "So sorry for the spelling mistakes."

For each of these parents, the trauma of their children could have led them down the path of self pity and remorse. Instead, they have not only overcome their grief, but in the process have also initiated efforts that are today benefiting many parents like themselves and their children. It has not been easy. But the obstacles and disappointments they faced while bringing up their children, gave

larly holds meetings and counselling sessions on Sundays, where it helps young students cope with their personal and educational



**Coping bravely:** (left) Mary Barua with a child from her school and (above) Shekhar and Neelam Krishnamoorthy with their children in happier days



# Parent bodie

Parents of special children are getting together to work for kids like their own. **Geeta Sharma** reports

wherein they learn to do block printing on wrapping paper, gift envelopes, carrier bags and letter pads and make decorative *diyas* and candles.

The Mumbai-based Make-A-Wish Foundation (an affiliate of

the US foundation) was the result of the personal tragedy that Geeta and Uday Joshi faced a couple of years ago, when their ten-year-old son Gandhara died of leukemia.

They had taken their son to

America for treatment and miserable when they found it difficult to meet medical expenses alone pay for a trip to Disney World that Gandhara wanted to go on. That was when they met a volunteer from

*Telegraph*

ouliers like themselves.

According to consultant psychiatrist, Prathama Chaudhuri, it is quite common for parents to work for a bigger cause in coming to terms with their child's disability. "In fact, when parents come to us for counselling, the reactions are typical. Either there is guilt, or frustration or plain denial of facts."

The parents are normally advised to come to terms with reality by associating themselves with an organisation through which they can know more about families facing the same problem. "This is what we mean by 'sublimation', in psychological terms. Not only does it serve an altruistic purpose, it also helps one come to terms with grief", avers Chaudhuri.

Take Mary Barua, for instance. Mary had put her autistic son in a special school that had just been set up for mentally challenged children. But she soon realised that the school was treating him like a mentally retarded child and decided to keep him under her wing. "Professionals

often tell the parents that we are not dealing with their child the right way, but I feel parents can make the best guides for children with special needs," she says.

Mary began networking with parents of autistic children across the country, and even went abroad to attend training courses. Enthused by the progress her son had shown, Mary took in two more autistic children at home and worked with them. What went on to become the School for Autism, in Delhi.

The School today has about 30 children and six teachers besides Mary. No method is followed as a recipe card at the school, but besides developing cognitive and academic skills, emphasis is laid on developing the social and communicative skills of the children. Her own son, Neeraj, now 17, can dress up on his own, express and cater to all his personal needs and even strike conversations by himself.

Sanjit Sengupta set up the Crisis Intervention Centre, an organisation in Calcutta which tries to inculcate positive thinking among children, after the suicide of his own daughter. She had killed herself after doing badly in her examinations. Today, the Crisis Intervention Centre regu-

has to go through Sengupta did.

"The greatest problem in coping with a disadvantaged child is when parents try to deal with the problem within the four walls of their house. You always feel the odd one out," says Rama Sarkar, vice-chairperson, Mothers' Association, a section of Reach, an NGO in Calcutta. Having faced the problem herself — her own child suffers from a chromosomal abnormality — Sarkar feels the biggest challenge that Mother's Association faces is to educate parents, especially mothers, on how to bring up a child thus disadvantaged.

"Our primary purpose is that of integration. It is quite the norm to see ordinary children or even adults view disabled children with almost a sense of abhorrence (to put it a bit harshly but realistically). What we want to do is to let children of both sides have access to each other's world," she says.

Activities in Mothers' Association include seminars, conferences, running a leisure

her daughter... through. "Till she was... she could not swallow anything so I had to mince the food in the mixer and put it down her gullet," she recalls.

Chona wanted to provide the best possible care to her daughter. But not finding much of a support system in terms of institutions dealing with the handicap, she travelled abroad to learn about the disability and ways to cope with it. Gradually Tamana began to cross the innumerable hurdles that had hindered her progress. Today she is pursuing a course in tourism and hopes to open a travel agency one day.

Though she got Tamana admitted in her own school in the hope of giving her a normal environment, Chona, with all the support she could muster from friends and contacts, set up a special school for children with disabilities and named it after her daughter. "I wanted to be able to extend the same kind of help and guidance to parents of other handicapped children," she says.



(Above) Children at the Tamana Special School and (top) a view of the school

includes teaching them yoga, dance, music and drawing. "We are also starting a Young Adults Centre which caters to people over 18. All I can say is that all the children are extremely happy to be a part of this set up and it helps us parents as well. We do not feel the odd persons out," says Sarkar.

Shyama Chona, principal of the Delhi Public School, R.K. Puram recalls that when her daughter was diagnosed with cerebral palsy people would tell her, "Why not? May be it is your karma." But what caused her

him up has been a valuable experience."

The need to provide vocational training and a means of sustenance to special children after they pass from school is what impelled her to set up Muskan. Muskan is an effort that has grown into the largest parent run vocational training and work centre, that also provides opportunities for fun activities, sports, games, painting sessions and workshops for children with special needs. Besides they are also into other creative pursuits

without any electricity or water. Today it is a completely independent school that educates and rehabilitates 140 mentally disabled children. About 40 per cent of the school's students, who belong to the weaker sections of society are beneficiaries of freeships.

Shanti Auluck, a lecturer with Lady Shriram College in Delhi, whose son suffers from Down's Syndrome, says she had learnt of her son's disability within two days of his birth. "I felt as if life was over for me and I wondered if anything would ever hold any charm for me. But my child has been a great teacher to me and bringing

cities after their the fill girl tum see Joy to g w's Br Fo Kr tee an Up tw to 11 A U a t t