

# DOUBLE Handic

**D**IPIN KASHYAP appears to be like any other 13-year-old with a passion for cricket and cars. But try speaking to him and he'll turn his head away. Sometimes, he may mutter something in your direction, not making any eye contact at all. Dipin is not even toilet-trained and cannot eat on his own. He insists on scratching you all over, but actively resists even being touched by anyone. He enjoys listening to music, but the sound of a crying child or a pressure-cooker whistle can tear him apart. And on those rare occasions when he sits at one place, Dipin rocks back and forth in a rhythmic motion for hours. Any change in his routine upsets him no end.

Dipin is an autistic child. But it took his Shimla-based parents six years to figure that out. The doctors they visited suggested every possible affliction, but not autism. "The paediatrician reassured us that it was nothing but slow development and delayed speech, the ENT specialist said he had a hearing problem, the psychologist insisted he was mentally sub-normal, the psychiatrist said it was attention deficit disorder, and our relatives ascribed Dipin's behaviour to negligence on our part," recalls Surendra Mohan Kashyap, Dipin's father, an assistant engineer with the Himachal Pradesh Public Works Department.

There is not a one-off case. Every parent with an autistic child has the same story to tell. Dustin Hoffman's Oscar-winning portrayal of Tom Cruise's autistic brother in *Rain Man* has done little to raise even the medical profession's awareness of the third most common developmental disorder, which is twice as widespread as blindness, and has derailed at least 1.7 million young lives in the country, a good fifty years after it was described by the American psychologist Leo Kanner.

Today, there's more misinformation about autism than any other disorder. Parents, according to a national survey by the Delhi-based NGO Action For Autism, have to visit an average of five doctors (the num-



ber can even go up to ten or fifteen). "This life-long disorder is still so much of a mystery that even senior doctors at well-known hospitals tend to dismiss autistic children as being mentally retarded," says Merry Barua, Director, Action For Autism. "The baseless belief that autism is a Western disorder also distracts doctors from arriving at the right diagnosis."

Reliable statistics confirming the number of autistic children in the country are hard to come

■ **When Indrani Chakravarty took Indraneel to the doctors, they told her she was worrying unnecessarily. A doctor even said she needed psychiatric help.**

dren. It is then that parents begin to panic.

"Autism can be recognised only by the presence or absence of certain characteristics," says

tachment to unusual objects.

"It is not that all autistic children will have all these traits," Chona continues. "Their behaviour can only be recognised if they show a combination of these traits. Most of them, however, are identified only when their social and communication skills are impaired." But each autistic child is dramatically different from the other, making it even more difficult for parents or doctors to identify the disorder. Certain autistic children



**P** For the Government, they don't exist; for neighbourhood doctors, they're a medical mystery. Yet, India has 1.7 million autistic children, who cannot even aspire for official aid because our arcane laws don't

**SHWETA RAJPAL**



**■ Satish and Sangeeta Bhandari take Nikhilesh to Phoenix, Arizona, every three months for a booster course in music therapy, which, they say, has made a difference. But each time the aircraft takes off, he screams in pain.**

are so few and far removed. No wonder Dehra Dun-based P. K. Mishra opted out of his fast-track career with a leading computer firm two years back to be able to look after his son Tejasvi. "He lives in his own world and I know that my presence makes no difference to him," says Mishra ruefully. "But he needs me and I have decided to give him complete attention."

Satish and Sangeeta Bhandari of Indore, meanwhile, take their eight-year-old son Nikhilesh to Phoenix, Arizona, every three months for a booster course in music therapy, which, they say, has made a big differ-

**■ Merry Barua remembers how doctors insisted that Neeraj was a spoilt brat who needed to be beaten up. When the beating didn't work, they said she wasn't hitting him hard enough.**

ence to their child. But even reaching their destination proves to be quite a challenge for them because Nikhilesh, who reacts strongly to loud sounds, finds the aircraft's take-off unbearable. "He just hold his ears and screams in pain," says Sangeeta, as she struggles to make Nikhilesh walk down the steps.

autism as a disability. "Without recognition, autistic children won't be eligible for government funding," explains Barua. "Persons challenged with autism are not even eligible for concessions unless they are diagnosed as being mentally retarded." It took a lot of lobbying, in fact, for autism to be included last year in the National Trust Bill for Mental Retardation, Cerebral Palsy and Autism, which provides for a national fund to finance the needs of the mentally and emotionally disadvantaged who don't have anyone to look after them. But the Bill, drafted in 1991, is still to be tabled, making a mockery of the expectations of parents like Barua from it. Autism, ironically, continues to find no mention in the Persons With Disabilities Act.

With no special services and funds to look after those challenged with autism, what is really worrying parents is the future of these children. Says Burman: "I get sleepless nights





■ **Bina Burman spends sleepless nights thinking about four-year-old Uttavan's fate once she isn't around. "Why can't the government do something to help us?" she asks in desperation.**

by, but it is estimated that 15 out of 10,000 children worldwide are autistic. The disorder is also known to be four times more common among boys than girls. But the condition and its causes continue to baffle doctors. The disorder is generally ascribed to a genetic or a neurological problem, but it doesn't register until a child turns two or three, and does not respond or talk like other chil-

Shyama Chona, President of the Delhi-based Tamana Special School, which is giving special education to 25 autistic children. These characteristics may vary from one autistic child to another, but there are certain traits that set all autistic children apart. An autistic child, for instance, prefers to be alone, avoids eye contact, is unable to talk meaningfully, tends to repeat certain words, and shows an at-

have normal IQs and well-developed reading skills, but others have a low IQ and cannot read at all.

Take the case of four-year-old Uttavan Burman, from Durgapur in West Bengal. He has a photographic memory — in fact, he's his family's television guide, keeping them updated on all the upcoming programmes. But Uttavan cannot speak more than a word at a time. "He is very moody and restless and hates to sit at one place," says Bina Burman, Uttavan's mother. "He starts howling without any reason and dislikes eating. But he loves travelling in cars and can be on the road for hours."

Unlike Uttavan, Kapil Tegta, a four-year-old from Shimla, hates travelling because traffic noise bothers him a great deal. "He just shuts his ears and starts howling whenever he hears any loud noise," says Paramjeet Tegta, Kapil's mother. "He is also very stubborn. If you don't listen to him, he'll start biting you or pulling your hair." The lack of professional advice or help in a small town like Shimla only compounded the woes of the Tegtas. "No doctor diagnosed his problem correctly till we came to Delhi and met experts," she recalls.

Not that those living in the metros are any better off. Barua, whose 18-year-old son, Neeraj,



autistic, was dismissed by all doctors as being a paranoid schizophrenic. "They said Neeraj was a spoiled brat who needed to be beaten up," Barua remembers. "When the hitting and beating didn't work, I approached the

psychiatric treatment. He just wouldn't acknowledge that my child had a problem."

The medical profession's failure to wake up to the problem leaves parents with no option but to find their own ways

to make Nikhilesh walk down the steps.

What agonizes most parents is the inconsistency in the behaviour of their autistic children. Inconsistency, in fact, is the hallmark of this disorder. At times, persons affected with autism may not even exhibit the behaviour patterns that are taken to be indicative of autism. "No doctor and no medicine can help an autistic child," says Chakravarty, who managed to

lenged with autism, what is really worrying parents is the future of these children. Says Burman: "I get sleepless nights thinking about what will happen to my son. Why can't the government do something to help us?" Disillusioned with the government, parents have decided to come together to form some kind of a network. Their main objective is to give vocational training to the children so that they can be gainfully employed when they grow up.

"Autistic children are generally good with mechanical work and work well with computers because it gives consistent responses," says Barua. "We can hone their skills and help them evolve into productive human beings. Neeraj, for instance, is not what he used to be a few years ago. He can now feed himself, bathe himself, and even go to the market and shop for himself. Most importantly, he's a happy boy today. I hate to be saying this as a mother, but autism is a fascinating disorder — you can never know enough about it."

Barua is a brave mother, so she can afford to say so. Her words may even inspire parents of autistic children not to give up hope so easily. But for those who continue to knock at the doors of ill-informed doctors, life continues to be a relentless journey into the dark. ■

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**SHYAMA CHONA,**

President, Tamana Special School, New Delhi



or again, and to my horror, told me that I was not hitting hard enough!"

Even Indrani Chakravarty in Delhi had to face a similar situation. "When I took my son to the doctors," she says, "they told me I was worrying unnecessarily. A doctor started counselling me and I needed some sort of psy-

chology of tackling it. What makes the situation more difficult is that the needs of autistic children cannot be satisfied by regular schools, which is why they are either denied admission or removed from the rolls later. So parents are left with no option but to put their autistic children in special schools, which are not always accessible because they

toilet-train her 11-year-old son just three years back. "A parent will have to learn to be the child's best friend. It is hard, especially because you are constantly rejected by your child. But persistence pays."

Even as distressed parents struggle hard to live with this mysterious disorder, the government hasn't even recognised