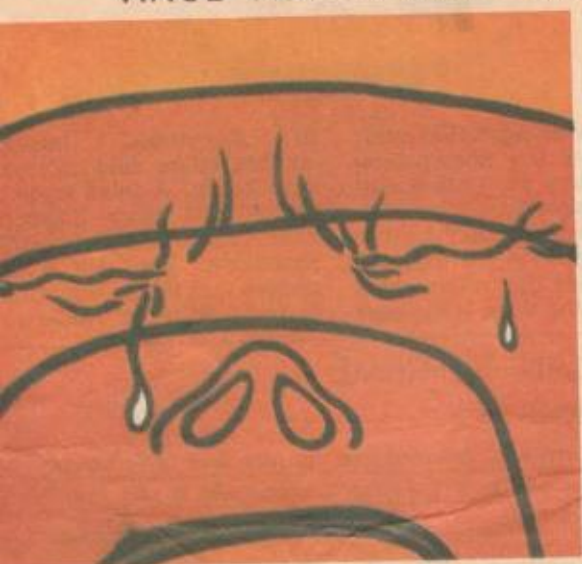


Wrongly dubbed as a 'Western' condition,
autism goes largely undetected in India.
VINOD KUMAR looks into the autistic mind.



OVER 16 lakh Indians cannot communicate with their brothers, sisters, teachers or friends. Yet, they are not deaf, dumb or blind. They are affected by autism, a very complex neurological disorder. And they can all be helped.

Autism is as common in Bombay as it is elsewhere in the world, and makes no distinction between rich and poor, even though many Indian doctors insist that autism is a 'Western' condition. Small wonder then that this disorder is so often wrongly diagnosed.

The mother of Shonali, a 15-year-old autistic girl in Madras, commented, "Since she was three, I had my doubts. But my paediatrician kept brushing me off. He said something was wrong with me, not Shonali. Whereas, I lived with her and knew she had a problem. The doctor saw her for just 10 minutes and didn't see what the problem was. Doctors should be aware of autism. Half of them aren't."

It was once believed that autistic children had severe emotional or psychological problems although the world's leading experts have consistently discarded this notion as outdated. Some doctors, teachers and family members continue to blame parents.

Autism primarily impairs the child's social interaction and imagination. And 80 per cent of those affected are male. Five-year-old Sunil, from Bombay, is an autistic child. He is able to complete a 100-piece jigsaw puzzle faster than his eight-year-old, non-autistic brother Rakesh can. Yet he is unable to communicate to his parents when he is upset by loud noises and screams when an aircraft flies overhead. Like most autistic children, Sunil looks no different from his brother or his cousins. In fact,

for a learning disability or behaviour problem. Yet its symptoms are such that doctors are wont to wrongly seek its origins in emotional and psychological problems, epilepsy and Attention Deficit Disorder. As mental retardation is suspected to occur in more than half the cases of autism, the disorder is commonly diagnosed as delayed milestone or mental retardation. But all these are separate conditions and do not always accompany autism.

Among the first signs of autism is late acquisition of basic communication skills and unusual use of language. For example, when Sunil is asked a question, he repeats it. Other autistic children such as 17-year-old Arindam use language only to express their basic needs — "Want water", "Go in car" or "roti". Anything even slightly more complex is beyond them.

Many parents notice early that their child doesn't mix with other children at all, although he may be very attached to his parents or those he knows well. Like many children with autism, Arindam is attracted to things his classmates at the special school don't notice, for example, spinning fans and wheels. Sunil collects pieces of string and loose threads, Arindam likes rulers that he can flick back and forth. Both boys often sit and play with these objects for hours without seeming to notice what happens around them. Yet, at other times, they are not able to focus attention even for a few minutes — particularly on school work — much to their parents' chagrin.

Often an autistic child prefers a certain routine peculiar to his own autistic mindset. Shonali from Madras becomes very upset if the taxi takes a different route to school each day, and she also likes to have a certain brand of biscuit with her tea each afternoon. Autistic children often, but not always, are extremely partial to music, and may insist on favourite songs being played

Autism: A Special

over and over again without tiring of them.

"Sunil will rush to the television when commercials are played," explains

development. Professionals the earlier the intervention cases even before two years the more accurate is the

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South Asia to observe teachers through a special two-way mirror.

A visitor to the school will notice that the teachers are full of energy, yet unbelievably patient as their students put them through one challenge after

another. As one parent remarked, "You don't need fancy equipment when you have teachers who care." This is because The Open Door believes in using a non-judgemental approach, so the challenging behaviour of the children is modified through love and acceptance rather than punishment and disapproval. The Open Door subscribes to the view that real learning takes place at home. Its own role is confined to providing training facilities for the child and its family.

The school also has several innovative programmes like inviting siblings of Open Door students to attend school on Saturdays and become more actively involved in the children's training.

Autism is regarded as a disability by the World Health Organization, but not by the Government of India, thus making it ineligible for funding schemes. The families of autistic children, too, are not eligible for the concessions and benefits offered by the government unless the child is diagnosed as mentally retarded. The father of 16-year-old Avinash explains, "I love my child, I don't mind spending money on him. But if all is spent now, what will he do when I am gone? I can't even get a concession on income tax because I cannot get a certificate saying my son is mentally retarded. And my son is not mentally retarded, but he does need help."

Although having an autistic child may not be something parents are prepared for, many families strongly reject the idea that their child is a burden. The mother of a nine-year-old boy explains, "Yes. It's not always easy to deal with this. The emotion

is overpowering — I get frustrated, I get angry. But over the years, I've been able to deal better. Now it's okay. No more tears. I've stopped feeling sorry for myself and I've started enjoying him much more. Had he not been around, I'd be a totally different person. I have something to look forward to. Every day is a challenge. This child has given me so much strength, understanding

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wrongly believe that the child is either naughty or slow.

While millions of dollars are being spent on research, no blood or genetic tests or brain scans have been found capable of indicating the presence of autism in children, although such tests may eliminate other conditions. The only way autism can be diagnosed is through close observation — by noting the presence of certain behavioural characteristics and by scrutinizing the history of the first three years of the child's life.

Although an autistic child may never speak at all, autism is a broad-spectrum disorder. In its milder form, it can pass

programmes." Parents often remark that their child can recite the alphabet, long poems or songs perfectly. This skill reflects the child's ability to memorize and should not be confused with his capacity for comprehension.

But many non-autistic children also go through these stages at times, which is why correct diagnosis is so often delayed. When a parent brings a two-year-old to a doctor complaining that he doesn't talk, the doctor often says, "Come back six months later and we shall see." However, if the child has other unusual habits, a successful early diagnosis of autism can make an enormous difference to the child's subsequent

like to be. This is because and family members are able to fully reduce autistic behavioural before they ossify.

Currently, the needs of autistic in India are not fully met in regular or special education. As Sunil's father, a Bombay-banessman remarked, "The problem that there are schools for retarded and normal children but in between." Autistic children structure and routine, but not the ure and rigidity found in regular

Autistic children are frequent admission in special schools teachers protest that they are ped to handle autistic children

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receive appropriate education. Many parents of autistic children are forced to keep their child at home, with no guidance about management or care.

Fortunately, over the past few years several schools in India have begun to focus on autistic children. One Delhi school, The Open Door, recognizes that the educational strategies used with autistic children must be highly specialized. A visitor to The Open Door will immediately notice that the students are of different ages, ranging from 4 to 18, and yet each child's work and goals are specifically designed. The Open Door has been designed to allow parents, teachers and professionals from all over

any more." But nearly all parents of such children fear that after them their children will be defenceless.

Autism is a lifelong condition, but it need not be a lifelong disability — if each of us is able to help these children with special needs develop their potential and communicate their needs. It calls only for a little bit of strength and lots of love.

For more information about autism, please contact the National Organization for Autism in India, Action for Autism, Post Box 3678, Defence Colony, New Delhi-110 024.