

They Have No Ill-will...

Bringing up a son with autism

Godavari Verma

Gaurav was born on September 29, 2010, in a hospital in Bhopal through a surgical procedure. At the time of birth, he weighed about 1.8 kg. and so was kept in an incubator for one week. From birth, Gaurav had jaundice. In spite of taking him out in the morning sunlight, he was not cured. So, we took him to the doctor and he was admitted to the hospital. Many tests were carried out, but the doctor was unable to find the cause for his jaundice. Finally, the doctor got the HIDA scanⁱ test done in a cancer hospital and Gaurav was diagnosed with Biliary atresiaⁱⁱ which has an incidence of one in 1,00,000.

The doctor told us that Gaurav needed to be operated upon within 60 days of his birth. Accordingly, he was operated, and the doctor told us that the operation was successful. Gaurav started recovering slowly and was discharged from the hospital after four months. His medication continued for the next eight months, approximately and then, he was completely cured of Biliary atresia.

Time passed slowly. Gaurav was two years old, but he had not started speaking. He would not even try to speak. He would go to all family members but not to strangers. He was afraid of any sound made by train, auto or machines. He was not very fond of toys and would not play with them much. He liked round objects a lot and would move his hands in circles. But we were not able to find out why he did that. Time went by and Gaurav turned three. We thought that when we admit Gaurav to school, he would start speaking in the company of other children. We got him admitted to a private school. But even after three months of attending school, there was no change of any kind in Gaurav.

We, then, took Gaurav to *Samarpan* institute and came to know that Gaurav has autism. We did not know what it meant. At *Samarpan*, we were told about *Arushi* – an organisation where children with such difficulties are trained through therapies, special education and other methods.

Gaurav started going to *Arushi* when he was almost four years old. After which there was a gradual improvement in his condition. With the help of speech therapy, he started speaking a little. Earlier, he was not able to understand anything but gradually, this improved. Gaurav was not able to express the problems he faced in school. He continued going to *Arushi* and his school. He slowly learnt to read and write Hindi and English.

At *Arushi*, they advised us to admit Gaurav to the Kendriya Vidyalaya. At present, he goes to *Arushi* and Kendriya Vidyalaya, both. His special education training continues at *Arushi*. Gaurav is in grade 2. I have to take more care of him compared to the other children because even today, he is unable to look after himself fully. Since his birth to this day, I have had to attend to him to a great extent because even today he is not able to make out what is good for him and what can cause harm to him. He displays many forms of repetitive behaviour if he is not attended to. He has to be told again and again to eat his food or to read and write.

Gaurav is now nine. Since his birth, I have not left him alone. I am doing everything possible to make Gaurav alright. Though he can do quite a lot of things on his own, he still depends on me for many things. I can see a lot of change in him though he needs to learn a lot more.

All our family members know about Gaurav being autistic and their behaviour towards him is absolutely normal. There is a lack of awareness about autism in our society. I would like to tell parents and teachers that these children want you to behave with them the way you behave with any other 'normal' child. They do not need your sympathy or pity. They only want your love and normal behaviour. They do

not expect anything from you. Gaurav and all the children, like him, want society to give them equal rights. Society should not look at them as inferior. They may lack certain things, but they do not have any trickery or ill-will.



ⁱ HIDA scan is a hepatobiliary iminodiacetic acid (HIDA) scan; an imaging procedure used to diagnose problems of the liver, gallbladder and bile ducts. (mayoclinic.org)

ⁱⁱ Biliary atresia is a rare gastrointestinal disorder characterized by destruction or absence of all or a portion of the bile duct that lies outside the liver. (rarediseases.com)



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