

Parents Should Seek Help Without Delay

Bringing up a son with cerebral palsy

Neeta and Nitin Nayak

Nirmit was born on July 12, 2011. At the time of birth, he weighed only 1.4 kg. We were quite shocked when we learnt this. We could not sleep for the whole week. We were under tremendous tension and scared as to what would happen in the coming days. Doctors were also not able to give us a clear diagnosis. After staying in the hospital for 20 days, we brought Nirmit home. We had no idea about the problems we would face in future. We only thought that Nirmit was a little weak. We consulted many doctors but there was no improvement and he was still slow in reaching developmental milestones. After ten months, we met Dr Tikkas who is a paediatrician in Hamidia Hospital. He told us that Nirmit was suffering from cerebral palsy (CP) and needs various types of therapies. He advised us to go to the CRC¹. We were really worried about the future of our son. However, we started taking him to the CRC regularly which was 15 km from our place. At home also, we started all the therapies that were done by the therapists at the centre. But not much improvement could be seen. We continued taking him to the centre for about three years. In between, we faced certain family problems and could not attend to Nirmit properly. His development had slowed down further. Meanwhile, Dr Tikkas told us about Dr Vikas Kadam who is an occupational therapist and whose therapies helped Nirmit in sitting up and walking.

We continued with Dr Vikas's therapies. Nirmit was now a three-and-a-half-year-old and we tried to put him in a playschool. A few schools refused to admit him. We enquired in many other schools and finally, he got admission in The Learning Tree. The teachers there were very helpful and Nirmit learnt to live together with other children. But our problem did not end here. Nirmit was able to walk a little but he was not able to read and write. It is at this point that we felt the need to put him in a special school. From friends and acquaintances, we came to know about *Arushi*, an organisation where children with disabilities are trained through therapies, special education and other methods. We went there and they understood our situation very well and thus began the special education of Nirmit. There was a gradual improvement in his condition. He began to understand and identify things. We also became more confident with regard to Nirmit's condition.

Rama Madam, a special educator at *Arushi*, helped Nirmit with his studies and because of her efforts, Nirmit started a little bit of reading and writing. Around this time, we faced some financial problems and found it difficult to send Nirmit to *Arushi*. But we got a lot of support from Sapna madam, Rama madam and others at *Arushi* and he started going there again. Nirmit is now studying in Kendriya Vidyalaya where he interacts and studies with non-disabled children. But he also faces certain problems there. Non-disabled children keep a distance from him and do not let him sit with them. In spite of these problems, a few things are good – many children take him to the morning assembly and washroom etc. They tell him about the homework and write classwork in his notebook. Because of their support Nirmit goes to school without any fear.

It is because of *Arushi* that Nirmit is confident and comfortable in the company of other children. He even performs confidently in the plays staged by the children of *Arushi*. For this, we are very thankful to *Arushi* and the teachers there.

Our routine has completely changed because of Nirmit's education and therapies. We get up early, drop him at the school, pick him up at 11.00 am and drop him at *Arushi*, bring him home from there at 1.00 pm, take him for his therapies at 5.00 pm and finally make him do his homework at home after returning from the therapy sessions. We also need to take good care of his diet in the morning,

afternoon and night, and make time for him to play. Both of us, together, take care of all his activities. We would like to share one important point with the parents of children with disabilities – they should not worry much about the future of these children. Rather, they should focus on their present, spend more time with them, play and laugh with them. Keep inspiring children to move forward without making them aware of their weakness. Our biggest regret is that we did not get to know of his problem and treatment at the right time and so Nirmat's treatment was delayed. We would request all doctors, parents, teachers, and therapists to give complete information about this disability to parents having children with CP—the treatment, how and what should be done and where one can go for treatment. They should also be made aware of the progress of the disability or its effects as a child grows up. This would prepare us to take necessary steps to help our children.

Thanks to *Arushi* – an organisation that has created a whole new world for these children where they get involved in various activities and enjoy themselves thoroughly.



¹ The Ministry of Social Justice & Empowerment has set up seven Composite Regional Centers for Persons with Disabilities at Srinagar (J&K), Sundernagar (Himachal Pradesh), Lucknow (U.P.), Bhopal (M.P.), Guwahati (Assam), Patna (Bihar), Ahmedabad (Gujarat) and Kozhikode (Kerala) to provide both preventive and promotional aspects of rehabilitation like education, health, employment and vocational training, research and manpower development, rehabilitation for persons with disabilities.



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