

Medicine and Society

The challenge of cerebral palsy in India

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My daughter Malini was born in 1966 in India with cerebral palsy. The doctors said, 'Your daughter has cerebral palsy. Brain damage is irreversible. Once the brain is damaged, it's damaged for life. Nothing can be done about it.'

I was 23, my husband 25. The finality of the statement 'nothing can be done about it' devastated us as young parents of our first child. Then began a long battle, a journey which took us away from this situation of negativity and ignorance to England, where my brother-in-law (Samiran Nundy) and sister (Mita Nundy) lived. There, Malini received excellent care and blossomed. We, too, as parents, badly needed the healing touch. After 6 years, we returned. The situation was the same! We were asked, 'What is a spastic? Are you talking about plastics?'

In 1972, by when we were more empowered and better educated about the condition, we launched the first Spastics Society (now called ADAPT, Able Disabled All People Together) in Mumbai to address the dearth of a professional approach to the management of cerebral palsy. What was different? It had a team approach, new to India, which was based on providing holistic treatment for this chronic condition. In this article, I examine 3 issues: in what way we were innovative, how we spread awareness and what has still not been achieved.

Cerebral palsy (CP) is damage to the infant's brain usually around the time of birth as a result of anoxia or the infant getting jaundice, encephalitis or meningitis. There is diffuse rather than localized damage. The associated manifestations could be movement and speech deficits, hearing and visual defects, intellectual retardation, seizures or epileptic fits, and behavioural and psychological problems. There is no fast cure, no quick tonic or panacea. To do justice to the child, holistic management is critical, combining education, treatment, and social and emotional development. This is best done by a large team of experts consisting of doctors, paramedical staff such as physiotherapists, occupational and speech therapists, special educators, psychologists and social workers, in partnership with parents. For effective long term management, there has to be a continuum of management which has a longitudinal element of continuity. This is possible in a school setting, together with good home management by the parents.

For successful management, the team needs to work cohesively, maintaining a trans- or inter-disciplinary rapport. The team comes to a consensus on common goals. The child is looked at as a child first, and then as being disabled. Sometimes there are invisible barriers between various disciplines. Breaking these walls is essential for the child's growth. Contrary to traditional methods of therapy, we developed a treatment model in which each professional's intervention is designed to converge around the overall goals of

treatment. For instance a speech therapist, besides communication, will also need to look at postural seating requirements to help the child to vocalize better; an occupational therapist will also work on walking with the goal of teaching the child to reach the washroom, classroom or playground; a physiotherapist will work on improving the use of the hands so that the child can push his/her own wheelchair or walker and join sports activities or participate in painting, art and crafts. The main aim is to normalize life as much as possible by facilitating a range of activities so that the child realizes that although she cannot do certain things, there are many other activities that she can engage in.

Early diagnosis is crucial. Substantial research indicates how critical the first 5 years of the child's life are. The child's cognitive, social and emotional development, and whatever experiences she is exposed to in the early years, be they good or bad, will mould her personality for the rest of her life.¹⁻⁶ It is now an accepted fact that just as the body needs nutrition and nourishment, so does the mind for mental growth and development. Both teachers and parents, who manage the child's development, need training and a systematic build-up of knowledge concerning the needs of the growing child. If CP is not detected and treated early, there is a high risk of the child developing secondary and tertiary disorders.⁷⁻⁹

Bearing this in mind, we took care to diagnose the condition as early as 10 days after birth and started working with the mother. Infant clinics were set up for high risk babies. The Vojta (a German neurologist) technique of evaluation was used to detect if a baby had what was known as 'central coordination disturbance'. This technique, known as a kinesiological examination, assesses 7 postural reactions. The child is tested in 7 different positions and on the basis of the responses seen, a developmental age is determined. This enables the therapist to prepare a checklist of the milestones and appropriate programme for the child. Identification and assessment of the child's needs are critical and cannot be done in a single examination, but over a period of time. The evaluation sessions are a means for the rehabilitation team to develop a rapport with the parents and the child and gain their confidence before educating them about their child.

What is interesting is that in 50% of children with CP, that part of the brain which controls intellectual development is not damaged. A person with CP is described as having 'an intelligent mind in a disobedient body'. Called 'Little's Disease', CP was, until the 1930s, commonly thought to be associated with mental defect; it was believed that the brain damage was necessarily widespread and that the intellect as well as the motor control areas of the brain were impaired. We now know that these assumptions were incorrect. Since treatment and education were largely unknown until the 1940s, the earlier assumptions about the low mental levels of children and adults with CP were based on observations of largely untreated and uneducated cases. Today we know that if a severely handicapped child is left untreated, he or

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she will deteriorate and remain physically and intellectually under-developed. Through our own work, we demonstrated that with slight modification in the curriculum framework and through new methods of communication, children with CP can benefit substantially from education.

Earlier (and even now), the physical, occupational and speech therapies were specializations with rigid boundaries, known only to the experts concerned. Discussion and conversation with parents were non-existent. Often an aura of professionalization prevails and it is not kept in mind that a humane approach is needed. The parent is not told what activity is being carried out and why. The child is more of a 'diagnosis' than anything else, to be discussed among colleagues. A leading doctor treating CP in India said, 'Parents are patients and you cannot share their file with them.'

Again, we changed that. Parents became our partners, our main stakeholders. Under the model of service, each parent is explained, in simple terms, the reason behind a particular therapy/activity. There is much more transparency and accountability. We do our best to empower the parents. Simple tasks are explained: how to carry and feed the child, the importance of proper seating and posture, self-help skills, how to build on language and communication, and how to give social and emotional support, both to the child and the rest of the family. Of course, for a period, each therapist observes the parents performing the exercises to ensure proper handling. This is the key to effective home management.

The quality of any organization depends on the quality of its staff. Training programmes for the management of CP were non-existent. We started training courses for doctors, teachers, therapists, community workers, parents and government officials to build capacity. This helped to create a much needed cadre of people at the national level. It also helped to decentralize services away from Mumbai to other parts of India (this model has been replicated in 18 of the 31 states in India).

This kind of treatment, in which doctors, paramedics, special educators, social workers and psychologists worked together with parents, took root and began to show results. The top-down bottom-up approach, which gave parents a prime position, marked a shift from a tight medical model to a community model. Holistic programmes combining education and treatment, provided through early infant clinics, helped to demystify cerebral palsy.

It is essential to provide continuity of treatment as the child moves from one class to another. Children with a little assistance have been able to appear for school and university board examinations, and have come through with flying colours in accountancy, journalism, finance, computing and other disciplines. Over 300 models of employment have been developed. What happened to Malini? Malini herself is a senior events manager at Oxford Book Store and has two master's degrees!

What then remains to be done? Looking back, a quantum leap has been made in that people like Malini, who were earlier forced to stay at home, are now able to come out and contribute to society. However, this is the case only with a privileged few in the cities.

Although we could not have achieved what we did without the help of the medical fraternity, it is still an individual effort. The system still fails to support children and adults with such profound difficulties as Malini. The majority of children with disability in India are out of work and at a high risk of getting deformed (World Bank, 2007).¹⁰

The health system needs to be improved. Piecemeal services with individuals delivering treatment privately abound. Health and educational services need to be synchronized. Medical and paramedical courses still do not provide the necessary training on how to deal with CP. The government's teacher training courses also need to be upgraded. The 'how' of management has still not been addressed in the classroom. Mindsets and attitudes need to be more inclusive. Only a systemic change will fill the gap, enabling the health and education systems to synchronize with each other and accept persons with CP as their responsibility.

Had my daughter been born in a rural area, would she have got any care? Would the existing healthcare system know what to do with her? Would her needs be met? Or would she be a victim of neglect and lack of knowledge, be misunderstood and be treated like the village idiot? Would we, as parents, be fooled into believing that 'nothing can be done for her'? I am sad to say that this would probably have been the case.

Having seen the success of many children and youth with disability, the question that faces us is 'who is disabled?' Is it them, who think, hear and speak differently, or is it us, who cannot see, understand or accept them?

Surely, we need to change our own mindsets, celebrate differences, become more inclusive, and above all ensure abolition of entrenched exclusive systems so that children with disability can exercise their constitutional entitlements on the bedrock of human rights and social justice.

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