

USHAS *Centre for Exceptional Children*

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Abstract

Cerebral palsy is the most common motor disability in childhood. Because of the developing nature of Indian health care in semi-urban and rural areas and the lack of technology used in these areas, cerebral palsy has been a visible problem in the country. In India, the average estimated incidence of CP children is around 3/1000 live births. This made the authors to dig deeper into the situation and understand the issues at the grass roots. The authors collected primary data from an organization (USHAS) which exclusively caters to CP affected children and conducted an in-depth study. This case study finds that the treatment, patient care & support, clinical processes, and patient quality of life are the major challenges to CP management in India. The findings also indicate that the management of CP is not problematic only because of lack of cutting-edge technology, medicine or sophisticated equipment to carry out procedures but has become more complicated as the society lacks awareness and also has failed to be empathetic towards CP affected people.

Keywords: Social Business; Mental Health Care Management; CP Management in India; Health Care in Rural Areas.

Case Summary

Currently the treatment of Cerebral Palsy (CP) offered in India is largely palliative, e.g., special schools, vocational training etc. Even for children with normal intelligence, there is no attempt to train on loco motor abilities. All that is offered are few perfunctory stretching exercises. This approach is several decades behind what is available in developed countries.

There are only a few centers exist in India that provide a dedicated, trained and qualified multi disciplinary team comprising of Developmental Pediatrician, Pediatric Orthopedic Surgeon, Pediatric Neurologist, Physiotherapist, Occupational Therapist and Orthoptist. Each of these specialists offers a

unique perspective that enhances the development of a comprehensive evaluation and treatment programme for each individual patient.

Raghu Okade who taught Human Resources to post graduate students, dared to be different - he wanted to provide these children a respectable and dignified life. He firmly believed that he had been sent to live on this earth for a bigger and better purpose. He would never let a chance to help others go waste. USHAS [1] is an effort of Raghu to help his student's daughter. In the process he helped many more.

About Raghu

Raghu always knew that he had come into existence for a big purpose, a cause greater than making money from livelihood and leading a comfortable life with all that he could provide for himself. He had always felt that he could provide a little bit of his skills and capacities for a larger lot of those who might actually need it. Plus, he always craved for the challenges. He was more than passionate to convince his family and friends to step up and commit to such an endeavor.

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The Endeavour

It all started when Alex, one of his students of the Organization Behavior class walked up very disconsolate with the news that his wife gave birth to a baby girl, and that the child was born with Cerebral Palsy (CP). Children with CP have varying degrees of physical disability. Some have only mild impairment, while others are severely affected. There is no cure for cerebral palsy, but if the child is diagnosed with it, a variety of resources and therapies can provide help and improve the quality of the child's life. Therapies can help kids with CP achieve maximum potential in growth and development. As soon as CP is diagnosed, a child can begin therapy for movement, learning, speech, hearing, and social and emotional development. In addition, medication, surgery, and braces can help improve muscle function. Surgery can help repair dislocated hips and scoliosis (curvature of the spine), which are common problems associated with CP. A team of professionals will work with the child and that team may include therapists, psychologists, educators, nurses, and social workers.

Alex felt totally defeated because he knew that access to all this was a distant dream. It would take centuries for these kinds of medical facilities to be made available in the small town of Hubli in Karnataka, India. Raghu was concerned for his student and genuinely wanted to help. He did what he knew best, he started reading about CP. He began visiting many medical libraries and was eager to know more about retardation. He understood that the pediatric physiotherapist has an active role to play in helping the child with special needs. A child with special needs can be a child, for instance, with mild cerebral palsy but normal intelligence attending a mainstream school. Or it can be a child with attention deficit disorder also attending a mainstream school but requiring a learning support assistant or a learning support teacher to help with the specific learning difficulties the child is experiencing.

The educational needs of some children with learning difficulties can not be met by a normal state school and these children, upon a careful educational assessment, will then attend a school for moderate (MLD) or severe learning difficulties (SLD).

Raghu's search for the physiotherapist began, and he succeeded in locating one. The physiotherapist promised to work on the child with the condition that Raghu be present during the sessions and pick up the home exercise program. The child took nearly

four years to walk. When Alex and Raghu saw the child walking, they were very happy. At this juncture Alex wanted to relocate from Hubli to Mumbai for further treatment.

Raghu had got emotionally involved in Alex's problem, Raghu's challenge lay ahead of him and he could see the purpose for his existence. He wanted to be instrumental in changing the lives of those children who came into this world with this dreadful condition. It was impossible to reverse the damage done in the womb but he knew he could make these children lead a respectful life by imparting the right kind of therapies. He now started giving a shape to his dream – a centre where the child can begin therapy for movement, learning, speech, hearing, and social and emotional development. Thus the concept of the USHAS took seed.

The Challenges

Raghu and Alex went all over India to explore the teaching methodologies for children affected with Cerebral Palsy so that they could incorporate the findings into their business plan. Later, they decided to have their center in Karnataka and for that they desired to assess the existing number of mentally challenged children in Karnataka. As there was no ready reckoner for them to get the exact number, they planned to host a camp. They sought support from National Institute of Mental Health in association with Rotary club. The camp was of three days, and on the penultimate day they had only 28 registrations. The worry was to keep the team of experts they had hired engaged during the days of the camp.

In order to create awareness, Raghu wrote an article for the local newspaper on cerebral palsy and also about the camp that was running. The outcome of the article was exceptional and gave a boost to the registration on the first day of the camp with an overwhelming registration of 60 children; which was indeed path breaking. On the second day all the leading national newspapers had captured the news on the front page. By the third day they had 418 registrations right from the northern part of Karnataka to down south. The positive response of parents encouraged Raghu to think of a special school for the special children. As each day passed Raghu became more and more confident about his dream of setting up a special school. He immediately decided to start working on his project – USHAS.

The primary requirement was land. Raghu was not very affluent, but was truly passionate about

servicing the society and people. He needed to really work on the funding and investment for the entire project. The easiest way out was to approach the local municipal body for land. What he got in return for his request was an old building with an asbestos roof shed. Raghu was not the one to feel defeated; he immediately sought the help of few friends painted the black board and the four walls of the old building. Raghu's next worry was to procure the teaching aids. During one of his visits to Bangalore he had the opportunity to meet the Principal of Sophia School, and during a casual talk he shared his idea of starting this school and his problem in arranging for the teaching aids and technical support team. The Principal was really touched with the idea.

The principal identified a special educator who would be apt to run the school. During the course of the meeting, Raghu was introduced to Sister Jayanthi and Sister Nayana and they agreed to support Raghu with teaching aids.

The three-day workshop had revealed that the small town of Hubli had at least 500 cases of children with CP, but much to Raghu's disappointment on the first day of the school only three children registered. When he tried to approach the parents of these children, he was surprised to learn that they were not willing to send their children to school as they were looking for medical treatment and not schooling! Raghu did not mind starting small, and with 4 children he started USHAS. The children at his school gradually increased to 20 by the end of 6 years.

Raghu continued in the single roof old building for 6 years, and later shifted the school to his ancestral house. Once, while Raghu was delivering a lecture on HR at an architectural college in Bangalore, he invited the students of the college to design a school for the physically challenged children. When one of the students asked him for the area of the land available, Raghu replied impulsively, "design the best school and then I will procure the land required". With this Raghu was able to get the blue print of a world class school design for physically challenged children.

Raghu wanted children of his school to be able to lead respectable lives. His instructional design was that all the children would first be toilet trained and later be trained on limb movements. There was no restriction on who could join the school. The primary criteria for admitting the child or the young adult was that he/she must be a patient of CP. Toilet training of the students was done so effectively that

the parents were extremely happy about their children's progress. Raghu was glad but he increasingly felt that he should work toward providing the best of physiotherapy facilities at the school. He explored nearby physiotherapy college and got connected to Dr. Kiran Bhat.

The doctor was a specialist in pediatric neuro physiotherapy and had just joined the local physiotherapy college. Dr. Kiran adored the centre and promised to come in the evening after completing her consulting hours. This put Raghu into a dilemma, for getting the children out of their homes in the evening was a big problem. Finding solutions for such situations had now become a routine for Raghu. He worked out a deal that Dr. Kiran would have her consulting centre at USHAS and would also be around for the students of USHAS free of cost.

Physiotherapy without the state of art equipments was a sheer waste. Raghu had by now generated enough curiosity and humanitarian emotions amongst his friends and colleagues. Raising funds for the equipments through donations was an easy job. He invested on the equipments, and his long cherished dream seemed to be falling in place slowly but surely. He started working on acquiring a speech therapist next and as luck would have it, Ms. Vinaya Gaitonde, a renowned speech therapist had shifted to Hubli, and volunteered to work for USHAS on some days of the week. Raghu was able to start on the speech and language development centre.

Soon, Dr. Madhu Lodaya, an occupational therapist with lot of expertise and experience at Manipal Hospital, enthusiastically came and helped the students at USHAS.

An affluent family of three sisters in Hubli decided to donate a good area of land to USHAS looking at the all the good work that was going into it. Raghu was ecstatic; the dream of the building for the centre fell in place. Slice by slice the big picture, the vision, and the dream started fitting together. Today USHAS is housed in about 14000 sq. ft built in area with 105 children and nineteen facilities and this was made possible by the generosity shown by public in the form of donations. At this juncture, Raghu's better half Rupa took the mantle and started heading the center.

The theme of a school premises for children who suffer from CP is unique one, wherein all the senses are used for learning. The objective is to create a learning environment. Each and every activity inside and outside the classroom is a holistic experience. The modular approach has specific intention to increase the learning curve of these children. The

facilities that needed to be set up included a hot and cold water swimming pool as part of hydro-physiotherapy. There was need for huge water bodies in and around the campus, not merely to create an ambience but also to engage with the children in water activities. All the materials used in the campus had to be from safe and reliable suppliers.

The long term plan also included setting up a research and resource centre with the relevant data and information and also training of teachers and staff. There was a plan to create training program at the rural and urban level centers which will have a multiplier effect in reaching out to more children.

Conclusion

Ushas, offers the highest quality individual educational support for children of all ages who have learning challenges by using strategies based on a child's strengths and learning style. They have also implemented Individual Educational Programme (IEP) as a special education which aims at providing a holistic environment for education. Likewise, Ushas introduced daily programmes that covered five domain areas such as Language & Communication, Motor Skills, Self Help Skills, Cognition and Social Skills.

It was a big challenge for Ushas to manage CP-child crossing 13 years of age, as they were finding it difficult to cope up with mainstream curriculum and this led to introduction of Vocational training (VT). The VT helped CP-child to learn how to live independently by obtaining job skills. Some children were also trained in prevocational skills based on their potential, current abilities and needs for support. However, to find a job for them has always been a challenging task as no company or organization would come forward to offer employment for CP affected children.

Raghu needed to contemplate if he should be in the business of doing good. So far, trust and goodwill was sufficient to get in the money from the donors and benefactors. This proved to be viable to a certain extent for him and he even thought of establishing such niche schools in other cities that lacked resources to handle CP cases. However, he was still in a dilemma as to how to engage CP-child after competing 14 years of age?

This study has used primary research methods to identify and discuss the major challenges of CP management. The case study finds that the treatment,

patient care & support, clinical processes, and patient quality of life are the major challenges to CP management in India. The findings indicate that the management of CP is not problematic only because of lack of cutting-edge technology, medicine or sophisticated equipment to carry out procedures but also has become more complicated when society has failed to be empathetic towards CP affected people. Therefore, the focus of current practice in CP Management should not only be limited to clinical treatment but also concentrate on providing a meaningful engagement for CP-people and thereby ensure them of leading quality life.

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