

## But he is Seizure Free Now!

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The couple walked into my cabin holding their seven-year-old son in arms and put him on the examination couch. The child who looked fairly malnourished, simply lied with intermittent dystonic posturing while I doubted whether he could even see or hear anything at the first glance. The next thing they did was put a huge file in front of me which had all the health-related documents filed in according to them. To my first question, "What are the current issues?", they informed me that "He has Otahara syndrome" but also added somewhat with pleasure that "He is seizure free for four years now!" All they wanted from me was to make sure that they could carry his medications with them to Singapore as they were soon going to Singapore with him.

Going through the pages of his 'file', all I could see was plenty of electroencephalograms, neuroimaging reports, metabolic investigation results and neonatal discharge summary. However, I could not see a single investigation to assess his bone health or any report by a dietitian or physiotherapist. It seemed that almost all the assessments by his doctors were focused on epilepsy and seizure control. The parents seemed surprised that I was asking about his sleep, pain, constipation, reflux, mobility, communication, emotional well-being, school, vision and hearing like things.

With nearly 2% disabled people living across India, nearly two third live in the rural areas. Among the children, nearly 17% are from the adolescent age group while only 5% from 0 - 4 years age group [1]. Needless to say, the healthcare needs of these children can increase with age as many factors like education, social participation etc. can add up in addition to their clinical needs. Still, largely modifiable factors like poor perinatal care, socio-economic status and consanguinity are directly linked to the disability in children in India [2].

The surge and dominance of the private and corporate sectors in the healthcare system has probably created an imbalance as the healthcare access to the poorer and rural sections of the country is still scarce. On the other hand, the corporate hospitals also get number of patients from nearby countries [3]. The public health sector still remains poor resource based and hence cannot cater the needs of an individuals with complex care needs. Such patients often need tertiary level health services which can be unaffordable for a growing number of people [4].

Children and young people with neurodisability have a range of impairments. Some of them although minor, can have complex healthcare needs. There are various issues such children can have which also include psychological or social issues. In the developed countries, community nurses and charities can play an important role within the multidisciplinary team to look after such issues. However, lack of such facilities cannot be simply blamed for the lacunae in the care of such individuals with complex care needs especially while working in the private sector in India.

Different professionals should work collaboratively towards shared objectives so as to provide a high-quality multidisciplinary service for children with complex care needs. Parents are the proxy for their children's quality of life and would want better emotional well-being

and social participation of their children [5]. But often they would not know whom to approach for these issues. It is the responsibility of the lead clinician looking after these children to either arrange or direct parents to such services. The role of a doctor should not only be limited to prescribing medicines and investigations but also to make sure that the care is holistic. A two-way communication during the consultation often can facilitate to set up the agenda and understand the issues by the parents as well as the child; so that decision making is focused on their needs [6]. The consultation must include discussions on the treatment and therapeutic goals with the families, and work on their priorities accordingly. Regular re-assessments and follow-ups are necessary to look at the neurodevelopment and the outcome of interventions.

People with disabilities come across many barriers while accessing the suitable health and rehabilitation services. The author had compared the impact of childhood disability between parents and doctors. There was obvious difference seen as the parents could perceive it more than the doctors [7]. Doctors seem to focus more on the 'medical' issues rather than social participation and well-being of these children. This may be the reason for apparent disparity between the goals of professionals and families.

Disabled children have the same needs as the children with no disability. They do not fall in a separate category. With the introduction of ICF classification it is easier to understand various factors that interplay with 'disability'. ICF describes disability as an umbrella term for impairments, activity limitations and participation restrictions and there is now more understanding of the environmental factors that interact with all these components [8]. These reflect the interaction between a person's body features and features of the society. The lead clinician can use ICF as the tool for measuring as well as improving functioning and participation of these children in the society; irrespective of the reasons for their impairments and simply 'treating' the impairments.

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