

Reviews

Child Rights and Cerebral Palsy Rehabilitation in India

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INTRODUCTION

The prevalence of Cerebral palsy (CP) is increasing worldwide and is currently estimated at 1 - 4 per 1000 live births (Gulati & Sondhi, 2018; Paul et al, 2022; Saranti et al, 2024). Though there is a dearth of high-quality studies from India, the observed prevalence of Cerebral palsy in the country is 2.95 per 1000 children surveyed (Sony et al, 2023). Due to this rising prevalence and increased awareness, comprehensive Cerebral palsy rehabilitation has become ubiquitous in India (Jindal et al, 2019). Children with Cerebral palsy undergo extended rehabilitation procedures which typically include muscle stretching and strengthening, massage, neurodevelopmental techniques, and gait training. These programmes often go on for several years (Heathcock, 2021). In addition, depending upon each child's needs, various other therapies are given to improve cognition, communication, behaviour, sensation and perception. While these are arguably done with the child's best interests at heart, are there checks and balances on how many hours of therapy the child requires? How do rehabilitation experiences balance with an enriching experience of childhood? Do we have any guidelines to follow? Are too many hours of shuttling between therapies an infringement on the quality of life for children?

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IMPACT ON QUALITY OF LIFE

Physical examination and rehabilitation processes for children with Cerebral palsy start in infancy. Their childhood is moulded by pain and stress, not only because of the nature of their disorder but also because of the long hours of painful rehabilitation procedures, and from having to live in an environment generally created for the "typical" child (McKearnan et al, 2004; Dydyk & Givler, 2024). The repercussions of the long hours of therapy are severe and result in:

1. Chronic pain syndrome and central sensitisation (Van Der Slot et al, 2012; Verschuren et al, 2016)
2. Fatigue (Majnemer et al, 2008; Jarl & Alriksson-Schmidt, 2021)
3. Low academic performance (Parkes et al, 2008)
4. Caregiver fatigue leading to abuse or neglect of the child (Liu et al, 2023)
5. Behavioural problems (Parkes et al, 2008)
6. Anxiety and depression (Ramstad et al, 2012; Ullenhag et al, 2024).

The above-mentioned factors are interconnected and overlap. Chronic pain reduces the quality of life of children with Cerebral palsy as it negatively impacts their comfort levels, recreation and sleep patterns, and consequently hinders their involvement in activities of daily living while causing anxiety, fatigue, and depression (Majnemer et al, 2008; Parkes et al, 2008; Van Der Slot et al, 2012; Verschuren et al, 2016; Ullenhag et al, 2024). Caregiver fatigue is another inadequately acknowledged and challenging consequence. Parents, often the mothers, bear the brunt of caretaking responsibilities (Liu et al, 2023). They not only handle the child's activities of daily living but also provide emotional support, and attend

appointments and therapy sessions, which can take a toll on their own quality of life. Often, these additional responsibilities hinder mothers' ability to manage routines, earn their livelihood, take care of other children, and engage in pleasurable activities. The toll on the caregiver's health has a direct effect on the well-being of the child, as has been reported in various studies (Liu et al, 2023).

These factors beg the questions:

- Are the long hours of rehabilitation necessary?
- Are rehabilitation professionals aware of the consequences?

Parental Expectations and Misconceptions

Rehabilitation professionals often do not give clear explanations to the parents of children with Cerebral palsy regarding the progression of the disease and the functional independence to be expected. This leads parents to believe that there is a cure and that their children may become normal if intensive and prolonged rehabilitation is undertaken. The health practitioners may imply that the children will improve faster if they undergo more hours of rehabilitation, but often the end point of improvement is unclear. The parents may construe the term 'improvement' to mean normalcy, so the children are forced to do things that are beyond their capability or may cause secondary problems like pain and anxiety; in consequence there is no time for enjoyment which, as per definition, equals neglect and abuse (Hutton, 2006; Ullenhag et al, 2024). In addition, unrealistic goals of parents put enormous pressure on the rehabilitation professionals, as they are afraid of the repercussions if their opinion is not similar to that of the referring doctors. From an economic perspective, professionals in private practice are concerned about 'therapist shopping' if they give contradictory opinions that do not satisfy the parents.

The aforementioned factors culminate in a cycle of long, and often, trial-and-error methods of formal therapy without much attempt at embedding therapy goals into routine activity. It is well-documented that therapeutic strategies must be part of the routine life of a child with Cerebral palsy as Cerebral palsy is a lifelong condition (Hutton, 2006; Moll & Cott, 2013). Sadly, this is not commonly practiced in India, due to lack of multidisciplinary teams and school-based rehab services. Samagra Shiksha Abhiyan (SSA), a government initiative, has a strong theoretical foundation but falls short in implementation for many reasons, including dependency on formal therapy which is rarely child-friendly. Anecdotal reports from professionals associated with SSA suggest that SSA has full-fledged multidisciplinary team services as the policy documents, but in actuality implementation is hindered by difficulties in staff hiring, high attrition rates, and inadequate individualisation of services and poor documentation. Occupational therapists, psychologists and speech pathologists are rarely present due to the dearth of professionals in these fields. Often the sole service providers are physiotherapists who visit the SSAs sporadically, and sometimes not at all. Block integrated education resource teachers (BIERT) often try to fill the gap and provide rehabilitation services within their abilities and expertise. Due to lack of training, the services may be erroneous and haphazard, potentially causing harm to the children. Furthermore, the assistive devices and mobility aids that the children receive from SSA are generic mass-produced devices that are not customised to the individual child. Another aspect of concern is the lack of adapted seating devices. Though the children are currently expected to sit in the school for more than 6 hours in a day, SSA fails to provide them with adaptive seating, resulting in bad posture and putting them at risk for the occurrence of deformities (Nagaraj / Santhosh / Sneha, via personal communication, 2023), all of which are painful. In a nutshell, though the intention behind SSA is noteworthy, the implementation is not up to the mark.

Schooling and Educational Rights

What is happening with the schooling of children with Cerebral palsy? Are they allowed to go to school like other children? From our experience in working with parents of children with Cerebral palsy enrolled in the SSA programme, priority is given to the quality of walking as the outcome of rehabilitation, and the educational needs of the child are considered secondary to independent walking (Anagha / Vinay, via personal communication, 2023). This practice potentially affects the quality of education of children with Cerebral palsy. Either many children are enrolled in school only after an average age of 10 years or some are not going to school at all (Chiarello et al, 2010). On the other hand, though mainstream schools are mandated to admit children with Cerebral palsy, they often do not take them. School authorities advise parents not to send their children to school until they are able to walk and use the washroom independently. The following case illustrates this. Anitha (name changed to maintain confidentiality) is a 9-year-old with athetoid Cerebral palsy of GMFCS level IV, with associated moderately severe communication disability. She has above-average intelligence and problem-solving skills, and is eager to socialise and go to school. Unfortunately she was denied admission in a mainstream private school under the misconception that she was “intellectually disabled” because she could not walk, talk and write due to the involuntary movements (Rani, via personal communication, 2023). The child has the potential to excel in school if provided with adapted ways to learn and communicate, which are currently very feasible with Smartphone applications. The provision of a wheelchair would have allowed her to go to the washroom and the playground independently. Is this not against the child’s rights to education? Issues such as these often lead parents to force their children to walk, regardless of their ambulatory ability.

Another matter of concern is parents’ disinclination towards employing mobility aids and seating devices, which are essential to decrease secondary orthopaedic misalignment. Parents are reluctant to buy these because they think that the children with Cerebral palsy will eventually walk normally. They consider mobility aids to be therapeutic devices which need to be used only during therapy and can be discarded when the child attains “normal” ambulation or sitting balance. Therefore, they continue to allow children to adopt inappropriate postures and walk in non-optimal fashion out of therapy hours (Raja, 2006). Inappropriate seating, and non-use of orthotic and mobility devices are risk factors for chronic pain, fatigue, and anxiety. Together these lead to low academic performance and behavioural problems (Ireno et al, 2019; Jarl & Alriksson-Schmidt, 2021). Chronic pain, fatigue and anxiety in Cerebral palsy, although well-documented, are rarely acknowledged by health professionals in India. Parents are often not counselled regarding these factors (Verschuren et al, 2016; Dydyk & Givler, 2024). The secondary effects of this on the growing child manifest as orthopaedic deformities requiring repeated surgeries followed by ever longer periods of therapy. Long painful hours of therapy for years together (average of 10 years) flies in the face of child rights!

Then what is the way forward? Rehabilitation is a necessity for children with Cerebral palsy throughout their lives, but there should be checks and balances on the cumulative hours of formal rehabilitation and the methods adopted. A general consensus should be arrived at, between the medical practitioners and the rehabilitation professionals, regarding informing the parents about the level of improvement they can expect, based on the well-documented and well-known functional classification systems. Moreover, clear communication about therapeutic measures, assistive technology usage and the involvement of parents in therapeutic functions as part of daily life, is essential. Another solution is the improved focus of school-based rehabilitation programmes like SSA, so that the child’s educational and recreational needs are equally addressed. The key recommendations for the optimum performance of SSAs, keeping in mind staffing problems are:

- BIERTs should be trained adequately for triaging and referrals as well as for the provision of routine rehabilitation services.
- A health institution with a multidisciplinary team should be one of the stakeholders of each SSA. The professionals should visit the SSA at frequent intervals and guide and train the BIERTs.
- Adaptive physical education including traditional Indian folk games should be part of the SSA curriculum. A study conducted by Rahman et al (2024) reported the use of folk games which would increase the physical activity level of children with Cerebral palsy and are easy to implement as they require minimum equipment and are widely accepted, being culturally embedded.
- Children should be guided adequately, and either sent to vocational training or continue with mainstream school based on their abilities after the completion of 10th standard, so that they can earn their livelihood in the future.

Let the parents have something to look forward to, so that children can enjoy their childhood regardless of their diagnosis.

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