

# FACTORS INFLUENCING INSTITUTIONAL BASED PAEDIATRIC REHABILITATION SERVICES AMONG CARE GIVERS OF CHILDREN WITH DEVELOPMENTAL DELAY

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## *Abstract-*

### **BACKGROUND:**

93 million children aged 14 and under around the world have moderate to severe developmental impairments or disabilities. Children with developmental delays and impairments are frequently excluded from policy decisions that could benefit their well-being because they are more likely to be invisible in official statistics. As a result, the quality of the health care they receive may be affected — owing to a lack of capacity, poor service provider training, or a lack of coordination between public authorities and community practitioners.

**METHODS:** Study Type: Conventional study. Study Setting: Children with developmental delay between the age groups 6 months to 2 years are selected based on inclusion and exclusion criteria from CDC of Saveetha college of Physiotherapy, Thandalam, Chennai. Sampling technique: Purposive sampling. Sample size: 100

### **RESULT:**

Out of the 100 total observations, 25 children had a habit of showing up for therapy. Nearly 32 children had missing or incorrect information. 43 were included in the data set that was used for statistical analysis. There were 31 men and 12 women among the total of 43. Children aged between six months and two reported for rehabilitation at a distance of 1 to 18,00 kilometres. There were 22 families from rural areas and 21 from cities. Most households belonged to the middle class, followed by those from the lower middle class.

### **CONCLUSION:**

This study found that the grade of hospital care and the distance from the institute had an impact on people's usage of rehabilitation services at tertiary institutions. When providing institutional rehabilitation to children, other aspects It is also necessary to consider factors like socioeconomic level, familial support, and social belief system.

**Keywords:** Developmental delay, factor analysis, and pediatric rehabilitation service

## **INTRODUCTION:**

One in ten children in India are thought to have a physical, mental, or sensory impairment, with the number of children with special needs ranging from 40 to 90 million<sup>(1)</sup>. The bulk of these are due to developmental delay or impairments, which affect 5% to 15% of children worldwide. A child is said to be experiencing developmental delay if they are unable to reach important developmental milestones in one or more domains, such as language, social, and gross/fine motor development, within the anticipated time frame<sup>(2)</sup>. The standard of hospital services is the main concern of the general public.

Up to 5% of children under the age of five experience developmental delay. This includes delays in the development of the motor, social-emotional, and cognitive systems. The early identification of behavioral and developmental issues in young children can be greatly aided by general practitioners<sup>(3)</sup>. To reach physical milestones like crawling, sitting, and standing, physiotherapy treatment can be helpful. Delayed milestone is the way a child grows and matures from birth to adulthood<sup>(4)</sup>. Physiotherapy can help to improve your balance, coordination, motor control, and posture; Boost confidence and independence in daily living activities.

Early intervention is often believed to improve results since moderate Higher rates of school failure, in-grade retention, and special education are associated with disabilities such language impairment, moderate intellectual disabilities, and learning challenges, as well as poorer health status<sup>(7)</sup>. In preterm neonates, low-birth-weight newborns, and kids from low socioeconomic backgrounds, early intervention has been found to boost IQ and result in higher scholastic achievement, increased adult employment, and less delinquency households, according to evidence from controlled studies<sup>(8)</sup>. However, chances for early intervention may be missed if developmental problems are identified too late.

It can be challenging to detect Delays in development in ordinary clinical practice. Continuous time restrictions were indicated as the major barrier by 82% of primary care physicians in one survey<sup>(9)</sup>. Additional obstacles to screening include conflicting clinical needs,<sup>(10)</sup> lengthy wait times for children to see subspecialists, a lack of available subspecialists for referral, staffing needs, a lack of agreement on the best screening tools, and a lack of physician confidence in their education and ability to effectively treat children's behavioral and emotional problems.<sup>(11)</sup> Other issues mentioned were a lack of reimbursement and a high personnel turnover rate, which calls for the need for training in tool management<sup>(12)</sup>.

A caregiver is a person who assists another impaired person with daily living activities. The majority of the careers' time is spent caring for their child, particularly if the child has serious delays and impairments<sup>(16)</sup>. This limits their ability to focus their attention or time elsewhere, which negatively affects their social life and overall quality of life (QOL). Compared to parents of typical kids, they experience a variety of difficulties, including disruptions in routine, family leisure time, family health, work absenteeism, physical and mental stress, and higher financial costs. Any developing child's primary source of support is their family<sup>(17)</sup>. Families with children with developmental delays make adjustments to various parts of life to suit the needs of the kid, which lowers their quality of life (QOL).

In terms of the expense of health care, educational assistance, and therapeutic services, developmental delays that lead to impairments have an effect not just on the child and family but also on society as a whole. Now, social rehabilitation is prioritized more than medical rehabilitation previously was<sup>(19)</sup>. There is evidence to suggest that treating developmental abnormalities early results in better outcomes for kids and lower societal expenses.

## METHODOLOGY:

### Inclusion criteria:

1. Both male and female
2. Cases diagnosed with developmental delay within 1 year
3. Age :6 months to 2 years
4. Children with neurological disorder

### Exclusion criteria:

1. People not interested in the study
2. Preterm babies
3. Children with spina bifida

Subjects within the Age 6 months to 2 years, Both males and females, Patient diagnosed with developmental delay within 1 year of duration, and children with neurological disorders are included in the study. Subjects with criteria like Preterm babies, children with spina bifida and people who are not interested are excluded in the study. The study setup was Saveetha physiotherapy OPD, Saveetha medical college, and hospital, Thandalam, Chennai. Patients with developmental delay and getting rehabilitation in our physiotherapy department between October and December 2022 were prospectively enrolled in the study. The informed consent was given to the patients parent and explained about the procedure through call. Open ended questionnaire was used to assess subjects. The open ended questionnaire consists of various questions where the patient needs to give the correct reason. All the reasons are clubbed together and are analyzed statistically.

## RESULT:

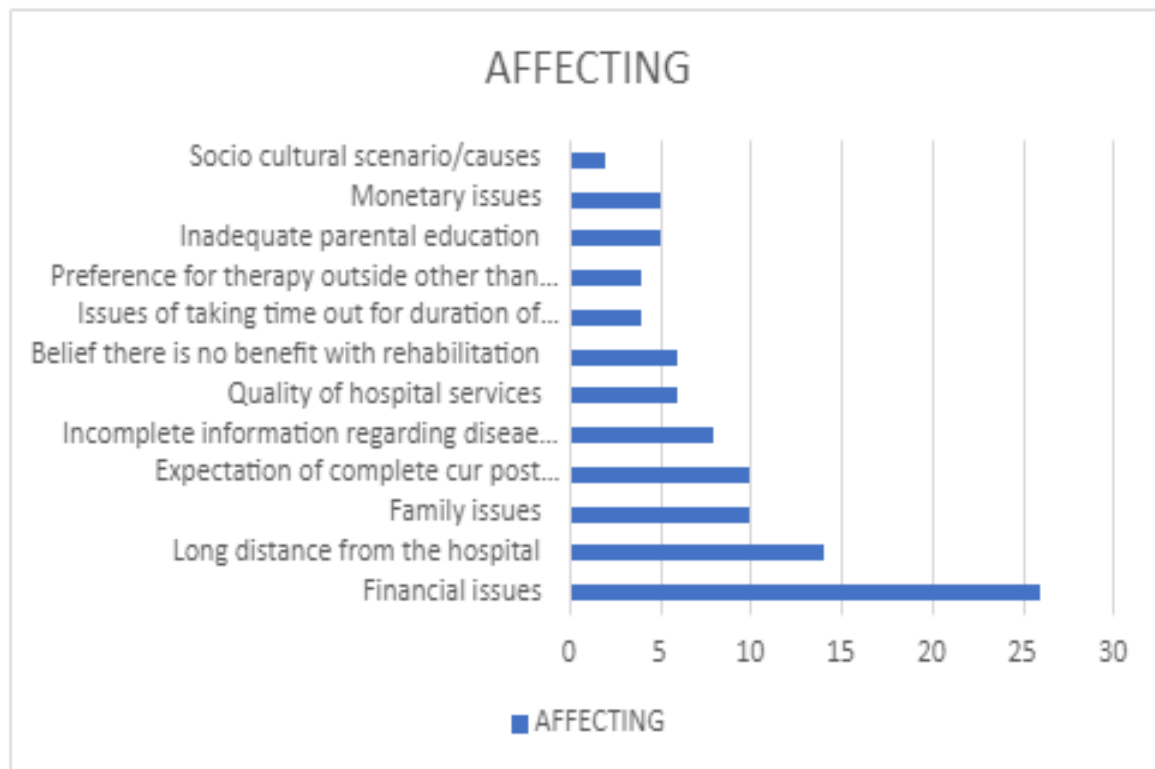
Out of the 100 total data points, 25 kids were frequently showing up for therapy. Nearly 32 children had missing or incorrect information. 43 were included in the data set that was used for statistical analysis. There were 31 men and 12 women among the total of 43. Children aged between six months and two reported for rehabilitation at a distance of 1 to 18,00 kilometres. There were 22 families from rural areas and 21 from cities. Most households belonged to the middle class, followed by those from the lower middle class.

For a one-time consultation, fourteen families were deemed to be distant. Six families thought that hospital services were an important consideration. Eight families claimed that their decision to forgo hospital therapy on a regular basis was influenced by the lack of accurate information regarding their child's health issue. Ten families reported various family problems, and two families claimed that their child's lack of frequent therapy was due to sociocultural factors. Five families cited financial difficulties as a major factor in the cessation of hospital therapy, while five families reported insufficient parent education as a problem. Four families experienced problems with time. Six families had the opinion that counselling was ineffective. Ten families anticipated total recovery, which rehabilitation did not provide

**TABLE 1:** The factors/reasons caregivers who were interviewed for discontinuing rehabilitation/poor compliance were most frequently cited as follows:

REASONS FOR DISCONTINUATION	NO. OF AFFECTED SUBJECTS
Financial issues	26

Long distance from the hospital	14
Family issues	10
Expectation of complete cure post rehabilitation	10
Incomplete details on a child's illness or state of health	8
Quality of hospital services	6
Belief "there is no benefit with rehabilitation"	6
Issues regarding taking breaks during treatment	4
Preference for therapy delivered elsewhere rather than at the institute	4
Inadequate parental education	5
Sociocultural scenario/causes	2
Monetary issues	5



**GRAPH 1:** A bar graph showing the frequency distribution of the main causes or justifications cited by caregivers who were interviewed for stopping rehabilitation or poor compliance

#### DISCUSSION:

The most frequent reason given for not using the service was long distance. It was discovered that distance was merely a perception; caregivers who lived as close as close to the institute as 4-5 km thought the distance was too much to receive the service. Therefore, the idea of "far distance" could be a major impediment to receiving recovery. This study supports the findings of earlier studies that suggested a significant barrier to reaching and utilising health services for people with disabilities is their physical accessibility. The structural components (such as frequency, intensity, staff, and facilities), the care processes (such as respectful and supportive care and treatment options), and the results all contribute to the quality of the health service (e.g., increases in functionality and service satisfaction). A research by Laskar et al., which found that people did not use government speciality rehabilitation services because of long wait times in line (57%), rude staff members, particularly those who required help and appliances (45%) and had difficult paperwork (36%).

According to the most recent research, 81% of carers appreciated the value of rehabilitation. Only 6% of families saw no benefit from counselling, and 10% anticipated total recovery without the need for rehabilitation. As a result, the majority of parents recognized the importance of treatment for their children. A research by Borker et al. found that 77.9% of disabled persons in rural Goa's poor use was mostly attributable to a lack of understanding about rehabilitation. Better knowledge among carers in the current study was presumably caused by an exposure to rehabilitation during their brief hospital consultation. Only 4% of these kids received therapy elsewhere, and the other 96% continued the home programme that had been outlined for them at the institute. With the same at-home training, some of them reported positive changes in their child's physical capabilities.

In 10% and 2% of families, Utilization was impacted by personal or societal factors such employment changes, elderly parents, more household duties, and death in the family (as reported by caregivers). This is consistent with a prior study by Borker et al., which discovered that just 9% of nonusers gave family problems as a defense. According to the recent study, 20% of parents had

low levels of education, which hindered their understanding of the system, the issue, and the remedial response. Furthermore, Padmamohan et al. found that the father's lack of education affected how frequently disabled rural children sought services. According to Patel and Ladusingh, socioeconomic and cultural issues will affect how persons with disabilities seek therapy, the place they live, their level of literacy, their gender, and other factors. Although these criteria were addressed in the current study, they only make up a minor portion of reasons for stopping therapy.

#### LIMITATIONS OF THE STUDY :

1. With a modest sample size, the study was completed quickly.
2. Data was collected through telephonic interview.

#### RECOMMENDATIONS:

1. A long-term study with a large sample size is recommended.
2. Regular follow-up should be done.

#### CONCLUSION:

This study, which offered a caregiver viewpoint, revealed the real-world issues parents of challenged children encounter while trying to access a tertiary care facility. Service providers went above and above their routine responsibilities of providing treatment and locating any potential backlogs in the current practice environment in an effort to close the gap between the provider and the receiver. If difficulties are identified and quantified in terms of actual situations, a friendly environment can be produced and caregivers may use services more frequently. Additionally, this would result in the creation of rehabilitation protocols that would actually assist these kids rather than just applying rehabilitation objectives in principle. This would improve the adequacy and accessibility, and usefulness of institutional-based rehabilitation in a given community because a plan made with these factors in mind might be easier to implement and more palatable to caregivers.

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