

# Challenges faced by Parents of Children with Multiple Disabilities

<sup>1</sup>K. T. Rafiq Ahamed and <sup>2</sup>K.S. Premila,  
<sup>1</sup>Research Scholar, <sup>2</sup>Associate Professor,  
<sup>1,2</sup>School of Education, Tamil Nadu Open University, Chennai, India

**Abstract:** Too many challenges faced by the mothers of Children with Multiple Disabilities (CwMD). This study aims to find the gap identifying challenges through purposive sampling. Data collected through semi-structured interview from 12 mothers of CwMD and analysed using thematic analysis. The challenges were emerged in to three themes: 1.Emotional Stress 2.Provision of Services 3. Work Load on Mother. Findings highlight that the challenges faced by the mothers of CwMD parents are multidimensional and keep increasing. Addressing these challenges requires a holistic approach.

**Keywords:** Multiple Disabilities, Challenges, Disability, Parents of Children with Disability

## Introduction

“Disability is part of being human. Approximately 1.3 billion people in the world experience significant disability; it represents 16% of the world’s population” (WHO 2023). Multiple Disabilities (more than one of the above specified disabilities) including deaf blindness which means a condition in which a person may have combination of hearing and visual impairments causing severe communication, developmental, and educational problems (RPWD Act, 2016).

Parenting a child has lot of responsibilities. Parenting a Child with Disability is difficult with lots of responsibilities. Parents of disabled children are fighting their own battles to raise their children (Antwi, T 2023).

Multiple Disabilities means any additional disability existing with a core disability being experienced by the same person. An additional disability does not only mean the challenges are added, but multiplies the challenges created by that particular disabled condition. Cerebral Palsy (CP) with Intellectual Disability (ID) is the combination of Multiple Disabilities used in this study.Parenting Child with Multiple Disabilities having CP with ID (CwMD) is more difficult with lots of responsibilities, due to their innate problems. The challenges faced by parents of special needs children are multifaceted and interrelated (Yee, et al. 2025).

## Methods

### Participants

The participants in this study were 12 mothers of CwMD (6 boys & 6 girls). The sample size was determined based on data saturation (Guest et al., 2006), where no new themes emerged from additional interviews, making the number of samples sufficient for qualitative analysis.

### Tools

Semi-structured interviews were conducted for this study. The guide for the interview had open-ended questions to explore the difficulties faced by the mothers of CwMD in day to day life. Probing questions were used to give opportunities to express their experiences.

### Procedure

This study adopted an existentialphenomenological and qualitative research design (Fernandez, 2024) to explore the experiences of mothers of CwMD. Purposive sampling technique was used to select the mothers of CwMDs, age range from 5 to 14 years, attending a full time special school in Chennai.

Necessary consent was obtained from all the participants. Interview was scheduled for 60 (2x30) minute session for each of the parent based on the availability. The interviews were conducted at the parent waiting hall of the respective special school that CwMD is attending. The interviews were conducted in Tamil or English based on the choice of the participant. Explanations were provided as necessary for clarity of questions and the responses were recorded. Additional questions as needed were asked by the researcher to drill down the experiences of the participants. Interviews in Tamil were translated to English for analysis. Secondary investigator reviewed the transcripts, codes, themes to provide unbiased perspective for the study.

Thematic analysis process involves familiarization of the data, coding and development of theme. The responses were coded and grouped into themes based on the responses. The themes were refined repeatedly to reflect the participant’s experience as narrated by them. This process to thematic analysis enabled to understand the specific challenges faced by the mothers of CwMD.

### Theme 1: Emotional Stress

Emotional challenges met by mothers of CwMD are:Accepting and Understanding the Disabilities Diagnosis; Emotional Overwhelm, and Lack of support from spouse / family members.

All the mothers went through a rough time to accept the diagnosis. Also, it is noted that they were thinking this is a disease and can be cured with the treatment. It took some time to understand the disability and accepting the diagnosis.

All the mothers had “why me?” feeling. All the mothers were homemakers; they are the first person responsible for the care of their CwMD. Due to the additional responsibility of fulltime care they have too much of emotional exhaustion.

Most of them are nuclear family (9 of 12). The support received from extended family members is less to none.

*“Initially I did not accept, as my first child is normal. But I quickly realized that I cannot deny the fact and I should be working on it.” (M1)*

*“It was twins; one of the twins did not have any disability and the second had disability. Even the appearance showed this is a child with CP. Very tuff situation; I was unable feel the joy of having a normal child.” (M3)*

*“I keep asking, why me? Why I have a CwMD?” (M6)*

*“I was very depressed. Nobody in our near family have CwMD like this”. Counselling by psychologists helped me to cope-up with the situation.” (M11)*

*“We have stopped visiting our relatives, as many of them are not welcoming my CwMD. (M2)*

*“The extended family members are not interested in provision of services to my CwMD, as they think it is waste of time.” (M6)*

## **Theme 2: Provision of Services**

After comprehensive assessment finding the appropriate therapeutic and special education services was another challenge. Finding the special school / resource centres; Long waiting List; Too much of travel on regular basis (moving from home town).

All the parents had difficulty in finding the right special school and the therapeutic centre. As the schools provide services to the CwMD are not much.

Due to the increased population of CwMD and very less number of special schools for MD, there is very long waiting list to get the admission.

As the special schools provide services to the CwMD are not available in the villages of Tamilnadu, the parents have to move from their home town to Chennai.

*“Finding the right school and services was very difficult. Access to school, the special teacher, and the therapist are to be accepted by the CwMD for better cooperation.” (M8)*

*“We have moved from our home town to Chennai to avail the services.” (M11)*

*“There long wait list in some good schools, as they have reached their maximum admission capacity.” (M5)*

*“As the requirement of therapy is needed, we have gone for the therapy privately. The costs of private therapeutic services are too high.” (M4)*

## **Theme 3: Work Load on Mother**

The work load on mother is too much as: They are the primary care givers to CwMD; Incomplete household chores; Lack of support from spouse / family members; Carrying CwMD one place to another.

As all the family are single income, the physical support from the husband is very less. They have to provide all the care to CwMD. This put too much of work load on mother.

As many of the CwMD are not walking, moving them from one place to another, positing for feeding, placing them in CP chair, carrying them on the stairs, etc. are difficult tasks for the mother.

*“I have to watch my son all the time. It is very difficult to do the house hold chores (cooking, washing, cleaning, etc.).” (M7)*

*“I get back painvery often, as I have to carry him to the second floor, as we don’t have elevators in our building.” (M3)*

*“I am the one to do all the care for Activities of Daily Living (bathing, brushing, changing, feeding, etc.)” (M10)*

*“Positioning while feeding is a Himalayan task as they have swallowing issues.” M12*

## **DISCUSSION**

Having a CwMD is lot of stress for the mother, acceptance is the key. All the mothers had initial shock and took time to recover and focus to provide services to the CwMD. Finding the right service provider is another issue. Access the school should be easier. The Special Educators, Therapists, Medical Doctors, and other professionals should provide good services to CwMD. Caregiver burnout is common as all the mothers express significant levels of exhaustion and stress. The unpredictable behaviours of children with special needs, coupled with the overwhelming caregiving responsibilities, contribute to this burnout (Phoenix, Smart & King, 2020).

In conclusion, the challenges faced by the mothers of CwMD parents are multidimensional and keep increasing. Addressing these challenges requires a holistic approach that considers emotional, financial, and systemic factors (Yee, et al. 2025).

## **References**

[1] RPWD Act, 2016

[2] Clinical evaluation and individualized standard IQ testing (APA, 2013, p. 33)

- [3] Antwi, T. (2023) The Unplanned Journey: Challenges of Parents of Children Living with Disabilities in Ghana. *Psychology*, 14, 635-655. doi: 10.4236/psych.2023.144033
- [4] Chakravarti, U. (2008) Burden of caring: families of the disabled in urban India. *Indian Journal of Gender Studies*, 15(2), 341-363.
- [5] Fernandez, Anthony. (2024) Existential Phenomenology and Qualitative Research. 10.4324/9781003247791-4.
- [6] Kamaralzaman et al. 2018, *Journal of ICSAR*, ISSN (print): 2548-8619; ISSN (online): 2548-8600, Volume 2 Number 1 January 2018
- [7] Phoenix, M., Smart, E. J., & King, G. (2020). 'I didn't know what to expect': Describing Parents' Expectations in Children's Rehabilitation Services. *Physical & Occupational Therapy in Pediatrics*, 40(3), 311–329. <https://doi.org/10.1080/01942638.2019.1665155>
- [8] Smith, J.A.; Larkin, M.H.; Flowers, P. *Interpretative Phenomenological Analysis: Theory, Method and Research*; Sage: London, UK, 2009.