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**Yogesh Dhakad**

Assistant Professor,  
Department of Political  
Science, Govt. P.G College,  
Bareilly, Raiesan, Madhya  
Pradesh, India

**Dr. Anupama Yadav**

Professor, Department of  
Political Science, Babulal  
Gaur, Govt. P.G College,  
BHEL, Bhopal, Madhya  
Pradesh, India

**Corresponding Author:**

**Yogesh Dhakad**

Assistant Professor,  
Department of Political  
Science, Govt. P.G College,  
Bareilly, Raiesan, Madhya  
Pradesh, India

## Children's developmental enfeeblements: Health and social issues in Bhopal

**Yogesh Dhakad and Dr. Anupama Yadav**

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### Abstract

Particularly in developing nations like India, there are little institutions and social supports available to assist people with developmental impairments. The goal of the current study was to identify the characteristics of children who appear with developmental impairments, the types of social supports that are accessible to their families and the typical issues that these children face. We saw that most cases particularly those involving hearing impairment were discovered after the fact. When these problems were discovered, the majority of parents experienced shame and depression, which eventually got better. The majority of respondents had financial and social difficulties. The majority of patients lacked proper nourishment. The study draws attention to the challenges faced by families and children with developmental impairments in Western Madhya Pradesh when it comes to diagnosis, treatment, and social support. We must take particular action to close the gaps in our community's medical, educational, and integrating services for children with disabilities.

**Keywords:** Disability, impairment, depression, social support

### Introduction

Disability is the word used to describe any limitation or inability to do an activity in a way or within a range that is deemed normal for humans as a result of impairment. According to Barbotte *et al.* (2001) <sup>[2]</sup>, handicap is a measurement of the social and cultural effects of an impairment or disability. Impairment pertains to the physical components of health. Disability is the loss of functional capability resulting from an impaired organ. According to estimates, between 10% and 15% of people on the planet are disabled (WHO, 2011 and 1989). In India, the incidence of all disabilities is 6.3%, with mental disabilities being the most prevalent (Ganesh *et al.*, 2008) <sup>[4]</sup>. Families with children who have developmental difficulties deal with a variety of challenges and issues. There aren't many facilities or social services accessible to assist them, particularly in developing nations like India. The goal of the current study was to examine the characteristics of children who appear with developmental impairments, the social supports that are accessible to these families, and the typical issues that these patients and their families face.

### Material and Methods

The location of this observational research was Bhopal. The research group consisted of fifty children with various developmental problems who were receiving special clinics and paediatric treatments at our institution. Six months passed throughout the research period (January to June 2022). For the study, a comprehensive questionnaire was created. Using the questionnaire, a single observer gathered all the data. The questionnaire addressed the following topics: specifics of the medical history and examination, paying particular attention to delays, deficits and disabilities; family support; the medical and social support networks that were available to them at the time of contact and at the age of one, three, five, ten, or fifteen years old (if applicable); issues and challenges that the parents and families faced and the response of the parents to their child's disability at the time of diagnosis and up to the present. The following categories of disability were covered: Any kid with abnormalities of posture and movement brought on by a nonprogressive lesion to an immature brain is said to have cerebral palsy (CP). Child with IQ below 70 is considered mentally retarded (MR), impairment of hearing (HI): child whose better ear has lost 60 dB or more. Visual impairment (VI): A child who cannot count fingers at a distance of three metre

in daylight or whose visual acuity is less than 3/60 in the better eye. We didn't include those with learning difficulties, those under one-year-old, people above eighteen, or those in situations where there wasn't enough real information. The gathered data was entered into a Microsoft Excel spreadsheet and subjected to the relevant statistical tests for analysis.

**Results**

For the research, 50 kids in all were enlisted. There were more men (31) than females (19), and most of the kids (36/50, 72%) were older than five. Profile of the study group's demographics: Of the patients that were recruited, 16 (or 32%) had cerebral palsy; in decreasing order of frequency, mental retardation (13, 26%), hearing impairment (12, 24%), and visual impairment (9, 18%) were also detected. Ten cerebral palsy patients exhibited spastic quadriplegia, whereas two cases each of dystonic cerebral palsy, spastic diplegia, and hypotonic cerebral palsy were seen. The age and sex distribution of the cases, as well as the family's socioeconomic standing at the time of contact, are displayed in Table 1. Class IV (lower class) accounts for just 5 (10%) of the instances, indicating that lower class individuals may be less inclined to use hospital or institutional services. Intervention recommendations and their application in the cases: We asked about the doctors' recommended interventions for each kid and the extent to which they had been carried out. Fourteen of the sixteen CP patients were recommended for PT at the time of diagnosis. Of those that could execute it regularly, ten (71.5%) cited transportation challenges and a lack of amenities in remote locations as their main reasons for non-compliance. The other two patients were advised that the child's condition would not improve with any kind of medical assistance. Three of the MR category (13) were recommended to undergo physiotherapy, and they could all carry it out. Four were urged to attend special education schools, and they did. Twenty percent of the children were informed that nothing could be done and that the kid would stay the same, whereas two children followed the advice and had oil massages. Only one of the seven HI children who were advised to have ear surgery - which would have cost between three and six lacs - could afford it. Three were recommended, and three were wearing, hearing aids. 21 people (16.6%) were informed there was no cure for the illness. Eight of the nine patients in the VI group had undergone one or more procedures. A youngster (11.11%) was informed that there is nothing they can do.

**Table 1:** Age, sex distribution and socioeconomic status of cases

| Parameter                   | Cases (%) |
|-----------------------------|-----------|
| <b>Age Distribution</b>     |           |
| 1-5 years                   | 14 (0.28) |
| 6-12 years                  | 26(0.52)  |
| 13-18 years                 | 10(0.2)   |
| <b>Sex distribution</b>     |           |
| Males                       | 31(0.62)  |
| Females                     | 19(0.38)  |
| <b>Socioeconomic status</b> |           |
| Class I                     | 11(0.22)  |
| Class II                    | 15(0.3)   |
| Class III                   | 19(0.38)  |
| Class IV                    | 5(0.1)    |

\* According to modified Kuppuswamy grading

child may be diagnosed with cerebral palsy as early as birth or as late as eighteen months of age. Within a month following the ag, more than half of the patients (10/16) had a diagnosis. Every child was born at a hospital. Prematurity (2/16) and birth asphyxia (10/16) were the two main risk factors for cerebral palsy. Conversely, in the majority of instances, mental retardation was identified after the age of six months (range: one month to 4.6 years). The two main risk variables identified were preterm (3/13) and Down's syndrome (3/13). Children with hearing impairments ranged widely in age from 6 months to 3 1/2 years upon diagnosis. Parents themselves identified seven of the instances, with other family members identifying the other eight. Strong family history (4), preterm (2), new-born hyperbilirubinemia (2), seizures (3), and ear infection (1) were the identified potential etiological variables. Four cases out of nine (44.4%) of the visually handicapped were diagnosed by a doctor at birth, two at three and six months, and one at nine months. Retinal illness (4), congenital glaucoma (2), retinopathy of prematurity (2), and meningitis sequelae (1) were among the etiological causes.

Cases with nutritional status: Upon clinical examination, 15 (30%) of the cases were wasted, 4% were stunted alone, and 28% (n=14) were both stunted and wasted. According to the WHO categorization, 34% of children had normal or somewhat inadequate nutritional status. When comparing children with cerebral palsy to the other three groupings, they showed worse nutritional characteristics. Financial assistance and support: Of the 50 pupils, 7 (HI-3, VI-4) or 14% received government funding in the form of scholarships. Private trusts were providing help to three youngsters (MR1, HI-2). Extended family members provided financial support for three patients with cerebral palsy. None accepted or received financial assistance from friends. One HI youngster was adopted by a family and received financial assistance for books, uniforms, and school fees. Parental response to diagnosis, family dynamics, and mental health concerns: At the time of diagnosis, the majority of parents of children with cerebral palsy were despondent; finally, half of them had recovered. A few (6/16) parents expressed remorse, but after some time, four of them no longer felt that way. A few (3/16) felt angry and in denial. They were angry at God, at their partner, or at the doctor for not guiding them. Guilt (10/13) was a common response to the child's sickness in the MR group, but the majority of them managed to deal with it. Few (4/13) at first rejected the diagnosis. The majority of parents in the HI and VI categories (16/21) stated that they were depressed when their kid was diagnosed, and as the child grew older, their main concern (18/21) was that they would be controlled or mistreated. Most parents (of all types) missed work during the diagnosis and early years because they had to often visit hospitals and rehabilitation centres, which also led to greater financial stress. Of the fifty, forty (80%) parents stated that their primary issue was money. Five children's parents (3CP and 2HI) complained about a lack of amenities. With the exception of one parent (HI kid), who did not receive any help from their family, family support was good for the majority of parents. Issues that parents and kids encountered: As the child's age rose, so did the anxiety for their safety. A total of 17 parents had this anxiety when their kid was in the 5-12 age range, and 7 parents experienced it when their child was in the 12-18 age range. In those with reduced eyesight and hearing, this was more noticeable. 11% of parents of children aged 1 to 5

Age of impairment detection and related risk factors: A

years, 20% of parents of children aged 5 to 12, and 6% of parents of children aged 12 to 18 reported feeling socially isolated. 20% of parents with CP children were afraid they wouldn't get pregnant again. While the majority of CP children (13/16) claimed that they got supportive treatment from neighbourhood kids, a small percentage of parents (3/16) stated that their children occasionally experienced humiliating conduct. Eleven MR youngsters got encouragement from local kids, while others had to deal with embarrassments (2) or a compassionate demeanour (3). During social outings, the degrading behaviour was encountered more frequently (5/13, 37%). Children with vision impairments, however, received encouraging behaviour from their neighbours and at social events.

## Discussion

The goal of the current study is to identify the typical issues that families of impaired children in Central Madhya Pradesh face. Children using outpatient services were the study's target population, and it was conducted at a hospital. The goal of this study is to gain insight into the issues facing families with developmentally impaired children in Central Madhya Pradesh, as well as their social surroundings and the support networks accessible to them. The data provides a composite image of the previous 18 years since children in the age range of 1 to 18 years have been included. The study contains a bias towards metropolitan locations and families that were able to attend hospitals or other institutions because it was performed in a hospital setting. Given their limited resources, the genuine situation in rural and tribal regions, as well as in very low socioeconomic categories, is probably different, and might even be worse. The bulk of the instances in our research included male children (62%) and most of them were older than five years old. According to certain research (GOI, 2003), men are more likely than women to be disabled (Ganesh *et al.*, 2008)<sup>[4]</sup>. The bulk of our cases fell under Classes I-III. This is not the same as the research of Mathur *et al.* (1995)<sup>[9]</sup>, which claimed that the majority of their instances included the less fortunate classes. The fact that this study is institution-based and not generally representative of the population may account for this discrepancy. The majority of impaired kids were either wasted, stunted, or both, according to a research by (Stevenson *et al.*, 2006)<sup>[11]</sup>. Across the board, the majority of parents adopted the medical advice and treatments that were recommended to them. We observed that, in contrast to CP, MR cases were typically discovered later, whereas HI cases were typically discovered first by parents or other family members. The majority of VI cases had a possible aetiology and were treated with several medical procedures. The degree of mental retardation, the thoroughness with which a child is diagnosed or treated, and the parents' level of education are all potential variables that might influence the age at which MR is diagnosed. By current criteria, any age at which an HI diagnosis is made beyond three to six months is considered late; hence, almost all of the patients in our research had late diagnoses. This is due to the fact that most hospitals and healthcare institutions, especially prestigious ones like medical colleges in our area, lack a facility or a process for screening neonates and babies for hearing loss. It is only very recently that certain institutions, including ours, have started to take this approach. Additionally, parents or other family members were aware of every occurrence. This is a depressing observation since it highlights the lack of awareness among primary care

doctors and paediatricians on clinical hearing screening methods, such as history and behavioural hearing tests, which they should be using in their daily clinical practice. We discovered that VI is identified rather early as opposed to HI. The average age of the developmentally impaired children attending the clinics was 4 years old, according to Paramleen *et al.* (2006)<sup>[10]</sup>. This emphasises the idea that parents should consider alternative options before sending their kid to a special education facility, or that these children are being referred to later. In contrast, children in the west are often referred for early intervention when they are 1.2 years old (Bailey *et al.*, 2004)<sup>[11]</sup>. Rehabilitating impaired people requires limiting their disabilities at an early stage when they are responsive to preventative and rehabilitative methods in order to minimise the progression of their impairment to a severe one. Rehab programmes are reported to assist very few impaired persons in India (GOI, 2003 and Kumar *et al.*, 2008)<sup>[5, 7]</sup>. A small number of children and their families were assisted by public and private trusts. The majority had to deploy their personal funds in order to pay for normal education and healthcare. Even with all of the programmes and initiatives aimed at improving the lives of handicapped people in our nation, a significant number of them merely receive little assistance. Parents must fill out several documents in order to receive financial assistance for their CP child's operation or a discount on train tickets. Even when years pass, the money is never returned. In order to offer comprehensive services to people with disabilities at the local level, the government has chosen to establish District Disability Rehabilitation Centres (DDRCs). Generating awareness, conducting surveys, identifying and intervening early, providing counselling, assessing the need for assistive devices, providing and fitting them, and monitoring and fixing them are just a few of the services that would be provided (DDR, 2015). Other therapeutic services offered would be physiotherapy, occupational therapy, speech therapy, referrals to and arrangements for surgical correction through government and charitable institutions, assistance in issuing disability certificates and bus passes, approval of bank loans, and encouragement of barrier-free environments. We looked at the parents' emotions and issues they had both during and after the child's condition was diagnosed. The parents' varied responses to the diagnosis included denial, wrath, guilt, sadness, and disappointment. Over time, these sentiments changed with the help of the family, patience, a greater understanding of the impairment, and the child's development in physiotherapy and special education. Many parents continued to have serious concerns about their child's safety as well as the actions of their neighbours and other kids. Ninety percent of parents experienced job loss and financial difficulties, particularly in the early age range of 1 to 5 years. Ten percent of them struggled with a lack of amenities at their place of employment. For 98% of the research participants, family support was satisfactory. Social isolation was caused by recurrent hospital admissions, the shame associated with having a handicapped kid, and the challenges of carrying a disabled child. Psychological assistance for patients and their families might be crucial. According to a recent study conducted on teenagers with mental disabilities, psychosocial intervention enhances quality of life and lessens the severity of impairment (Ganesh *et al.*, 2011)<sup>[4]</sup>. In India, social isolation of the disabled is widespread, mostly because of cultural and religious reasons. According to Kumar *et al.* (2012)<sup>[8]</sup>,

integrating handicapped people into the workforce through vocational training and rehabilitation will enhance their mental and physical health and lessen the strain on their family.

### Conclusion

Males above the age of five made up the majority of our cases. The majority of the parents said they followed and put the recommended medical treatments into practice. Since MR and HI were found later in our case cohort, extra care must be taken to ensure early identification and prompt treatment. The majority of the kids, particularly CP, lacked enough nutrition. Many families were not receiving enough financial help. Parents and kids dealt with a variety of social and psychological problems. It is imperative that these significant shortcomings be acknowledged, and that a multidisciplinary strategy be developed to address them and ensure that children with developmental disabilities have a higher quality of life.

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