Multidimensional Struggles of Parents Raising Children with Disabilities in Jammu, India

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Abstract

This chapter explores the multidimensional challenges faced by parents raising children with disabilities in the Jammu region of India, a context marked by infrastructural inadequacies, cultural stigma, and policy gaps. Utilizing a mixed-methods approach, the study draws on in-depth interviews with 60 parents—equally divided between mothers and fathers—of children under the age of 18 diagnosed with hearing or visual impairments. The findings reveal pervasive delays in diagnosis, lack of awareness about disability etiology, and limited access to specialized services. Educational exclusion, absence of after-school integration programs, and widespread psycho-social strain within families further compound the burden. Mothers bore the brunt of caregiving responsibilities, often at the cost of their mental health, employment, and personal agency. Fathers, while less expressive, reported acute emotional and financial stress. The study underscores the invisibilization of parental labour in India's disability discourse and calls for urgent structural reforms. Drawing from international models, it advocates for early detection systems, inclusive education reforms, mental health support for caregivers, and long-term respite and sibling care mechanisms. The chapter situates parental struggles not merely as private burdens but as pressing public health and human rights concerns demanding coordinated institutional response.

1. Introduction

Disability, though increasingly addressed in policy and public discourse, remains a marginalised issue in the Indian developmental landscape. According to the 2011 Census of India, nearly 2.21% of the population lives with some form of disability, a figure widely believed to be underreported due to stigma, definitional ambiguity, and diagnostic gaps. Children with disabilities experience a compounded invisibility, stemming from their status as minors with limited capacity for self-advocacy and their reliance on caregivers—typically parents—who navigate a complex system of inadequate services, cultural misconceptions, and policy gaps.

Parents of children with disabilities in India frequently encounter a continuum of emotional, logistical, and financial exigencies. These challenges are often amplified in resource-limited environments such as Jammu & Kashmir, where the confluence of conflict, infrastructural deficiencies, and limited medical outreach creates significant obstacles to effective caregiving. Traditional developmental models in India have historically underemphasized the critical role of the family unit, placing the onus of care largely on untrained and unsupported parents, predominantly mothers.

This chapter presents a case study conducted in the Jammu district, which offers a detailed examination of these experiences and provides a grounded understanding of the systemic failures that complicate caregiving. The chapter argues that parental struggles in this context are not isolated family issues but represent significant public health, educational, and human rights concerns, necessitating a comparative framework for reform informed by global best practices.

2. Methodology

A mixed-methods research design was employed, incorporating semi-structured interviews and qualitative analysis, to investigate the experiences of 60 parents (30 mothers, 30 fathers) of children under the age of 18 with disabilities. The participants were recruited from both urban and semi-urban areas within the Jammu district of Jammu & Kashmir, India. The primary disabilities represented in the children were hearing impairment (70%) and visual impairment (30%). Interview data were analyzed thematically, with quantitative summaries used to highlight key patterns and trends within the data set.

3. Findings and Thematic Analysis: The findings of the study are presented as follows

3.1. Lack of Awareness: Medical, Social, and Educational Dimensions

Table 1: Awareness and Diagnosis Timelines

Category	Number of Parents	Percentage (%)
Aware of disability etiology	12	20
Unaware or misinformed	48	80
Diagnosed before age 3	18	30
Diagnosed after age 3	42	70

The data presented in Table 1 indicate that a significant majority (80%) of parents lacked a correct understanding of their child’s disability. Etiological misconceptions were prevalent, with many parents attributing the condition to factors such as divine punishment, superstitions, maternal nutritional deficiency, or the "evil eye." This lack of accurate information contributed to delays in seeking appropriate interventions, potentially worsening the child’s functional outcomes and inducing feelings of guilt, particularly among mothers.

Furthermore, the findings reveal that a substantial proportion of children in the sample received a diagnosis after the age of 3, despite the presence of observable signs during infancy. Early symptoms were frequently misclassified by health workers as developmental lag, and access to timely and accurate diagnostic tools was limited due to unavailability or obsolescence. As one mother of a 9-year-old child with bilateral hearing loss reported, “We were told he will speak late, but no one suggested a hearing test until he was 5. That delay changed everything.”

3.2 Scarcity of Trained Personnel and Rehabilitation Services

Table 2: Access to Services and Education

Category	Number of Parents	Percentage (%)
Access to speech therapy	13	21.7
Access to audiology services	10	16.7
Enrolled in special school	15	25.0
Withdrawn from mainstream school	36	60.0

The data in Table 2 highlight the limited access to essential rehabilitation services. Only 21.7% of parents reported having access to speech therapists, and a mere 16.7% had access to audiology services. In rural areas of the Jammu region, access to special educators was particularly limited, with many schools lacking these professionals entirely. Even in urban areas, special educators were often overburdened and underqualified, with only two schools in the entire study region having dedicated special educators. These findings are consistent with national data, such as the National Sample Survey (76th round), which indicates a ratio of specialized therapists to children in need of less than 1:10,000.

3.3 Breakdown of Educational Access and Inclusion:

Despite legal mandates for inclusive education under the *RPWD Act (2016)* and *RTE Act (2009)*, practical implementation remains deeply flawed. Among the respondents, 80% reported that their children experienced consistent exclusion within educational institutions, manifesting in the form of bullying, lack of academic accommodations, and general unresponsiveness from school administrations.

Most distressingly, 60% of children were withdrawn from mainstream schools—either due to emotional trauma from bullying or due to perceived academic "failure" without any tailored support structures like Individualized Education Plans *(IEPs)*. While IEPs are a legal right under the RPWD Act, not a single parent reported being offered one.

Some parents cited that teachers would simply ignore the child or actively recommend that the child discontinue education, citing "disruption to class dynamics."

Table 3: Educational Exclusion Factors

Exclusion Factor	**Number of Parents**	**Percentage (%)**
Reported bullying incidents	48	80.0
No access to Individualized Education Plan (IEP)	60	100.0
Child withdrawn from mainstream school	36	60.0
Referred to special schools by school staff	28	46.7
Reported discriminatory treatment by teachers	32	53.3

This gap between rights and reality reflects not just negligence but a fundamental misunderstanding of inclusion, where integration is mistaken for equality without support. It also highlights the urgent need for capacity building in teacher training and school audits that go beyond infrastructure and focus on attitudinal shifts.

3.4 Lack of After-School and Social Integration Programs:

Despite the recognized importance of structured peer engagement and rehabilitative continuity beyond school hours, the study revealed a complete absence of after-school programs for children with disabilities in the Jammu region. None of the 60 participating families reported access to formal programs such as skill-building workshops, recreational activities, or supervised peer interaction initiatives.

Parents—especially mothers—felt solely responsible for maintaining the child’s engagement, education, and emotional well-being throughout the day. This often meant that caregiving extended well beyond the school day, eliminating opportunities for rest, employment, or social connection. Several families also expressed concern that the child’s unstructured post-school hours resulted in regression of therapy gains, social isolation, and dependence on screens for stimulation.

Furthermore, fears about “what will happen when we are no longer alive” were common. This anxiety stemmed not only from the absence of after-school programs but also from the lack of long-term care planning, respite care, and supported living services.

Siblings, too, were rarely included in any interventions or awareness efforts. Many parents expressed guilt over unintentionally burdening their non-disabled children with caregiving roles or emotional responsibilities.

Table 4: After-School Support and Integration

Indicator	Number of Parents	Percentage (%)
Access to structured after-school rehabilitation	0	0.0
Child attends peer inclusion or play-based programs	0	0.0
Parent expressed concern about child's post-school isolation	48	80.0
Fear about child’s future post parental death	54	90.0
Siblings involved in disability support/interventions	5	8.3

The total absence of such programs signals a critical policy vacuum. In contrast, countries like the UK and Canada mandate respite services and inclusive social programm**ing** as essential components of developmental support. Without these structures, the Indian caregiving model remains unsustainable, overburdened, and deeply inequitable.

3.5 Psycho-Social strain and Familial Burden:

The psychosocial burden on families—especially mothers—is profound and chronic. A staggering 85% of mothers and 60% of fathers reported symptoms consistent with anxiety or depression, although most had no formal mental health diagnosis or access to therapy. Mothers described feelings of isolation, identity loss, and constant exhaustion due to 24/7 caregiving responsibilities. Many had quit jobs or education, sacrificing personal and professional aspirations.

Fathers, although less vocal, expressed distress through other vectors—primarily financial stress and emotional withdrawal. Several fathers admitted to feeling “helpless,” particularly in the face of bureaucratic roadblocks or social stigma.

The strain also extended to the entire family ecosystem. 55% of parents believed their non-disabled children were being neglected. Siblings were often expected to "understand" without support, resulting in behavioral issues, jealousy, or social withdrawal.

Table 5: Reported Psycho-Social Impacts on Families

Impact Category	Number of Parents	Percentage (%)
Mothers reporting anxiety/depression symptoms	51	85.0
Fathers reporting emotional or financial stress	36	60.0
Reported family conflicts	24	40.0
Decline in marital intimacy or communication	24	40.0
Reported neglect of non-disabled siblings	33	55.0

These findings align with international literature on *caregiver burden* but are amplified in the Indian setting due to systemic gaps and cultural expectations around gendered caregiving.

4. Discussion

The findings of this study illustrate a systemic failure across the disability care ecosystem in India, encompassing a lack of awareness, institutional exclusion, and caregiver burnout. In contrast to Western contexts where coordinated services often provide support to families, the Indian context is characterized by a withdrawal of state support, which exacerbates the challenges faced by individual families. Existing policy frameworks, including the RPWD Act of 2016, the Right to Education (RTE) Act of 2009, and the National Policy on Education (NEP) of 2020, are often poorly implemented, under-resourced, and disconnected from the realities experienced by families. Consequently, the burden of advocacy, planning, execution, and emotional resilience falls disproportionately on parents.

5. The Way Forward: A Multilayered, Global-Local Approach

To address these systemic failures, a multi-layered approach is needed, integrating global models with India-specific actions:

5.1 Universal Early Detection Systems

- **Global Model:** The U.S. mandates universal newborn screening and the Individuals with Disabilities Education Act (IDEA) Part C for infants with developmental risks. Finland employs a system of tracking developmental milestones at each immunization checkpoint.
- **India-Specific Action:** Expand the Rashtriya Bal Swasthya Karyakram (RBSK) to include trained community health workers in screening for sensory and cognitive delays. Establish Early Identification Clinics at district hospitals, with linkages to tertiary care centers.

5.2 Parent Empowerment and Mental Health Integration

- **Global Model:** The UK's Family Partnership Model incorporates mental health support, coaching, and skill-building for parents. Australia's Carer Gateway offers 24/7 emotional and informational support to caregivers.
- **India-Specific Action:** Integrate caregiver mental health services into the National Health Mission (NHM) and Primary Health Centers (PHCs). Establish accredited Parent Counseling Centers through the National Institute of Mental Health and Neuro Sciences (NIMHANS) or regional All India Institutes of Medical Sciences (AIIMS). Recognize parents of children with disabilities as informal health workers and provide skill stipends.

5.3 Inclusive Education Reforms

- **Global Model:** The U.S. utilizes Individualized Education Programs (IEPs) with legal enforceability, while Sweden deploys inclusion assistants in all schools. Teacher evaluations incorporate inclusion metrics.
- **India-Specific Action:** Implement mandatory IEPs in all schools. Train 200,000 special educators under the NEP 2020. Include inclusion as a key compliance metric in school audits conducted under the RTE.

5.4 After-School and Sibling Support Structures

- **Global Model:** Canadian Respite Care Programs provide scheduled relief for caregivers. The UK's Sibs organization offers support to siblings of children with disabilities.
- **India-Specific Action:** Launch government-funded Respite Daycare Centers (e.g., 3–6 PM model). Develop sibling-focused educational and psychosocial modules through non-governmental organizations (NGOs).

5.5 Legal, Financial, and Employment Security

- **Global Model:** The UK provides the Disability Living Allowance (DLA), and the U.S. offers tax credits for families.
- **India-Specific Action:** Streamline the process of disability certification. Provide income-linked disability caregiving grants. Reserve one government job per family with a severely disabled member.

6. Conclusion

In India, families raising children with disabilities often experience a lack of adequate institutional support, leaving them to manage complex challenges independently. The impact of disability extends beyond the child, affecting the well-being of the entire family unit. Addressing the systemic gaps in diagnosis, education, rehabilitation, and family support services is crucial to ensure that these children and their caregivers are no longer overlooked in India's developmental priorities.

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