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Parents' Voices on Disability Legislation: Insights from the Study on the Impact of Orientation among Parents of Children with Autism

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Abstract: ***This paper offers a comprehensive exploration of the perspectives, challenges, and advocacy journeys of parents raising children with autism in India, with a specific focus on the intersection of family life and disability legislation. Drawing from a mixed-methods doctoral research study, this paper focuses on two core objectives: (1) understanding parental perspectives on disability laws and their implementation, and (2) analyzing the psychosocial dimensions of raising a child with autism, with particular attention to sibling adjustment. The study employed a descriptive research design, integrating quantitative data from structured questionnaires with rich, qualitative data from ten detailed family case studies. Quantitative findings revealed that 88.46% of parents recognized significant psycho-social impacts on their family, while 100% of siblings reported personal or emotional challenges. Qualitative analysis unearthed critical themes, including the transformative role of siblings, profound adjustment difficulties, and distinct gender-based patterns in coping. Furthermore, the research identified a pervasive gap between the existence of progressive laws, such as the Rights of Persons with Disabilities (RPwD) Act, 2016, and parents' practical ability to leverage them. As both a researcher and a parent of a child with autism, I interweave personal reflection with empirical findings to argue that targeted orientation is the crucial bridge that transforms legislative intent into tangible family empowerment. The study concludes that empathetic, parent-centric policy frameworks, systematic awareness programs, and a deeper inclusion of familial voices are imperative to achieve genuine inclusion and justice for children with autism and their families.***

Keywords: autism, parental perspectives, disability legislation, sibling adjustment, inclusion, advocacy, RPwD Act 2016, family systems, orientation, India

1.Introduction

The journey of raising a child with autism is a profound and transformative experience, uniquely shaped by an intricate interplay of love, challenge, advocacy, and resilience. As both a parent navigating this path and a researcher seeking to understand it, I have lived the stark contrast between the promise of disability legislation and the often-frustrating reality of its implementation. This dual identity forms the cornerstone of this paper, which seeks to amplify the voices of parents who, like me, find themselves at the crossroads of caregiving and citizenship, striving to secure the rights promised to their children by law.

India has made significant strides in its legal commitment to persons with disabilities. The landmark Rights of Persons with Disabilities (RPwD) Act, 2016, which replaced the more limited 1995 legislation, expanded the list of recognized disabilities, strengthened provisions for non-discrimination, and emphasized inclusive education and community participation. This act, alongside the Right to Education (RTE) Act, 2009, and the overarching principles of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2006), creates a robust, interconnected legal framework designed to ensure inclusion, protection, and equal opportunity. However, the existence of a law on paper is a far cry from its efficacy in practice. The chasm between legislative intent and lived experience is often wide, and it is a chasm disproportionately felt by parents who serve as the primary advocates, navigators, and caregivers for their children with disabilities.

My doctoral research was born from this very disconnect. The primary motivation was deeply personal: to understand how parents of children with autism perceive, understand, and apply the disability rights frameworks meant to protect their children. Why, despite progressive laws, do so many parents remain unaware of their entitlements? What are the barriers procedural, informational, and psychosocial that prevent them from becoming effective advocates? This paper focuses specifically on Objectives 1 and 3 of that research: to explore parental perspectives on disability legislation and to analyze the psychosocial dimensions of disability orientation within the family system, particularly as it affects siblings.

Conceptualizing Autism: Beyond the Diagnostic Criteria:

Autism Spectrum Disorder (ASD) is a complex, heterogeneous neurodevelopmental condition characterized by persistent challenges in social communication and interaction, alongside restricted, repetitive patterns of behavior, interests, or activities. The diagnostic criteria, as outlined in manuals like the DSM-5, require that symptoms be present in the early developmental period and cause clinically significant impairment in important areas of functioning. Parents often notice the signs within the first two years of life - a lack of responsive smiling, limited eye contact, delays in babbling and speech, or an intense focus on specific sensory aspects of their environment.

However, to reduce autism to a mere checklist of symptoms is to miss its profound impact on the entire

family ecosystem. Autism is not just a condition residing within an individual; it is a experience that radiates outward, shaping daily routines, social interactions, financial planning, and the emotional landscape of every family member. While early behavioral and speech interventions can significantly help children with autism acquire self-care, social, and communication skills, the journey is lifelong. It is crucial to acknowledge the neurodiversity paradigm, which posits that neurological differences like autism are natural human variations that should be recognized and respected, not merely "cured" or eradicated. This perspective advocates for acceptance and support, focusing on building strengths and accommodating needs, rather than striving for a normative ideal. For some individuals, this means developing strategies to live independently; for others, it requires lifelong, intensive support. The family, therefore, becomes the primary and most consistent system of support, advocacy, and love.

It is within this complex context that disability legislation operates. The RPwD Act, 2016, explicitly includes autism, guaranteeing rights to education, health, accessibility, and non-discrimination. Yet, for families, these rights remain abstract concepts unless they can be translated into actionable steps - a school admission secured, a therapy subsidy accessed, a discrimination complaint redressed. This translation is the core function of parental orientation, the impact of which this study seeks to measure and understand.

Objectives 1 and 3 of my doctoral research aimed to explore these parental perspectives and to analyze the psychosocial dimensions of disability orientation. Specifically, the study examined how siblings, as secondary participants in the family system, experience and adapt to the presence of autism. Through this lens, the research combined descriptive analysis and qualitative narratives to highlight the lived experiences of parents navigating autism-related legislation and caregiving realities.

2.Literature Review: Situating the Study

The critical role of parents as advocates and the challenges they face in navigating legal and administrative systems is well-documented in both international and emerging Indian literature. A growing body of research highlights the significant gap between the comprehensive nature of disability laws and their ground-level implementation.

The Legislative Framework and the Awareness Gap

Studies consistently identify "lack of parental awareness" as a primary barrier to the effective implementation of the RPwD Act. For instance, Banerjee et al. (2024), in a systematic policy review, identified this as a top implementation barrier, noting that families who received orientation were significantly more likely to complete disability certification and access accommodations. Similarly, Agarwal & Choudhury's (2023) large longitudinal study across eight Indian states found alarmingly low awareness levels, with only 9% of parents able to name five or more of the 21 disabilities listed in the Act. This awareness gap is not uniform; it is exacerbated by socioeconomic and geographic disparities. Urban parents in their study were 3.2 times more likely to utilize education provisions than their rural counterparts, highlighting a deep digital and informational divide.

The Psychosocial Burden of Advocacy

The process of securing rights itself can be a source of significant stress. Khan and Desai (2023), in a groundbreaking citizen science study, documented the bureaucratic challenges faced by parents through structured diaries. Their analysis revealed that 68% of these challenges occurred during peak morning hours in government offices, and only 22% of parents could correctly reference specific legal sections when contesting school admission denials. This constant negotiation with bureaucratic systems takes a toll. Desai and Rao (2023) found a direct correlation, demonstrating that caregivers with poor awareness of legal entitlements reported significantly higher psychosocial burden, depression scores, and help-seeking avoidance.

Sibling Dynamics in the Disability Context

While much of the literature focuses on the primary caregiver (often the mother), the impact on siblings is a critical, though less studied, area. The findings from this study resonate with global research indicating that siblings of children with disabilities can experience a range of outcomes, from increased psychological distress to the development of exceptional empathy and maturity. The gendered patterns observed in this study, where female siblings often assume more nurturing roles, align with broader societal expectations of caregiving (Mitra & Banerjee, 2022). Understanding these intra-familial dynamics is essential for developing holistic support systems that address the needs of the entire family unit, not just the child with a disability.

This review underscores that the problem is not a lack of law, but a failure of its dissemination and a lack of support for the families who are its intended beneficiaries. The present study contributes to this discourse by integrating the analysis of legislative awareness with a deep dive into the familial psycho-social context, arguing that the two are inextricably linked.

3.Methodology

The study was designed to capture both the breadth of parental experiences and the depth of individual family narratives. A **descriptive research design** was employed, utilizing a convergent mixed-methods approach where quantitative and qualitative data were collected concurrently, analyzed separately, and then integrated to provide a comprehensive understanding of the research problem.

Participants

The study participants included parents (both mothers and fathers) and the siblings of children with a formal diagnosis of autism spectrum disorder. To ensure diversity of experience, purposive sampling was used to recruit families from a variety of sources, including special schools, inclusive education resource centers, autism-specific therapy clinics, and parent support networks in urban and semi-urban settings. A total of 52 parents completed the structured questionnaire. From this larger pool, ten families were selected for in-depth case studies to provide rich, contextual insights into the quantitative trends. The selection of case study families aimed for maximum variation in terms of socioeconomic status, parental education level, family structure, and the age and support needs of the child with autism.

Data Collection Tools and Procedures

1. **Structured Questionnaire:** This instrument was designed in two parts. Part A collected detailed demographic information about the family, the child with autism, and their access to services. Part B consisted of closed-ended and Likert-scale questions designed to gauge:
    1. Awareness of specific provisions within the RPwD Act, RTE, and other relevant laws.
    2. Perceived psycho-social impact of autism on the family system.
    3. Sources of information and support (e.g., doctors, schools, NGOs, other parents).
    4. Sibling adjustment and relationships, as reported by the parents.
2. **Semi-Structured Interview Guides for Case Studies:** Separate, flexible interview guides were developed for parents and siblings. The parent guide explored their advocacy journey, experiences with bureaucracy, understanding of rights, and the impact on family dynamics. The sibling guide, used with appropriate ethical considerations for minors, encouraged them to share their feelings, experiences, and challenges related to having a brother or sister with autism.
3. **Field Notes:** Detailed notes were taken during and after home visits and interviews to capture non-verbal cues, family interactions, and contextual details that enriched the case studies.

4.Data Analysis

Quantitative data from the questionnaires were cleaned, coded, and analyzed using descriptive statistics primarily frequencies and percentages with the aid of statistical software to identify patterns in awareness levels and psychosocial reports.

Qualitative data from the case study interviews and field notes were transcribed verbatim and subjected to a rigorous process of thematic analysis. This involved:

- **Familiarization:** Repeated reading of transcripts to gain a deep understanding of the data.
- **Generating Initial Codes:** Identifying significant phrases or ideas relevant to the research objectives.
- **Searching for Themes:** Collating codes into potential overarching themes.
- **Reviewing Themes:** Checking if the themes work in relation to the coded extracts and the entire dataset.
- **Defining and Naming Themes:** Refining the essence of each theme and creating clear definitions.
- **Producing the Report:** Weaving together the thematic narrative with compelling data extracts.

The integration of quantitative and qualitative findings provided a nuanced, multi-layered understanding of how legislative awareness and family psycho-social dynamics are deeply intertwined.

Data Analysis and Findings

Quantitative Findings: The Landscape of Awareness and Impact

The analysis of the questionnaire data painted a clear picture of the widespread psycho-social impact of autism and the variable levels of legal awareness among parents.

- Psycho-Social Recognition: A overwhelming 88.46% of parents acknowledged that raising a child with autism had significant psycho-social effects on their family. This included strain on the marital relationship, financial stress due to therapy costs, social isolation, and constant anxiety about the child's future.
- Universal Sibling Impact: A striking finding was that 100% of parents reported that their typically developing children experienced some form of personal or emotional challenge. These challenges ranged from internalizing behaviors like anxiety, sadness, and social withdrawal, to externalizing behaviors such as acting out for attention, to more complex feelings of embarrassment, resentment, or confusion.
- Awareness and Its Correlates: The data on legislative awareness revealed a significant deficit. While most parents (over 90%) had heard of the RPwD Act, their understanding was superficial. Fewer than 35% could name specific entitlements beyond the disability certificate, such as the right to inclusive education (Section 16), the 4% reservation in government jobs (Section 34), or the provisions for guardianship (Section 14). A clear correlation emerged between higher parental education levels, urban residence, and more detailed legal knowledge. Families who had connected with an advocacy NGO or a structured parent-training program demonstrated markedly higher awareness and higher rates of successful service access.

Further interpretation revealed nuanced insights:

- A majority of parents (70%) acknowledged that despite the challenges, their typically developing children also developed positive traits like empathy, patience, and a strong sense of responsibility through their caregiving experiences.
- A significant proportion (65%) expressed profound difficulty in balancing attention and resources between

their children, often leading to feelings of guilt and worry about neglecting the needs of the non-autistic sibling.
- The data underscored that awareness alone is not enough. A subset of parents who were aware of certain provisions still failed to act on them, citing barriers such as fear of stigma (67%), complex application procedures, and a lack of confidence in dealing with authority figures.

Qualitative Findings: The Lived Realities from Ten Family Case Studies

The ten case studies provided a window into the complex, emotional, and deeply human stories behind the numbers. Three key themes emerged, illustrating the profound interplay between disability, family, and law.

Theme 1: The Transformative Role of Siblings

"Natural Therapists" and Unsung Heroes

In seven of the ten families, siblings emerged not as passive bystanders, but as active, nurturing agents of change. The role they played often extended far beyond typical sibling interactions.

- Case Study 4: A mother described her 12-year-old daughter as her "co-therapist". The daughter had intuitively learned to use Picture Exchange Communication System (PECS) cards to help her non-verbal 8-year-old brother communicate his needs. She would create new cards for his favorite toys and patiently wait for him to point, celebrating his smallest efforts. "She has a patience I didn't know a child could possess," the mother shared. "She doesn't see it as a burden; she sees it as teaching her brother how to talk to her".
- Case Study 7: A father recounted how his older son, a teenager, had become his brother's chief advocate at the local community park. When other children would stare or make unkind remarks, the brother would confidently explain, "He has autism, so his brain works differently. He likes to flap his hands when he's happy. Do you want to see how he plays on the swing?" This reframing of behavior as difference, not deviance, fostered a more inclusive environment and demonstrated a level of advocacy many adults struggle to achieve.

These narratives reveal that siblings can develop profound emotional intelligence, resilience, and advocacy skills. They become translators of their sibling's world, both within the family and in the broader community.

Theme 2: Adjustment Difficulties and the Shadow of Stigma

In three cases, the family narrative was dominated by significant emotional strain and difficulty in adjustment. These stories highlight the real risks of psychosocial maladjustment when support systems are absent.

- Case Study 3: A father, with visible anguish, described his 14-year-old typically developing son who had become increasingly withdrawn. "He never brings friends home anymore. If we have to take his brother with us to a mall or a restaurant, he will find an excuse not to come. He once told his mother, 'I just want to be a normal family for one day.' It breaks our heart". This case illustrated the internalized stigma and the sibling's longing for a life unmarked by disability.
- Case Study 9: A single mother of two described the intense resentment that had built up in her daughter. "She screams at me, 'You love him more! His autism is your favorite child!' No matter how much I try to explain, she feels neglected". This family was trapped in a cycle of guilt and anger, where the demands of caring for the child with autism were so all-consuming that the emotional needs of the sibling were consistently sidelined, leading to a deep-seated sense of alienation.

These cases underscore the critical need for professional counseling and sibling support groups to provide a safe space for these children to express their complex emotions and feel seen and heard.

Theme 3: Gendered Patterns in Sibling Response and Caregiving

A notable pattern across the case studies was the influence of gender on sibling roles and coping mechanisms. This aligns with societal narratives that often assign caregiving and emotional labor as feminine domains.

- Female Siblings: In six of the ten cases, daughters were consistently described in terms of their adaptability, compassion, and proactive involvement in care. They were more likely to be their sibling's playmate, helper, and defender. One mother noted, "My daughter just takes over. She'll feed him, try to calm him during a meltdown, and read to him. It's like her maternal instinct kicked in at age seven".
- Male Siblings: In contrast, the sons in the case studies were more frequently described as being frustrated, confused, or withdrawn. They were less likely to engage in daily care tasks and more likely to express their distress through avoidance or anger. A father observed, "My son doesn't know how to connect with his brother. He gets frustrated when he can't play football with him like other boys. He just retreats to his video games".

While these are not universal truths, the pattern suggests that societal conditioning plays a powerful role in how children are permitted or encouraged to respond to a sibling's disability. It highlights the need for conscious efforts to engage male siblings in positive, strength-based ways and to challenge restrictive gender norms within the family.

5.Discussion

The findings align closely with **Objectives 1 and 3** of my research: to analyze parental perspectives and examine the psycho-social adjustment of families with autistic children. From a policy viewpoint, these findings

highlight that while parents are deeply aware of autism's emotional and social impact, many remain only partially informed about existing disability legislation.

As a parent-researcher, I resonated deeply with this gap. When I first learned about the Rights of Persons with Disabilities Act (2016), I realized that many legal provisions were not effectively communicated to parents at the grassroots level. Orientation programs, though valuable, are often conducted in urban settings and fail to reach families in rural or marginalized contexts. My study showed that parents who participated in community awareness sessions displayed stronger advocacy confidence and were more likely to seek entitlements for therapy and inclusive education.

The sibling dynamics presented in the case studies also illustrate how disability orientation indirectly affects family well-being. Increased knowledge and sensitivity among parents led to improved communication and emotional resilience in siblings. These findings reaffirm that **parental empowerment through orientation** has ripple effects across the family system enhancing acceptance, reducing stigma, and fostering inclusive values.

Personal Reflection

Conducting this research while raising my own child with autism transformed my understanding of disability legislation from a theoretical framework into a lived reality. Every parent I interviewed echoed a familiar sense of determination mixed with fatigue. I saw myself in their narratives - the constant balancing act between hope and challenge.

This journey taught me that laws and policies acquire meaning only when parents understand and apply them confidently. My dual identity as a researcher and parent enabled me to translate academic insights into human stories reminding policymakers that behind every statistic lies a family striving for dignity and belonging.

6.Conclusion and Implications

This study demonstrates that orientation and awareness play crucial roles in bridging the gap between disability legislation and real-life advocacy among parents of children with autism. While most families recognize the psychosocial dimensions of autism, there remains a need for more systematic dissemination of legal knowledge.

Policy Implications:

- Government and NGOs should conduct localized orientation programs focusing on practical application of disability rights.
- Schools and clinics should involve siblings in awareness activities to strengthen empathy and coping.
- Future research should expand this model across regions and explore digital orientation interventions to improve accessibility.

In conclusion, empowering parents through awareness and legislative understanding transforms not only advocacy but also family well-being. As I reflect on this journey, I am convinced that when parents' voices are heard and respected, disability legislation moves from paper to practice - ensuring equity, dignity, and inclusion for every child.

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