

**PARENTING CHILDREN WITH DISABILITIES:
A SOCIOLOGICAL EXPLORATION IN
KOLKATA**

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Abstract

Introduction:

The policies and provisions related to disability were found to have been largely informed by the medical understanding of disability, which looked at disability as a personal tragedy and constructed it as a problem. Looking at disability as a tragedy makes it undesirable for people in the society and viewing it as a problem requires solution to it. The policies and legislation, thus, focused on the prevention of disabilities or rehabilitation as a solution to the problem of disability. It was in 2011 that disability discourse in the Indian state shifted from its charity model to a rights-based model, where dignity and independent living were highlighted more, than providing them with charity and welfare. Within this larger and general discourse surrounding disability, specific understanding, discussions, and research on intellectual and disabilities has remained a limited venture. It was in the disability bills of 2014 and 2016 that have place premium on the people/ children with intellectual disabilities. In these bills, family and care agencies were charged with the responsibilities of caring for children with diverse needs. The responsibility of care for children with disabilities and their need for rehabilitation has been found to have been inflicted upon the family and parents as the primary caregivers. Though the bills of 2014 and 2016 recognized the importance of family and home in legal discourses on disability, the contributions of family members and the caregiving challenges, which are frequently associated with isolation, stigmatization, violence, and frustration, went unnoticed. Thus, "caring and receiving care becomes a paradoxical experience of enabling/constraining, love/duty, agency/dependence" (Ghosh & Bannerjee, 2017, p. 03) for the parents, where the so-given situation gets further jeopardized by varying acquired and accessible social, cultural, and economic resources for the parents.

Literature Review:

The existing literature on disability and parenting has been extensively reviewed, tracing perspectives and empirical stances both from the global north and southern realities to debunk the invisible cord that connects parenting, disability, and care. Different models of disability (medical, social, cultural, and relational or transactional) have been discussed. The impact of such models on the wider disability policies of the Indian state was looked into. The research has attempted to look at whether and how the parents of children with disability have perceived their children's diversities in the light of such models.

The dominance of the medical model was found to have around the ways parents understood disability of their children, either as a tragedy or as a problem. Either way, they looked at medical knowledge and interventional procedures as the only solutions to their children's problems of disability. Reviewing the works of Rapp (2000), Skinner and Weisner (2007) revealed that parents initially adhere to the medical model when confronted with the reality of their children being diagnosed with a disability. However, as they encounter the everyday realities of disability and deal with the daily challenges associated with their children's disabilities, parents begin to realize that it is socio-cultural limitations, rather than their children's disability conditions, that have made their lives more difficult.

The works of Stryker (2004), Stets (2006), Turner (2009), and Trettevik (2016) have helped in understanding how parents develop their understanding of self after encountering the reality of their children being detected with a disability; how parents evaluate themselves on others' assessments through their interactions at different societal levels; and how such self-evaluations result in feelings of pride or shame among individuals. Arlie Hochschild's (1979) works have been used to explain the socially gendered nature of emotional expression and display. To have a deeper understanding of how parents' emotions, self, and identity coincide with their gender and their role in care, works by Arlie Hochschild (1979 & 1989), Tronto (1998), Karla Elliot (2016), Ruby and Scholz (2018), and Hanlon (2012) have been referred to.

Many researchers have found that families with disabled children experience “courtesy stigma” whereby the family members are stigmatized or perceive the interaction to be stigmatized because they are related to the stigmatized individual (Birenbaum 1970; Scambler & Hopkins 1986). Erving Goffman’s theory of stigma has been extensively engaged to understand the experience of stigma among the parents. Existing literature on parenting and disability reflects that parents who viewed professional services and knowledge to be non-functional and non-productive for their children, and for whom the existing social networks were non-effective in coping with their daily life challenges, often expressed their agency and developed their capacities for advocacy to improve the lives of their children (Rosalyn Benjamin Darling, 1988).

The works of Anita Ghai (2002), Upali Chakravarti (2008), Nilika Mehrotra (2011, 2020), Shuhangi Vaidya (2016a, 2016b, 2016c & 2016c), and Nandini Ghosh (2016) have been reviewed to understand and explain the realities of parenting children with disabilities in India. In India, the burden of caring for children with disabilities mostly falls upon the family members and parents of these children (Upali Chakravarti, 2008), particularly upon the female members of the family (Dalal, 2002). Closer scrutiny of the acts and policies undertaken by the Indian government reflects a ‘binary perspective’ in handling issues related to children with disabilities. On one hand, most of these policies were enacted to include children with disabilities within mainstream social networks by promoting the idea of inclusive education in regular schools. On the other hand, these policies included the provisions for and talked about the necessity of special schools for these children, which contradicts the idea of inclusive education.

A lacuna was found to have existed between the policy and its implementation as to how the legislation would ensure that families of the disabled children would bring their disabled kids to the special schools, overcoming the stigma that they might have had to face while managing children with diverse needs in public (Sen, 2016, p. 66). Inadequate and non-inclusive public infrastructure makes it burdensome and difficult for parents to gain access to public places with their children who have disabilities.

Research Objectives:

The research intends to look into the experiences of parenting children with diversities from three broad dimensions.

1. The first objective of the research has been to explore how parents have confronted the reality that their child has been detected with a disability.
2. The second objective of the research has been to reveal the challenges that parents have been encountering in raising their children and managing their disabilities.
3. The third and final objective of the research has been to look into the diverse coping mechanisms that the parents have devised and adopted to overcome the life strains caused by their constant exposure to the challenges of parenting and caregiving.

Methodology:

A social-constructionist lens of understanding the nature of reality was found relevant to understand that parents' perceptions, reactions, and responses to disability were products of social constructions. The current research employs a qualitatively driven mixed-method design. It has adopted the partially mixed concurrent dominant status mixed-method design using the QUAL+ quan model, where the qualitative dimensions and methods dominate the entire research process, with quantitative methods being used only as a supplementary backup to ease the presentation of the findings. With regard to the epistemology of the research, I have embraced the interpretive paradigm for knowing, observing, measuring, and understanding social reality with regard to parenting children with intellectual, cognitive, and developmental diversities.

The Kolkata Metropolitan Area formed the field of research. Sixty parents who had children with intellectual and cognitive disability conditions were selected as samples. Selection of samples was conducted using non-probability purposive and snow-ball sampling techniques. Data was gathered employing face-to-face interview methods

using a semi-structured interview schedule. Besides, the parents, three doctors, three special educators, and three school teachers of regular schools were interviewed for a holistic understanding of the parental encounters with disability with micro and macro levels of interaction.

I have thus adopted approaches from critical disability theories to situate Indian disability discourse within Indian social, cultural, political, economic, and historical reality. A few feminist approaches were employed to explain the parenting realities of balancing care and chores. A general feminist theoretical lens was used to understand the gendered dimension of caring for disabled children and managing their diverse needs. The approaches of symbolic interactionism and social constructionism were employed along with certain critical disability and feminist approaches to connect the findings with larger theoretical constructs for the purpose of generalization. The broader theoretical perspectives that have been used to contextualize and ground the research include perspectives from symbolic interactionism, sociology of emotions, sociology of care, feminist perspectives on gender and care, general disability, and approaches from critical disability perspectives.

Findings:

When the parents encountered the fact that their children were born with some problem or defect, they encountered a reality that was different from what they had expected. This sudden counter-interaction with a different reality made the parents sink into feelings of shock, despair, denial, fear, confusion, helplessness, stress, stigma, and trauma, followed by periods of emotional crisis.

In-depth interviews and conversations with the parents revealed several issues that parents had encountered in raising their children with disabilities. Their accounts did not only reflect their experience with other people, friends, relatives, professionals, and doctors as individual actors from different social systems in society but also exhibited their encounters with the wider social structures and institutions while managing and dealing with their children's diversities. Parents' engagement with the wider contextual macro-level societal interactions was observed in many instances when they had applied for the disability card in the government hospitals and needed to pass the bureaucratic maze; when they had taken their child for admission to a school; or while choosing whether to put their children in regular or special schools; and even when they experienced hindrance about the mobility of their children with disabilities in the structural and architectural planning of public places and poor transportation facilities and arrangements that barred the parents from carrying their children. In all those encounters, both at the micro-individual and macro-societal level with which parents were engaged, the definitions, meanings, and understanding of disability were constantly constructed and re-constructed.

It has been observed that parents' responses to the stressors, with regard to the diversity in their children, varied in kind and intensity depending upon the availability of capital that these parents had at their disposal. Positive or negative emotions and perceptions were found to be predisposed by social networks to which the parents had access; at the same time, they assisted the parents in coping by connecting to other social networks, which provided them with the necessary positive emotional motivations and rewards.

Parents demonstrated agency and advocacy in various episodes of their encounters with disability. Whether it was a local community level parental advocacy or an

organized state/regional level (registered in some cases) activity aimed at advocating the children's rights and entitlements with regard to disabilities, they were all aimed at the betterment of these children's lives by creating awareness among the masses regarding the diversities; among parents and family members by sharing experiences; and, providing support. In doing so, these advocacies were observed to be facilitating the construction of a re-definition and re-conceptualization of diversity, in particular, and of disability, in general.

Conclusion:

The research has explored different dimensions of parenting and care in raising children with intellectual and cognitive diversity. The challenges were discussed and analyzed in light of the perspectives of the sociology of care. The research was desperate in highlighting the gaps that were evident between the policy frameworks on paper and their real-life implementations in the lives of children with disabilities. The research demonstrated that functional limitations (both physical and mental) encountered by children with disabilities in general and intellectual and cognitive disabilities in particular when operating within mainstream socio-cultural contexts are the result of system-level dysfunction. The dysfunctions at the system level—health, education, and infrastructure—were unable to accommodate the needs and requirements of these children in order for them to function to their full potential.

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