

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

**Synopsis submitted for the partial fulfilment of the requirement for  
the degree of Doctor of Philosophy**

**In**

**Sociology**

**By**

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**Under the supervision of**


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# **Parenting Children with Disabilities: A Sociological Exploration in Kolkata**

## **SYNOPSIS**

### **1. Contextualizing the Research Problem**

For a significant period, the global discourse on disability was dominated by a western understanding of disability. It was from the 1980s that non-western societies began to develop their own understanding of disability. In Kolkata, the discourse around disability has remained embedded within the wider cultural, ideological, and social history of the country. The state was found to have adopted provisions and devised laws related to disability that were mostly based on the justifications of the medical, charity, and welfare models of disability. 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 society and viewing it as a problem requires a solution to it. The policies and legislation, thus, focused on the prevention of disabilities or rehabilitation as a solution to the problem of disability. In 2006, following the recommendations of the United Nations Convention for the Rights of Persons with Disability, Indian state laws were amended, which were profusely informed by the social model understanding of disability. The laws and bills were so amended to highlight the ideas of dignity and independent living. This was clearly evident in the disability bill of 2011<sup>1</sup>, which emphasized the dignity and independent living as rights of people with disabilities over charity and welfare.

Within this larger and general discourse surrounding disability, specific understanding, discussions, and research on intellectual disabilities have remained a limited venture. In the following years, the Rights of Persons with Disabilities Bill, 2014<sup>2</sup>, and the Mental Health Care Bill, 2016<sup>3</sup>, have given due emphasis to issues of mental health and intellectual diversity. It was for the first time that families and

parents were brought under the purview of legal discourse in which family and care agencies were charged with the responsibilities of caring for children with diverse needs. The responsibility of caring 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.

Although 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 the varying acquired and accessible social, cultural, and economic resources of the parents.

## **2. Sociological Rationale of the Study**

For a long time in the history of human civilization, disability has been portrayed as a “problem” (Titchkosky and Michalko, 2017, p. 127-128). The problem dimension of disability did not arise out of the bodily condition of a disabled individual but was presented, constructed, and created through social interaction within the wider social and physical environment. Disability is produced and created through the “social production of knowledge” (Titchkosky, 2000, p. 198). The portrayal of disability as a problem, which required a solution in the form of prevention, cure, and rehabilitation, recognized the understanding of disability from a medical perspective (the medical model). But the emergence of the social constructionist model (the social model) in the 1980s brought about a shift in the disability discourse, putting much emphasis on the social creation and cultural reproduction dimension of disability. The meaning and understanding associated with disability, thus, have undergone a radical shift from a medical individual-centric model—which believed in disability as a personal tragedy—towards a social constructionist perspective, which has attempted to comprehend disability as a social and cultural construction. This new approach to disability has suggested that disability was a problem of social organization (Oliver, 1990), and the

solution to such a problem rested on a systematic change in the social, cultural, political, and economic dimensions that created disability (Hughes, 2004, p. 45).

Many sociological works, such as those by Michel Oliver (1990) and Barnes, Mercer and Shakespeare (1999), have contributed to the development and conceptualization of disability. Barnes and Mercer (2010) have presented the emergence of disability models and shown how the agency has developed from the disabled people's group and turned gradually into the disabled people's movement. They have also stressed the role of agency and self-reflexivity in enabling disabled people to change their living conditions. It is important to note that all these works have helped in the generation and conceptualization of disability from the perspective of disabled people, ignoring adequate accounting of the significance of family members, parents, and caregivers of children with intellectual, developmental, and cognitive diversities.

With the emergence of post-colonial and post-modernist understandings of disability, coupled with the growing popularity of critical disability perspectives, one can notice a growing literary, academic, and intellectual thrust among scholars and researchers to develop disability discourse and theory that could address the disability issues and understandings specific to the countries of the global south, including India. A vast literature on disability in India has been found to have existed, but that too often has disregarded the sociological understanding of the family and parents who were associated with the children with intellectual and cognitive diversities. The existing literature base, which has focused on the challenges of parents in raising and caring for their children with disabilities in India, has been limited to discrete empirical facts. With little scope for developing a coherent sociological theory that would have explored the relationship between parents' understanding of disability and their reflexivity to broader social reality, research on childhood disability, parenting, and care has been left incomplete and compromised. With this context in mind, I attempted to investigate the lived experiences of parents raising children with intellectual and cognitive diversity. I have tried to explore whether and how parents' interactions relating to the diversities in their children, both at the micro and macro level, have shaped their perception of disability; and whether and how such perception has framed their conduct both as a parent and an individual within society. In the course of the research, the attempt has been to observe whether and how parents' interaction with the wider social institutions and structures has created

necessary conditions for developing and expressing agency and for participating in different non-governmental activist programs, to voice for their children.

### **3. Research Objectives**

The objectives of the research have been:

1. To explore how parents have confronted the reality that their child has been detected with a disability.
2. To reveal the challenges that parents have encountered in raising their children and managing their disabilities.
3. 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.

### **4. Methodology: Research Design and Parameters**

A social-constructionist lens of understanding the nature of reality was found relevant to understand parents' perceptions, reactions, and responses to disability, which were products of social construction. The current research uses a qualitatively driven partially mixed concurrent dominant status design (Leech & Onwuegbuzie, 2007, p. 273). The research was conducted by engaging a qualitatively driven mixed-method design, with qualitative methods of inquiry remaining the primary method of understanding the research concern. The quantitative approach has been used as an aid to qualitative interpretations, particularly for understanding the demographic status of the respondents (parents of children with disabilities). The research used 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 and interpretation 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 the research. Sixty parents who had children with intellectual and cognitive disabilities were selected as samples. The

research has included parents who had children detected with different conditions like Autism Spectrum Disorder (ASD), Down Syndrome (DS), Attention Deficit Hyperactive Disorder (ADHD), Specific Learning Disability (SLD), Cerebral Palsy (CP), Multiple Disability, and Congenital Rubella Syndrome (CRS). Since all of these categories of disability show limitations in the intellectual and cognitive functioning of the children, the research has conceptualized the disabilities under the umbrella term of “intellectual and cognitive diversity”. The non-probability purposive and snowball sampling techniques were used to select samples. 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. The data was transcribed, analyzed, and interpreted, resulting in thematic interpretation and detailed descriptions.

The research has employed constructionist (ontologically) and interpretive (epistemologically) paradigms, which have driven the choice of theoretical approaches that could satisfy the methodological paradigms and parameters so selected. A critical disability theory was engaged 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 theoretically include perspectives from symbolic interactionism, sociology of emotions, sociology of care, feminist perspectives on gender and care, general disability, and critical disability perspectives.

## **5. The Literary Journey of Parenting and Disability**

### **5.1. Conceptual and Conjectural Journey of Disability**

Multiple discourses exist in the way disability has been conceptualized in this research and leave room for a reconceptualization of the same at different times, spaces, and contexts.

#### **5.1.1. Foucault and the Medical Hegemony**

Traditionally, disability has been understood as a “problem” residing within the individual with disabilities and revolves around the concept of “normal functioning of the body,”<sup>4</sup> which refers to the idea that there is a pre-assumed standard of how humans should function and direct their actions and roles. Any deviation from the norm of functioning has been considered a disability or a disease. Conceived in this way, disability has been understood as a “lack of ability” within an individual. The yardstick which has measured the degree of “normal” and the criteria which have been portraying some people as “normal” as compared to others based on such yardsticks have mostly been derived from the knowledge of biological sciences. The medical paradigm had given birth to the idea that it was the physical flaws within people that had given birth to their disabilities. This dominant medical perceptive approach to disability was dubbed “the medicalization of life”<sup>5</sup> by Illich (1975) (Ghosh, 2016, p. 03).

The research has traced back to Foucault’s conceptualization of power and knowledge to understand the medical hegemony that had made the parents become subject to the expert knowledge on disability and accept them as it was nurtured and exercised by the medical professionals. This research has been found significantly relevant to Foucault's explanation of disciplinary power<sup>6</sup> and panopticon<sup>7</sup>. Engaging Foucault’s conception of power has helped to illuminate the process through which parents (as social individuals) and their children with disabilities are “made subjects”<sup>8</sup> (Roberts, 2005, p. 34). It also aided the research in understanding how the parents and their children were identified and labelled as distinct. The labelling of diversity was done



through the use of disciplinary power and the formation of an invisible gaze, which Foucault referred to as the panopticon. This kind of medical gaze has been found to have encircled parents' comprehension of their children's diversity, and this has been well reflected when parents looked at medicine and medical expertise to be the only solution to the "problem of disability"<sup>9</sup> in their children.

### **5.1. 2. Medical Gaze of Disability: The Structural Functional Perspective**

Within sociological understanding too, disability has long been contextualized around the medical gaze and has almost become central to any sociological discourse on disability. For Parsons (1952), illness is not just a biological condition but carries a social dimension with a set of expected norms and values attached to the individual who claims the illness. To Parsons, becoming ill is, thus, a deviance. And to maintain social stability and equilibrium, the deviations have to be minimized. The need to resolve this deviance made the prescriptions of medical expertise the dominant means of social control. According to research, parents believe that the medical and health care systems are the only ways to cure their children's disabilities (Bricout, Porterfield, Tracey, and Howard, 2004, p. 47).

### **5.1. 3. The Social Model and the Construction of Disability**

The emergence of the social model of disability in the 1980s replaced the person-centric approach to disability with a social-centric approach that recognized the role of the socially disabling environment in creating disability. The social model has thus recognized the institutional barriers that have existed and reproduced disability. However, the social model of disability has been criticized for failing to include an intersectional understanding of reality about the lives and experiences of disabled people. Later, different models of disability branched out, keeping the ideas of the social model understanding of disability at their core. This has led to the emergence of the cultural, relational, and transactional models of disability.

### **5.1. 4. Socio-Cultural, Relational and Transactional Perspectives of Disability**

The cultural model emphasized culture as an important tool for explaining disability and showed it as a "site of resistance and source of cultural agency", both of which

were suppressed earlier (Snyder and Mitchell, 2006, p. 10). The transactional and relational models have stressed the role of social relationships and networks in the creation of disability and the stigma attached to it. The transactional model takes into account the interaction of the child with a disability and his/her parents with the schools, social agencies, various support systems, and other transpersonal factors that shape the quality of life of the child with diversity (Ferguson, 2001). Seeing disability from a transactional perspective enables us to examine how a non-supportive and non-cooperative environment creates and reproduces disability.

## **5.2. Parenting and Disability: Global Reflections**

### **5.2.1. Juxtaposition of the Medical and Social Models**

Reviewing the works of Landsman (1998), Rapp (2000), Skinner and Weisner (2007) brought to light that parents adhere to the medical model in the initial stages when they encounter the reality of their children being detected with disability. However, as parents encounter the everyday realities of disability and deal with the daily challenges associated with their children's diversity, they begin to realize that it is the socio-cultural limitations that have made their lives more difficult rather than the disability condition of their children.

### **5.2.2 Interface of Self, Emotion and Identity: Symbolic Interactionist Perspective**

Parents with disabled children identify themselves with a new identity once their children are born or once they are diagnosed with intellectual or developmental disabilities. Their already presumed ideas of self and identity as parents encounter a reality that is completely different than what they were expecting. The parents begin to identify themselves as parents of disabled children, which is internalized by them as a deviation from the norm of having a healthy child (without any intellectual, developmental, mental, or physiological diversity). The identification of norm deviation emanates from the internalization of the expected moral and cultural codes by parents, which they have learned for years through cultural socialization about parenthood and parenting. This creates an already assumed picture of how their baby would be born before them. It is never a conscious phenomenon that parents are guided by the wider socio-cultural moral codes of parenthood and parenting, which

leads them to identify themselves as deviants because they are parents of children having intellectual and developmental diversities. The research engaged works from the sociology of emotions to understand the parents' experiences. The works of Stryker (2004), Stets (2006), Turner (2009), and Trettevik (2016) have been used to better understand the interface of self, emotion, and identity among parents when their child is diagnosed with a disability. Their works 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.

### **5.2.3. Management of Emotions and Parenting**

Care work has often been understood as the responsibility of women. For example, women are expected to display sympathy and nurturance to elevate the moods and feelings of others, while men are expected to act in a manner that suppresses sympathy (Fields, Copp & Kleinman 2006, p. 166). Erickson, Gerstle & Feldstein (2005) have suggested that the emotional work involved in caregiving demands ample time, effort, and energy on the part of the caregivers. For her, caring should be redefined as emotional care work, which involves providing emotional support and enhancing the well-being of others. Emotional care-work, thus, should be considered and acknowledged as important household work. Hochschild's (1989) work on gender and emotions has highlighted the areas where the "framing rules" that shape the "feeling rules", are guided by gender ideological frameworks. Thus, whether mothers feel guilty for prioritizing their job commitments, which reduces quality time with their children; whether they prioritize both their professional commitment and child care responsibility by weaving a balance between the two; or whether they compromise their career for the sake of child care, is determined by the gender ideological frameworks they choose to adhere to, and which guides the feeling rules they should exhibit. Arlie Hochschild's (1979) works have been used to explain the socially gendered nature of emotional expression and display, who believes that feelings and emotions are "deeply social" (p. 555) and framed by certain socio-cultural ideologies. 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 and 1989), Tronto (1998), Karla Elliot (2016), Ruby and Scholz (2018), and Hanlon (2012), and have been referred to.

### **5.3. Parenting and Care Giving: Global Approaches**

#### **5.3.1. Care and Context of Parenting**

Studies show that women continue to perform the majority of caregiving activities and care work within families (Guberman, Maheu, & Maille, 1992; Bédard, Kuzik, Chambers, Molloy, Dubois, & Lever, 2005). To Hochschild (1989), women are often found to juggle three domains in their everyday life- “job, children, and housework”, while fathers have been observed to manage two—jobs and children (P. 9). Thus, caregiving for mothers demands their commitment to three different roles: “being an employee”, “being a mother”, and “being a home manager/housekeeper”. For fathers, their roles are managed between 'being an employer' and 'being a father'. The question of which role the parents prioritize and to what extent the parents balance their roles in different domains relies on their affiliation to gender ideology. Hochschild (1989) has mentioned three types of gender ideology: traditional, egalitarian, and transitional—to which men and women of a household subscribe. Various research in the field has shown that there is little research and literature that includes a discussion of fatherhood while discussing masculinities, and there are few studies on fatherhood that adequately reflect on masculinities (Ruby & Scholz, 2018, p. 77). The current research has engaged some recent sociological works that have attempted to unearth the connecting links and contradictions hidden within the relationship between masculinity, fatherhood, and caregiving/care-work (Brandth & Kvande, 1998; Ranson, 2015; Hunter, Riggs & Augoustinos, 2017). The concepts of “Caring masculinities”<sup>10</sup> (Elliot, 2016) and the “Generative fathering”<sup>11</sup> framework (Erikson, 1950; Dollahite & Hawkins, 1997) have also been engaged to understand father’s involvement in care work.

#### **5.3.2. Reality, Resource and Response in Parenting: Pierre Bourdieu’s Perspective**

Pierre Bourdieu’s concept of “habitus”<sup>12</sup> has aided the research in developing an understanding of how the “outer” “social” and “inner” (Grenfell, 2008, p. 50) selves

of the parents shape each other in their encounter with disability and wider social structure. The “habitus”, in conjunction with the “capital”<sup>13</sup>, which an individual possesses within a specific “field”<sup>14</sup>, gives rise to practice. The inter-relationships between these concepts have been encompassed in the current study on parenting, to look into whether and in what manner: i) parents’ personal, cultural, social, and economic resources (capital) have shaped their understanding of both parenting (care) and disability; ii) parents’ capital has structured their habitus; iii) parents’ capital and habitus have been both influenced and given rise to a reality (field), based on the context in which parents have been engaging themselves in interactions and actions related to caring and managing the disability of their children; and iv) the “capital”, “habitus”, and “field” of the parents, leading expression of their agency.

### **5.3.3. Parental Response to Disability**

Stryker (2004) theorizes that individuals who are capable of sharing affective meanings are more likely to form social networks. Emotions impact the extent to which social networks are created by individuals. Parents' support groups and positive social relationships were found to have helped cope with the stress of managing their children with disabilities. The works of Simon (2014, p. 437) and his concepts of “exposure hypotheses” and “vulnerability hypotheses” have been referred to in understanding the relationship between parents' experiences of raising diverse children and the socioeconomic profile in which they are located. It has been suggested that individuals who are unprivileged, disadvantaged, and hence marginalized or stigmatized, experience higher and more intense symptoms of emotional distress than individuals who are comparatively placed higher in the social hierarchy. A large body of research has shown that raising disabled children places enormous pressure and stress on parents and other family members (Falik, 1995; Freedman and Boyer, 2000). The works by Kandel and Merrick (2007) were found significant in explaining the “role strain” that parents undergo when they have children with disabilities. As Falik (1995, p. 335) puts it, families that have a child with a disability undergo a tragic experience, leading to a three-dimensional interaction: first, the child who experiences the diversities and dysfunctions within the family; secondly, the family that suffers the impact; and thirdly, the external environment where disability is negotiated and manifested.

## **5.4. Parenting and Stigma**

### **5.4.1. Conceptualizing Stigma**

Parents often experience a feeling of courtesy stigma and perceived stigma due to their close association with their children with disabilities (Titchkosky, 2000). For theoretical grounding, Erving Goffman's (1963) theory of stigma has been employed in this research.

### **5.4.2. Social Reproduction of Stigma**

The manner in which Goffman extended his explanation of stigma as a social construction leaves space for understanding 'normalcy' from the standpoint of "who and what is stigmatized" (Titchkosky, 2000: 204). Studies show that stigma is generated across different identities and positions that individuals hold in a society, ranging from visible and non-visible diversities (disabilities), physical impairments, different body shapes or marks, and mental illness, to different aspects of gender, sexuality, race, and class (Titchkosky, 2000). Goffman (1963) has suggested that people use diversity as a tool to exclude or avoid others, leading to the dimension of social exclusion and marginalization of certain people or groups over others. Studies have shown that the isolation of parents from larger social structures and interactions results directly from the limitations of their activities outside the home due to stigmatization (Sayce, 1998; Clarke, 2014).

### **5.4.3. Encounter and Perception of Stigma**

Many researchers have found that families with disabled children experience "courtesy stigma"<sup>15</sup> whereby the family members are stigmatized or perceive the interaction to be stigmatized because they are related to the stigmatized individual without possessing any characteristic of an undesired attribute of their own (Birenbaum, 1970; Scambler and Hopkins, 1986). Birenbaum (1970, p. 196) regarded these family members as "normal yet different". Goffman (1963) constructed a distinction between "the discredited"—when the stigmatized attributes are apparent—and "the discreditable"<sup>16</sup>—when attributes containing stigmatizing features are not so apparent or invisible. Parents of children with disabilities become discreditable in

that they do not possess any characteristics that can be negatively attributed. But, they are still stigmatized because they are associated with their disabled children.

#### **5.4.4. Response to Stigma and Development of Agency**

Existing literature on parenting and disability reflects that parents (of children with disabilities) 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). Sociologist Dennis Hogan (2012) observed that most of the policies are framed in a way that shifts the responsibility of care work from concerned institutions to families without making adequate arrangements for the support that these families might need to encounter the challenge of the special care work needed for their children. Parents of children with disabilities often express their agency and capacity for advocacy. Pierre Bourdieu's theory of capital has been vividly engaged in this research. Parents are expected to perform multiple roles as doctors, nurses, therapists, educators, and advocates, plus the central role of being parents.

### **5.5. Recognition of Intersectional perspective in the Global South:**

#### **Critical Disability Perspective**

The critical disability perspective was found to be significant in this research. Critical disability perspectives help to conceptualize disability within national and local contexts. It offered the disability discourse of the global south with reference to its own history, culture, language, and diversity. It helped the research to explain the discriminatory attitudes of the state, especially in the context when there are a good number of policies to protect the rights and benefits of children with disabilities (Meekosha and Shuttleworth, 2009). Using critical disability perspectives assisted in conceptualizing disability within national and local contexts, providing a disability discourse of the global south with reference to its own history, culture, language, and diversity (Nguyen, 2018). Hoskin (2008) has recognized the room left vacant by critical disability studies for including multidimensionality and intersectionality as an essential component of theory building and consequent policy framing and implementation. Multidimensionality and intersectionality have the potential to

observe and understand disability as it has been experienced by disabled people in their everyday interactions, both at the micro-individual and macro-structural level; and have the capacity to reflect the diverse realities faced by disabled people, based on the different social intersections connected with their identity (like country, ethnic group, class, gender, age, forms and extent of disability).

## **5.6. Reproduction of Disability Discourse in India**

### **5.6.1. Parenting and Disability in India**

The 2016 bills recognize the importance and role of families in providing for children with disabilities, but the realities of isolation, stigma, violence, and frustration that parents face are never addressed. The works of Anita Ghai (2002), Upali Chakravarti (2008), Nilika Mehrotra (2011), Shuhangi Vaidya (2016), and Nandini Ghosh (2016) have been reviewed to understand and explain the realities of parenting children with disabilities in India.

### **5.6.2. Medical Gaze and Parental Perception of Disability**

Most of the existing discourse on disability in India revolves around medical recognition and certification of disability. The sole emphasis on medical expertise has made the medical definition and understanding of disability the dominant discourse, both in legal parameters and among the general population. It cannot be denied that medical and legal discourses surrounding disability have provided a general framework for understanding disability.

### **5.6.3. Shift in Approach: From Welfare to Rights**

The Rights of Persons with Disabilities Bill, 2011<sup>17</sup> was drafted, where the legal capacity, equality, and dignity of people with disabilities were recognized in India. The ideas of “inherent dignity, individual autonomy, equal opportunity, accessibility, respecting diversity, and acceptance for all” were emphasized in this new bill. This Bill was a reflection of the shift in approach that was taking place in the disability discourse in India, and for that matter, in the policy frameworks, from the “charity paradigm to a more rights-based approach” (Ghosh, 2016, p. 13).



#### **5.6.4. Marginalization of the Marginalized**

The disability rights movement has clearly shown that disability as a social category is not a homogenous group, and hence the social contexts and experiences of all disabled people are not similar. Even within the Disability Rights Movement, one cannot hear voices representing all the categories of disability in India. People with intellectual, developmental, and cognitive diversity were observed to be further marginalized within the disability group/s. Subhangi Vaidya (2016) has mentioned that for people with intellectual and developmental disorders, voices for them are represented by others for them as self-advocacy becomes difficult due to their different states of body and mind; they continue to be "spoken about" rather than speaking for themselves (p. 98).

#### **5.6.5. Place of Family within Disability Discourse: Recognition of Care**

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). The main reasons for such gendered care division have been a lack of family resources and an inadequate institutionalized support system in India. Balancing the double burden between caregiving and earning a living leaves no choice for the parents, other than one of them being compelled by the situation to resign from their earlier employment, particularly when they are not in a position to hire an external caregiver for their children.

#### **5.6.6. Parenting Children with Disability and Education System in India**

In India, the struggle of the families and parents of children with disabilities has turned more difficult when it comes to the question of providing them with education and putting them in schools. Closer scrutiny of the acts and policies undertaken by the Indian government reflects a 'binary perspective' in handling issues related to children with disabilities. Most (if not all) of these policies were enacted in an attempt to include children with disabilities within mainstream social networks by paving the paths to equal access and opportunities in the fields of education and employment. However, on the contrary, special schools were also included within these provisions to facilitate education among these children. Anita Ghai (2001, p. 32) has said that

“integration is an illusionary concept in a country where schools continue to marginalize children for being different”.

### **5.6.7. Children with Diversity and External Structural Barriers**

A lacuna was found to have existed between the policy and its implementation as to how the legislation would ensure that the 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.

## **6. Confronting Disability**

The knowledge and confrontation of the detection of diversities were observed to be a “complex and powerfully emotive experience for parents” (Avdi, Griffin and Brough, 2000, p. 243). A constructionist understanding of the lived experiences of the parents has revealed that parents’ responses and reactions did not emanate from the ‘diversities’ or ‘conditions’ that created disability, but emerged out of the social and medical negotiations that parents encountered during the process of detection and diagnosis of the disability.

### **6.1. Construction of Disability**

#### **6.1.1. The Art of Disclosure and Creation of Disability**

Responses from the parents reflected that when the diverse health conditions of the children were communicated to them in an understandable and comprehensible manner, it became easier for parents to accept and adjust to the reality of their child’s disability. During the interviews, three doctors acknowledged that regulation of emotions and expressions of objectivity towards the diagnosis often made them hard to accept by the parents. Empirical observations have shown the existence of a reinforcing connection between how the medical experts and professionals disclosed

the information about the diversities that were present in the children and the life-long impact such disclosure had upon the parents.

### 6.1.2. Comprehending the Cause of Disability

Parents understood the cause of disability in their children in a variety of ways, including blaming their fate, committing wrongdoings in the past, being ignorant during pregnancy, biological imperfections in themselves and their children, and genetic disorders. For some families, the solution to the disability condition was to cure what they assumed to be a problem. Families who believed that their child's disability was caused by inappropriate interactions with social and cultural environments or by inappropriate or uncomfortable experiences were found to seek behaviorally-based interventions as a solution to the problem of disability.

**Table No. 3.1: Cause of the disability as per the perception of the parents**

Cause of disability as believed by parents	No. of respondents	Percentage (%)
Destined / was in fate	17	28.32
Wrong deeds of past life	4	6.66
Ignorance or faulty pregnancy care	7	11.66
Biological imperfections (in parents)	9	14.99
Genetic disorder in children	11	18.32
Biological factors in children themselves	12	19.99
<b>Total</b>	<b>60 (N)</b>	<b>100</b>

### 6.1.3. Parents' Reaction to Disability

The parents were observed to hold complex emotional states, showing diverse reactions at different points of time during their articulation. The initial process of knowing made the parents confront a reality that they had never expected to encounter. Parents of children with disabilities had different reactions once they understood that their children had one or more exceptional health traits, which were described as impairments or ailments according to medical parlance. The initial reactions and their consequent legacy until a certain point in time did not show any discrete pattern, nor were the reactions mutually exclusive, but the emotional responses of the parents were witnessed to be profoundly interwoven into one

another. In most of the accounts, the feelings of self-blame, grief, guilt, denial, fear of stigma, confusion, helplessness, stress, and emotional crisis have been retrieved.

**Table No. 3.2: Parents’ reaction after knowing their children’s disability**

Reactions	No. of respondents	Percentage (%)	No. of mothers	Percentage (%)	No. of fathers	Percentage (%)
Denial	43	71.66	29	90.62	12	50
Guilt	26	43.33	21	65.62	5	17.85
Grief	41	68.33	26	81.25	15	53.57
Fear of Stigma	39	65	28	87.5	14	50
Self-blame	15	25	15	46.875	3	10.71
Confusion	39	65	23	71.87	18	64.28
Helplessness	46	76.66	29	90.62	17	60.71
Stress	54	90	31	96.87	26	92.85
Emotional Crisis	56	93.33	31	96.87	25	89.28
Trauma	49	81.66	30	93.75	19	67.85

## 6.2. Gendered Expression of Emotions

A deeper understanding of the narratives revealed a difference in the emotional responses between the mothers and the fathers. Narratives reflected mothers being more succumbed to stress and anxiety as compared to the fathers. Mothers expressed their concern about the responsibility, care, and dedication they would have needed to develop, in order to care for their children. Fathers were more concerned about their capability to financially respond to the child's care and rehabilitation needs and the perception of their future bonding with the child and wife. Fathers were observed to have adopted “surface acting”<sup>18</sup> (Hochschild, 1983, p. 48) in displaying their emotions when they encountered the reality of their children’s disability. And it was through the “framing rules” that provided the framework for the fathers to express their emotions in such a situation where they encountered the reality of their child's disability. When fathers learned that their children had certain diversities, they were found to be more

prone to feigning their true emotions. Instead of displaying their grief, stress, and confusion, which they actually felt inside, they chose to talk to the doctors about the future prognosis concerning the disabilities.

### **6.3. Parents' Reaction to the Disability: Emotions that Speak**

#### **6.3.1. Denying the Diagnosis- "This Cannot Happen to Me/Us"**

Parents' reaction of denial to their child's disability condition was observed to have been different for different disability conditions the children had. Denial, for parents who had children with cerebral palsy, directly stemmed from an understanding of difference and a sense of the "other". In the case of certain conditions such as Autism, Down syndrome, and ADHD, confrontation with an "unmatched reality" triggered a denial response. For mothers, the reaction of denial primarily came from a disbelief in the reality they had encountered about their children's disability; from a sudden encounter with an unmatched reality. For fathers, the response of denial was related more to questioning the pregnancy follow-up procedures that could not diagnose the diversity in their child.

#### **6.3.2. Trauma: Contesting the Given**

Though the reaction of shock followed by a 'traumatic phase' had been reported by almost all parents involved in the study, the duration of the 'traumatic phase' was found to be varied across the 'dual-stimuli' ('internal inducements' and 'external inducements') within which the parents were able to reflect back on their trauma. The first stimulus aroused out of the type and intensity of the disability, which can be entitled as 'internal inducements' of trauma. The socio-cultural ideology possessed by the parents, their economic and professional profile, and their educational standards altogether made up the 'external inducements' that spawned traumatic emotional waves among the parents. In cases where the children exhibited a greater degree of complexity concerning their disability, the parents were found to be prone to undergoing trauma for a longer period of time. In such instances, the trauma experienced by parents was analyzed to have reinforced a feeling of loss, despair, pain, and hopelessness about the future of their child. Here, the reaction of trauma for

parents could be inferred as induced by a ‘perception of rejection’. The trauma was found to have been rooted in the ‘perception of stigma’ by the parents. The ‘external inducement’ was also rooted in a ‘perception of challenge’. This has occurred when parents feared implementing the recommendations and suggestions made by the doctors and experts as a part of treatment and therapy for their children. The major challenge emanated from concern about the expensive medical costs involved in attending all the therapeutic sessions that were recommended for the child.

### **6.3.3. Predominance of Guilt: “Am I the Cause?”**

Among sixty respondents, twenty-six parents reported feeling guilty about the disability condition of their children. Twenty-one of them were mothers. The guilt was found to stem from the methods and techniques used by parents to parent their children with conditions such as autism, ADHD, Down syndrome, and learning disabilities. Five mothers had left their jobs because, to them, it was because of their absence that the children might have developed the disability condition. Guilt among parents had led them to lose their confidence in parental practice leaving them to reconsider their parental practices (before knowing about the disability), which they thought might have improved the situation for them in dealing with the disability of their children.

### **6.3.4. Grief: “Why Me (Us)”?**

Grief among parents has resulted from an inconsistency between expectations and the reality of being presented with a child having intellectual and cognitive diversity. “Discrepancy between expectations and the presentation of the developmentally disabled child continued to bring feelings of grief” (Anto, 2018, p. 139). The inconsistency stemmed from an unmatched reality and the parents' constructed reality of a child's body image. The expression of grief among parents confirmed a gendered response and was found to have affected mothers and fathers differently. Even though both mothers and fathers expressed their intense emotions, mothers found it more difficult to accept their children's differences.

### 6.3.5. Accounting the “Blame Game”: Who is Responsible for the Disability?

Parents in my research, particularly the mothers, reported feelings of self-blame and encountered blame from others. Many of these mothers have been framed as “cold mothers” or “refrigerator mothers”<sup>19</sup> (Leo Kanner, 1943) who could not take good care of their children and who failed to inculcate and teach the expected cultural norms in their children. Five mothers claimed that their mother-in-law blamed them for their grandchildren's disabilities. Three mothers reported that everyone, including the husband (father of the child), blamed the mother for the disability, which later resulted in marital separation (divorce) for some. Five mothers said that they were blamed, though not directly, by everyone or anyone who saw the child react violently, behave aggressively, or just run around randomly.

**Table No. 3.3: Information on mothers blamed for the disability in their children**

Mothers were blamed by	Number of mothers	Percentage (%)
Mother-in-law	05	38.46 %
Husband and other in-law family members	03	23.07%
Generalized others (husband, immediate family members from both in-laws and parental side, extended family members and neighbours)	05	38.46%

Self-blaming was also reported by mothers with lower educational attainment. Parents with good academic or educational backgrounds did not follow or believe in religious judgments to explain the cause of their children’s disability. Parents with higher degrees were found to be more coherent in their approach to their children's disabilities and to rely more on scientific rationality in explaining their children's disability health conditions. Exposure to expert knowledge and access to early disability diagnosis had aided the parents in understanding their children's disabilities.

**Table No.3.4: Response of self-blame expressed by parents**

<b>Educational level</b>	<b>No. of respondents</b>	<b>Percentage (%)</b>	<b>No. of Mothers</b>	<b>Percentage (%)</b>	<b>No. of Fathers</b>	<b>Percentage (%)</b>
<b>Higher Secondary</b>	2	11.76	1	6.66	1	50
<b>Graduate (B.A/B.Sc./B.com)</b>	13	76.47	12	80	1	50
<b>Post-Graduate (M.A./M.Sc./M.Com)</b>	2	11.76	2	13.33	0	0
<b>Total</b>	<b>17</b>	<b>100</b>	<b>15</b>	<b>100</b>	<b>2</b>	<b>100</b>

**6.3.6. Confusion- “What is it? How to deal? Shall I (we) be Able to Manage it?”**

In most cases, the parents reported that this initial phase of confusion was majorly generated by not having access to proper knowledge about the diagnosis of their children. Many parents were not able to decode the medical terminologies that were often written on prescriptions and reports. Parents had developed “multiple, ambivalent, and often apparently conflicting meanings” (Avdi, Griffin and Brough, 2000, p. 251) in connection to the diagnosis of their children. The parents reported that doctors and medical professionals had disclosed the diagnosis of their children’s disability in explicit medical terms with excessive use of medical terminology, leading parents to comprehend nothing of it. This mystified parents’ knowledge of what actually happened to their children. Confusion was observed to be more intense and common in cases where children were diagnosed with conditions such as autism, ADHD, and learning disabilities. The confusion was more intense among parents with comparatively lower educational achievement.



### **6.3.7. Stress among the Parents**

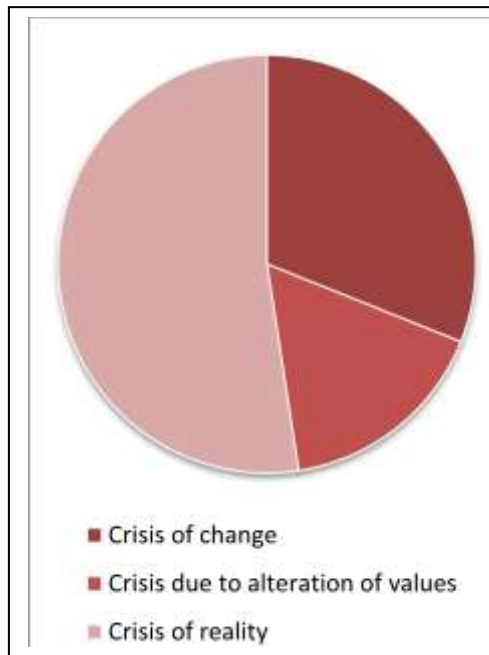
Interviews with the parents revealed a persistent response to stress when they learned that their child had been detected with certain disabilities. The kind of disability, the extent of physical or intellectual restriction of the child due to the disability, the level of interventions required, chances of improvement, parental financial affordability, parents' personality traits, parental cognitions, and beliefs were some of the variables that caused stress among the parents. The extent of parental stress was found to have been dependent upon the extent of social vulnerability of the child due to disability; the degree of intervention required as part and parcel of treatment or therapy; the resources and affordability of parents; and most importantly, the accessibility of such intervention or therapeutic centres. The lower levels of stress were noticed among parents with higher income brackets. Constant therapeutic sessions with the children and allied counselling sessions offered the parents the avenue to accept their child's unique ability to act and respond to things around them. Thus, parents had learned to accommodate these special abilities into the socially accepted discourse on what was understood to be 'normative'. Understanding of disability in such a manner was reported only by eight parents.

### **6.3.8. Emotional Crisis**

Kandel and Merrick (2007) classified parental reactions to disability and the consequential emotional crisis encountered by them into three categories: "the crisis of change", "crisis due to alteration", and "the crisis of reality" (p. 1802). All three categories of crisis have been observed to have been exhibited among the respondents. The degree and intensity of emotional crisis have also been observed to vary based on the socio-economic profile of the parents. After their child was diagnosed with a variety of health issues, thirty-two parents reported a "crisis of change". A thorough analysis of their conversation had unmasked a reaction to a crisis about which they had no preceding knowledge or understanding. Parents had conveyed their feeling of crunch due to a sudden break in their life contexts. The second crisis, which was related to the alteration of individual respective values as a consequence of a certain crisis, has been seen to have been exhibited by seventeen parents. The parents' understanding of their children's disability condition had pushed the parents to reconsider their previously understood perception of family, children,

and parenting. A “crisis of reality” has been observed by almost all parents. This was mainly related to certain mundane conditions which were shaped by the wider socio-economic contexts of the parents and the infrastructural facilities that were provided by the respective society.

**Figure No. 3.2: Emotional crisis of the parents**



**Table No. 3.6: Information on the emotional crisis of the parents**

Category of Crisis	No. of parents (out of 60)	Percentage %
Crisis of change	32	53.33
Crisis due to alteration of values	17	28.33
Crisis of reality	54	90

The kind of medical interventions recommended for children with disabilities (with regard to the type and extent of the special health state of the child), coupled with the therapeutic suggestions advised, made it an overly expensive affair to be sustained. Consequently, parents who could survive the cost were able to get the best clinical recommendations for their children compared to parents who could not afford all of them. According to Titchkosky and Michalko (2012, p. 129), people encounter and receive the world as a "framed" reality. Disability in general and conceptualizations centering on intellectual and cognitive conditions in children, in particular, were presented to parents through such ‘frames’ that guided their perception, emotional expressions, and comprehension of the disability and diversity of their children.

## **7. Challenges of Parenting: Care and Contests**

Parents, who were assumed to be the primary caregivers, tended to develop ‘dual identities’ for being a ‘parent’ (like any other parent) and for ‘being parents of children with disabilities’ – both of which were directly associated with their children’s identity of similarity or diversity when they were compared with other children without disabilities.

### **7.1. The Medical Gaze of Disability**

#### **7.1.1. Knowledge Supremacy and Real Contradictions**

From the moment parents learned that their children had been detected with disabilities, they found themselves surrounded by a gaze of medical supremacy and hegemony. The disclosure of disability to the parents; discussion and decision-making for future medical prognosis; medical and therapeutic interventions; and interaction with the specialized professional facilitators had reflected medical professionals’ inclinations and reliance on the medical model perspective to understand and explain the diversities detected in the children before the parents. This, in turn, was observed to have shaped how parents perceived disability and diversity in their children. The research traced back to Foucault’s conceptualization of power and knowledge because it has helped to illuminate the process through which parents (as social individuals) and their children with disabilities were “made subjects” (Roberts, 2005, p. 34) to the medical knowledge, belief, and understanding about disability.

#### **7.1.2. Encountering a Bureaucratic Maze: “My Child but Not My Decision.”**

Parents had pointed out that only doctors of government hospitals had the authority to certify the levels of disability of a child, which were required to be shown in the government offices in order to get the disability card issued. Receiving a disability card was a real challenge for them. Government offices and departments hardly had any coordination among themselves. Papers demanded by one office were not certified by another, and even sometimes doctor’s certifications were rejected on different technical or medical grounds. The whole process caused a lot of physical,

mental, and emotional drain on the parents. Eleven parents in my research had never applied for a disability card. These parents believed that having only cards would not help them in any way unless the structural barriers of the public spaces were worked upon.

**Table No. 4.1: Parents’ response towards accessing the disability card**

<b>Responses on disability card</b>	<b>No. of cases*</b>	<b>Percentage (%)</b>
Applied for disability card and did not receive yet (waiting time varied between 6 months to 1 year)	07	21.87
Applied for disability card and received (time period between applying and receiving was between 9 months to 1.5 years )	05	15.62
Applied for disability card and stopped trying to get one	09	28.12
Never applied for a disability card	11	34.37
<b>Total</b>	<b>32</b>	<b>100</b>

**\*The number of cases refers to the number of children for whom the parents have applied or not applied for the disability card.**

### **7.1.3. Non-Recognition of Parents’ Knowledge: “I Know My Child the Best.”**

The parents' constant interaction with their children's daily needs and requirements trained them to be experts in understanding their behaviour and communication. The interaction between parents and medical professionals was observed to have followed a structured pattern which was manifested through interplay among “field”, “habitus”, and “cultural capital”<sup>20</sup> (Bourdieu, 1990). The field constituted the social context and positions held by the parents and the professionals, and closer scrutiny revealed a power dynamic that remained inclined towards the professionals, and which also remained embodied in the form of cultural capital possessed by them through long-administered training in medical knowledge and expertise. The habitus of the parents had directed them to accept and understand the diversity in their children as it was portrayed by the professional knowledge about disability. And capital, as a cultural embodiment of knowledge, has received recognition from both professionals and parents in terms of managing their children’s diversity. The interplay of “field”, “habitus” and “capital” has been observed to have directed the “rule of the game”<sup>21</sup> (Bourdieu, 1990, p. 64) by which the professionals expected that parents would have

listened to them without any questions or contradictions raised. The professionals were observed to have believed that, because they were the best knowledge providers in the field, the parents would just receive the detection and prognosis of the disability as recommended by them passively. On the other hand, parents were required to understand and comprehend the disabilities of their children in the way they were reflected by the doctors and medical staff. The parents in my research claimed that they knew their children better than anyone else did, and such knowledge derived from their caregiving realities and encounters with disabilities often contradicted the one possessed and exercised by medical professionals.

**Table No. 4.2: Parents’ responses to the relationship they developed with the doctors**

Responses		No. of cases*	Percentage (%)
Category	Modes of interaction generating the categories		
Positive	Explaining the diversity in non-medical language	08	25
	Collaborating with parents at different stages of decision making with regard to interventions.		
	Encouraging or motivating parents in encountering the diversity		
	Generating optimism about future*		
Negative	Dis-belief and dis-trust by doctors to parents’ observation	18	56.25
	Talking to parents in strict medical terms		
	Recommending interventions without discussing the affordability or other related resources the parents required to have.		
Indifferent	Very impersonal levels of interaction without much reciprocity.	06	18.75s
	Majorly one way interaction that followed from doctor to parents, and the latter accepted it as general interaction pattern between doctors and patient.		
<b>Total</b>		<b>32</b>	<b>100</b>

\*This was observed in cases where the children had scopes for improvement.

\*\*The number of cases refers to the number of children for whom the parents have applied or not applied for disability cards.

#### **7.1.4. Delayed Identification and Diagnosis: Ignorance to Parents' Observation**

The primary challenge for most of the parents came from the inadequate number of early detection and intervention centres in Kolkata. Though there were few NGOs that provided services and interventions for children with intellectual and cognitive diversities, inaccessibility and other difficulties encountered by the parents on a strategic level (expense, time of sessions, dissatisfaction with the services, dissatisfaction with the professionals, distance, and so forth) had caused them to remain unreached by many parents and children. Parents reported that medical staff and practitioners did not listen to them; they did not pay any heed to their observations as parents about their child's development. Parents had emphasized that they knew "something was wrong with their child"; that there were certain problems in the way their children were developing and responding to the natural stimuli around them. However, the observations and knowledge of the parents about their children were discounted against the existing medical diagnostic procedures.

In instances where the diversities in the children began to show or develop during the early years of their developmental stage, like in the cases of Autism Spectrum Disorder, ADHD, and learning disability, the parents claimed that it was due to delayed medical diagnosis which had hindered the early identification and intervention of the disabilities in their children.

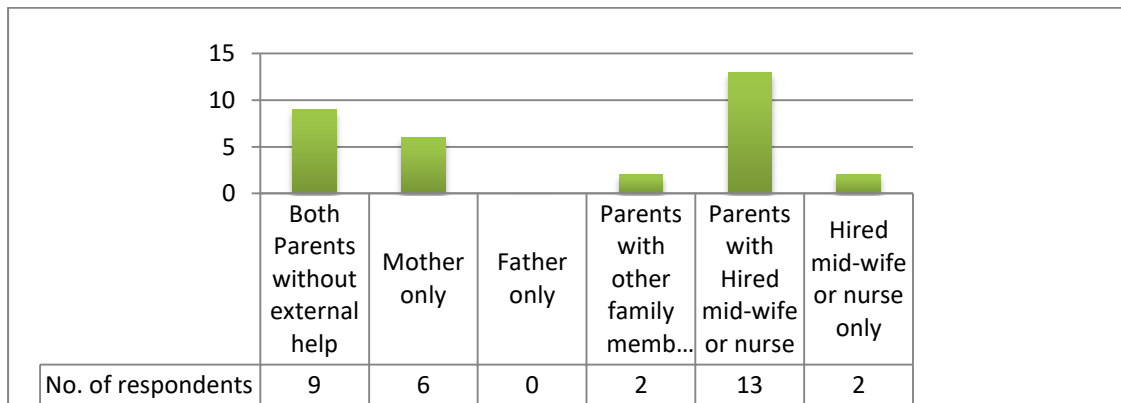
### **7.2. Care and Parenting Realities**

#### **7.2.1. Parent as the Primary Care-giver**

Within the recent context of disability and care, the home has been observed to have institutionalized into a rehabilitative space where people with disabilities are taken care of, where their daily interactions with other people in the family turn into "teaching moments" and where the therapists and special educators come and go throughout the day (Sarrett, 2015, p. 260). Parents and families began to look for ways to extend lessons of self-care and sustenance to their children in a social context where social support systems outside the family were inadequate (if not absent), and "insufficient educational, therapeutic, and respite resources" (Sarrett, 2015, p. 261) characterized the demography of the society. It became evident that whether parents

received care assistance for other family members or through hired care workers, the primary burden of care was dealt with by them. Moreover, hired care assistance turned out to be a luxury service for many (fifteen) household units whose financial positions were just enough to sustain themselves with dignity, along with the essential medical expenses that were required to manage the disability condition of their children.

**Figure No. 4.1: Distribution of the care work in the household for the children with disability**



### 7.2.2. Father's Encounter with Care Work

In child care, fathers were considered secondary, with mothers bearing the primary burden of caregiving (Gupta, Rowe and Pillai 2009, p. 64). Though very little literature on fatherhood and fathering in the Indian context was available, the existing literature conveyed a distant and passive role played by the fathers for their children, at least up to the initial years (Ghosh & Banerjee, 2017; Chakravarti, 1998). In my research, fathers shed much of the care-work burden on their wives (mothers) as it often became difficult to negotiate with the schedules, energy, and time that came in between their job commitment and child care tasks. The gendered nature of caring for children with disabilities has been understood using the gender ideological frameworks<sup>22</sup> proposed by Arlie Hochschild (1989). A thorough analysis of the responses revealed that mothers were less confident in entrusting the child-care tasks of their children with disabilities to their husbands (fathers of the children). This kind of “hegemonic motherliness”<sup>23</sup> (Ruby & Scholz, 2018, p. 78) has been observed

among mothers, and the father becomes the “junior partner”, the “everlasting trainee”, or the “guilty student” (Behnke and Meuser, 2012, p. 131).

**Table No. 4.4: The father’s involvement in managing the household chores and care-work related to the child**

<b>Father’s involvement towards household and care-work</b>	<b>Fathers</b>	<b>Percentage (%)</b>
Uninvolved fathers	05	17.85%
Fathers involve in sharing care-work	14	50%
Fathers involved in sharing both household chores and care work	09	32.14%
<b>Total</b>	<b>28</b>	<b>100</b>

Table No. 4.4 shows details of the fathers’ engagement and involvement with their children, household, and care activities. Five fathers in the research were found to have remained completely disengaged from the daily work of care and chores. In terms of care and chore activities, these fathers maintained a clear conventional gender division of labour (traditional gender ideology). Fourteen fathers were observed to have chosen a middle path. Though they valued their wives' contributions and involvement in household chores and child-care activities, they did not share the physical burden of managing daily household tasks (transitional gender ideology). Nine fathers were found to have supported their wives both emotionally and materially by sharing the tasks of care and chores (egalitarian gender ideology).

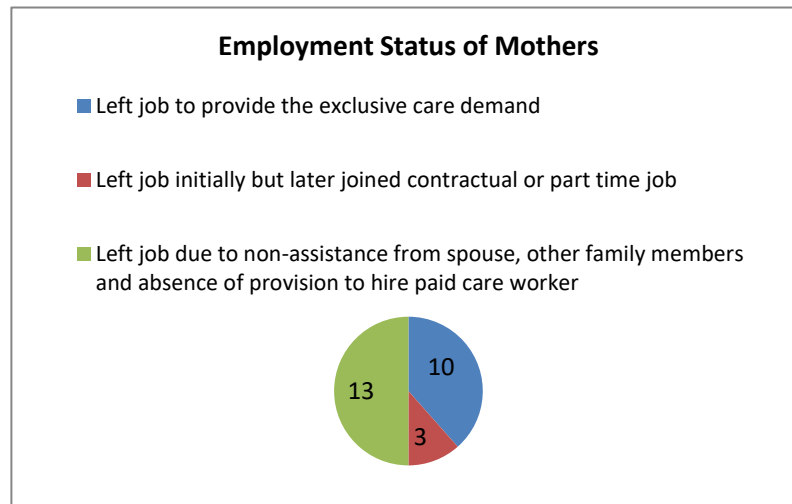
### **7.2.3. Seeing Mothers as the Epitome of Care: Internalization of Motherhood**

Seven mothers in my research, who were working previously, believed that the caregiving role and the career prospects of a mother could not go hand-in-hand, and they were found to have left their jobs in order to provide care and attention to their children and manage the diversities well. Changes in the employment status had a significant impact on the identity development and self-perception of the mothers. In-depth conversations with the mothers reflected a strong affiliation of the mothers toward “intensive mothering”<sup>24</sup> (Hays, 1996; O’Reilly, 2005, p. 05). Adreinne Rich (O’Reilly, 2004, p. 6) believed that children did not constantly ask their mothers to



meet their needs, but that it was the gaze of others (social, cultural, and medical/biological) that expected mothers to be capable of meeting them.

**Figure No. 4.2: Mothers’ employment status after their children were detected with disabilities**



**\*Total number of mothers was 32, among which the number of mothers in the paid labor sector at the time of the interview was 09. The rest 23 of them were homemakers at the time when the interview was taken.**

**Table No. 4.5: Mothers’ responses on their perception of care**

Responses	No. of mothers	Percentage (%)
Mothers are and should be the sole caregiver for their children	07	21.87
Mothers should be assisted by others (spouse, family members, hired workers) in providing care	14	43.75
Could not manage care work and paid work due to non-assistance but with assistance they could manage both house and work	11	34.37
<b>Total</b>	<b>32</b>	<b>100</b>

Table No. 4.5 explains the realities of the mothers' perceptions and actions towards careers and care. While seven mothers believed in the idea of intensive motherhood for caregiving, eleven mothers believed that career and care could have been managed in the presence of proper care assistance.

#### **7.2.4. Mother's Experience in Providing Care-work: Juxtaposition of Identities**

In my research, mothers were observed to have played multiple roles: providing care for the child; spending quality time; keeping in tune with the recommendation; specific play and activity engagements; practising the speech recommendations; carrying the children to regular visits for medical follow-ups; attending different interventions and therapeutic sessions. Mothers often find themselves completely engulfed and immersed in managing and fulfilling the needs and requirements of their children. Their identity as mothers took hold over their other roles and identities. Working mothers described situations in which important job commitments were jeopardized by the urgent needs of children requiring immediate medical attention. In each of these cases, they had prioritized their role as mothers over their identity as women who had other work commitments. The research revealed that raising children with disability conditions had altered their priority and position with regard to their engagement in the paid employment sector. The alterations have been observed to be more intensive for mothers in comparison to fathers.

#### **7.2.5. Gendered Nature of Care: Stories of Affirmations and Deflections**

With regard to child-care and the involvement of the parents in employment, I have adopted the “male breadwinner/female caregiver model” and the “dual breadwinner/female caregiver model”<sup>25</sup> (Bruhn & Rebach 2014, p. 19) for this research. The “male breadwinner/female caregiver model”, which explains the realities of care and chores in family units where mothers were not employed in paid sectors and fathers were the only earners (twenty-three), was found to be appropriate. According to the “dual breadwinner/female caregiver model”, women looked upon themselves both as “mothers and workers, breadwinners and homemakers; they had refused to choose breadwinning over caregiving or equate equality with assimilation to the male sphere” (Boris and Lewis 2006, p. 85). Ten mothers in my research opted to resign from the previous jobs that demanded full-time employment and commitment from them. The parents were also found to justify their roles against their beliefs, in particular gender ideologies about the division of labour relating to household chores and childcare.

Thus, fathers who were actively involved (nine) in household chores and caregiving activities were observed to have adopted an egalitarian ideology justifying their equal share in managing caregiving activities and household chores along with their wives. Fathers, who chose to remain uninvolved and dis-engaged (five) both in terms of caregiving and household activities, were observed to have adopted a traditional gender ideology to justify their disengagement with care and chores. These fathers saw caregiving and chores as women's roles and identified themselves as family providers, providing economic security, food, and other material necessities required to manage the family. Similarly, a mother's gender ideology determined how she placed herself and her husband (father of the child with a disability) within the household regarding both domestic chores and the care activities for the child. Seven mothers in my research were observed to have adopted a traditional gender ideology to justify their role as the only and indispensable caregivers. Fisher and Tronto (1990, p. 16-17) identified four components of care: “caring about”, “caring for”, “care-giving” and “care-receiving”. “Caring about” was to become aware of the need for care. “Caring for” someone involves assuming responsibility for providing care. “Caring-giving” activities involve individuals (and/or organizations) who are directly engaged in meeting the care demand and performing the required care work.

**Figure No. 4.3: Father’s engagement in care work based on the phases or components of care provided by Fisher and Tronto (1990, p. 16-17)**

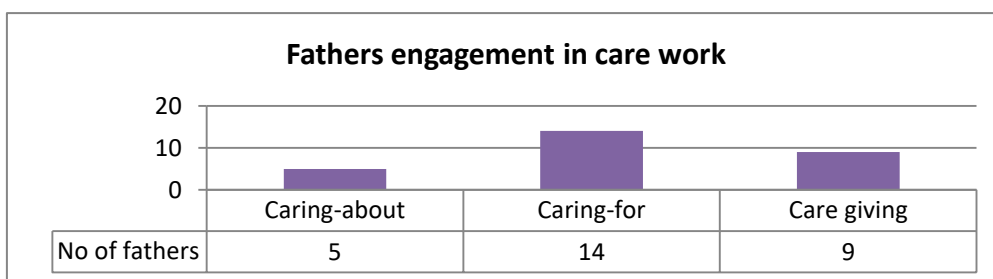


Figure No. 4.3 shows that most of the fathers (fourteen) in the research adopt the “caring for” role for their children with disabilities. Only nine fathers were found to be directly involved in caregiving functions in the household.

### **7.2.6. Parenting Children with and without Disabilities: Context of having Siblings**

The research found five instances (household units) where parents had another child, generally an elderly child, with no potential diversity. The needs, requirements, and care demands of the child with disabilities were not similar to the care requirements of his/her sibling without disabilities. The major challenge for parents was to distribute the time and manage the different kinds of parenting required for both of their children, with different demands and care requirements. In most cases, the older child (who had no potential diversions) took charge of their own time and leisure, while the parents were required to spend more time with their disabled siblings. The parents had reported that their elder children accepted and understood the fact that their brother or sister needed some special care and that their parents were required to devote more time to them. Parents tended to portray an incongruous inhibition among the older siblings about their children with disabilities. On one hand, the older children without disabilities tended to provide additional care at times, love and support for their younger siblings and extended assistance to their mothers in performing the care work. They had withdrawn from providing such support at times and expressed negative emotional outbursts, complaining that they did not receive the adequate attention, care, and love they deserved from their parents because they had siblings with disabilities. These were the really difficult moments for the parents that they had to deal with.

### **7.2.7. Raising a Daughter with Disability: “After all, she’s a Girl!”**

All the parents of thirteen girl children in my research had acknowledged fear with regard to sexual abuse that their daughter might face in the future. All thirteen of these children's parents openly expressed their concern about their daughters being subjected to sexual abuse in the future. There were two instances where the parents narrated how their daughters had experienced sexual abuse and molestations. In the first instance, a fifteen-year-old girl with rubella syndrome was abused by her physiotherapist at her own house without the knowledge of anyone, including the girl herself. In another instance, a fourteen-year-old girl with cerebral palsy was physically abused by the husband of the full-time maid whom the parents hired, as

both of them were employed. There were two instances where the parents narrated how their daughters had experienced sexual abuse and molestations.

### **7.2.8. Juggling Between the Roles: Scrapes of Rigid and Inflexible Schedules**

It has been confirmed by both parents and clinical experts that children with disabilities prefer adherence to a routine lifestyle with fixed schedules for their daily needs. Inflexible routines often exposed them to distractions, constant nagging, and complicated expressions of behaviours that sometimes ran out of control. In order to avoid such complications and diversions, parents tried their best to stick to fixed routines and remain as organized as possible.

### **7.2.9. Limited Personal Space**

Rigid confirmation of the tasks (which were prioritized, fixed, and recommended by the therapists and experts) connected to their everyday lives offered limited room for the parents to get outside the everyday norms, which would have given some space to the monotony they experienced. Mothers reported that they did not even get a good bath or could not spend a long time enjoying their meal of choice. Most of the parents reported sleep deprivation as one of the greatest daily challenges in raising these children, leading them to develop other critical health (physical and mental)-related issues.

## **7.3. Confronting Disability at the Systems Level**

### **7.3.1. Parents' Encounter with Schools: Contradictions Inherent in Inclusion**

Parents of seventeen children in my research looked at special education schools as a better option to manage their children with disabilities. The primary rationale for these parents' putting their children into special education structures was not only because of the exclusive and specialized approaches that were followed in these schools, which were directed towards the special needs of their children, but also because the regular schools did not have adequate arrangements to accommodate their children with disabilities. In four cases, despite favouring special schools as the best option for their children's grooming, parents could not put their children in special

schools due to the non-availability of special schools located within a comfortable range of travel and insufficient financial resources to bear the expenses that were related to accessing special education services. Accessing special education was found to be an expensive affair for many parents.

**Table No. 4.6: Parents’ responses on their perceptions of kind of schooling they preferred for their children to achieve inclusion.**

Responses	No. of parents	Percentage
Children would be a part of inclusive education system.	09	28.12
Children would remain unattended by the teachers and chances of stigmatization from peers	17	53.12
Lack of expert knowledge and training of the teachers and staffs.	06	18.75

### **7.3.2. Limited Social and Public Access**

Parents have expressed their inconvenience and anxiety while taking their children out in public places. Most of the restaurants, cinema halls, parks, and transport facilities in Kolkata do not accommodate the needs and flexibility required of these children. Inadequate transport and conveyance facilities topped the list of places where children could not access public spaces. The absence of ramps had been the primary reason that had restricted the free and easy movement of wheelchairs. Thus, disability was created on the ground that children with disabilities were “misfits”<sup>26</sup> (Garland-Thomson, 2017, p. 593) in the public sphere.

### **7.3.3. Parents’ Experience of Stigma in Managing the Disability**

During the conversation with the parents, it was observed that in instances where comments were made by people, sometimes with sympathy and sometimes without any judgments, which were directed at the diversities of their children, they were extended and diffused among the parents. Thus, parents were often evaluated as “discreditable” because of their close association with the diversities of their children (Goffman, 1963, p. 4-5). Parents narrated instances where public comments were attached with negative attributions. Parents were often exposed to the feeling of

stigma and felt stigmatized due to their self-perception of stigma, which Goffman (1963, p. 31) called "courtesy stigma" when they found themselves being observed or stared at by others. This became more pronounced in public situations where the children suddenly started screaming or shouting. It had been pointed out by parents that the use of wheelchairs made a difference in the way people perceived diversities in their children, which to some extent had contributed to the stigma that the children and their parents were observed to have encountered.

## **8. Coping and Development of Agency among Parents**

### **8.1. Understanding Parents' Resources to Coping**

#### **8.1.1. Reflecting on Bourdieu's 'Forms of Capital'**

The narratives and life stories of the parents had uncovered an invisible string of association between parents' habitus<sup>27</sup> and the kind of coping strategies they had adopted. For deeper sociological insight, this chapter has attempted to unmask such associations by applying Bourdieu's theory of capital. Pierre Bourdieu introduced the concept of capital as an effective tool to understand the social world. For Bourdieu, "capital" was the social energy that people, as social agents and actors, had accumulated over long periods of time through various social processes. It was observed that parents' coping strategies, their perceptions of the difference between perceptions of stressors, and the perceived impact of the stressors on their lives relied heavily upon the economic, cultural, and social resources they had possessed, acquired, and had access to.

#### **8.1.2. Economic Capital and Parental Coping**

It was observed that parents' coping strategies, their perceptions of the diversity between perceptions of stressors, and the perceived impact of the stressors on their lives, relied heavily upon the economic, cultural, and social resources they possessed and had access to. Parents who had better economic avenues and income were observed to have coped with the stressors much earlier and in a more organized manner in comparison to parents who had less financial access to resources. It was

found that parents who had good accessibility to finance could transact their economic capital with the diverse and continuous intervention procedures and therapeutic sessions for their children, leading to better outcomes in their behavior, actions, and overall health state.

**Table No. 5.1: Distribution of the income of the parents (Income of both parents=1 unit)**

Monthly Income range in Rupees	No. of household units	Percentage (%)
11,000-30,000	01	03.12
31,000-50,000	14	43.75
51,000-70,000	08	25.00
71,000-90,000	05	15.62
91,000-1,10,000	02	0.25
1,11,000-1,30,000	01	03.12
1,31,000-1,50,000	01	03.12
<b>Total</b>	<b>32</b>	<b>100</b>

### 8.1.3. Cultural Capital and Parental Coping

It was discovered that the parents' educational qualifications and occupation were determining factors in understanding the perceptual frame with which the parents attempted to understand and conceptualize the disabilities in their children.

**Table No. 5.2: Information on distribution of educational (formal) qualification of the parents**

Last Attended Degree		No. of parent	Percentage (%)	Mothers	Percentage (%)	Fathers	Percentage (%)
<b>Higher secondary</b>		3	4.99	1	3.12	2	7.14
<b>Graduation</b>	B.A./B.S c./ B.Com	20	33.32	15	46.87	5	17.85
	B.E.	9	14.99	2	6.25	7	24.99
<b>Post-Graduation</b>	M.A./M. Sc./ M.Com	15	24.99	11	34.37	4	14.28
	MBA	8	13.32	2	6.25	6	21.46
	M.Tech/ M.E	3	4.99	1	3.12	2	7.14
<b>Doctorate</b>		1	1.66	-	-	1	3.57
<b>Post-Doctorate</b>		1	1.66	-	-	1	3.57
<b>Total</b>		<b>60 (N)</b>	<b>100</b>	<b>32</b>	<b>100</b>	<b>28</b>	<b>100</b>



Parents with higher educational exposure and higher professional attainments, or particularly, parents, who worked as teachers, were the ones who had developed positive perceptions of coping with the stressors related to managing the diversities.

**Table No. 5.3: Information on the occupational distribution of the parents**

Categories	No. of parents	Percentage (%)	Mothers	Percentage (%)	Fathers	Percentage (%)
Home maker	23	38.18	23	71.87	0	-
Self-employed	3	4.99	2	6.25	1	3.57
Other services	6	9.99	0	0	6	21.46
Business (owns shop)	4	6.66	0	0	4	14.28
Small Entrepreneur	2	3.33	1	3.12	1	3.57
Banker	4	6.66	0	0	4	14.28
Engineer	9	14.99	1	3.12	8	28.56
Teacher	8	13.32	5	15.62	3	10.71
Doctor	1	1.66	0	0	1	3.57
<b>Total</b>	<b>60 (N)</b>	<b>100</b>	<b>32</b>	<b>100</b>	<b>28</b>	<b>100</b>

The parents who had developed their potential cultural capital and capacity towards advocating the needs of their children and who could turn their capacity of agency into institutionalized operation (creating support or community groups or establishing NGOs) were observed to be representatives from among the professional group of teachers and doctors.

**Table No. 5.4: Acquisition of cultural capital by parents to cope with the stress in managing the disability of their children**

Initiative by parents to develop cultural capital	No. of Mothers (out of 32)	No. of Fathers (out of 28)	Percentage of Mothers (%)	Percentage of Fathers (%)
Undertook full time special education program	02	-	6.25	-
Attended short-term courses	08	01	25	3.57
Attended seminars and workshops	16	04	50	14.28
Subscribed to journals and articles related to disability	01	03	3.12	10.71

However, there were many instances where the mothers, who were not employed, took an active role in forming, expressing, and even institutionalizing their potential

to advocate for the needs of their own children, as well as those of others. They extended their agency and advocacy to other parents who also had children with disabilities.

#### **8.1.4. Social Capital and Parental Coping**

Access to social networking groups, community groups, and relationships that extended positive emotional and material support provided an important means for parents to cope with the stressors. The social connection had offered the parents emotional and material support, common sharing and understanding of experiences, and mutual reciprocity of feelings. Almost all parents, regardless of gender, education, profession, or income, and regardless of the type or severity of the difference, agreed that encounters and interactions with social networks, as well as relationships with close or distant family members, friends, or neighbors, resulted in negative perceptions of disabilities in their children on many occasions (if not all encounters). While connecting to social networks of parents having children with similar or other kinds of diversities, getting associated with parental community groups, or getting connected to parents from schools or doctor's chambers who had similar life challenges relating to their children's disabilities, was found to have assisted them in coping with the life strains. Sharing experiences, information, and other resources helped them to develop a positive perception of diversity.

## **8.2. Coping with the Disability**

### **8.2.1. Coping Resources for Parents**

It was found that accessing social resources had assisted the parents in coping with the disability of their children and had reduced stress among them. Parents reported that talking to friends and close acquaintances regarding their life strains and challenges helped them vent out their negative emotions, particularly when they received positive and optimistic responses from them. Parents had also confirmed that getting connected to community groups of parents who also had children with disabilities helped them cope with the everyday struggle and monotony of meeting the extensive care work demands and interventional recommendations. Six parents agreed that assistance from family members, both materially and emotionally, had contributed to

reducing the stress. But nine parents complained that assistance received from other family members sometimes increased their stress levels, where it was expected that assistance would help in reducing the stress.

### **8.2.2. Formation of Negative Perceptions in Coping**

In India, where childhood disability has been comprehended as a “tragedy” (Gupta and Singhal, 2004, p. 23), parents' perceptions of disability were found to have remained clinched to a negative portrayal of their lives and experiences. In some cases, it was observed that conversations with relatives, neighbors, and friends often elicited negative comments or the use of words that reflected feelings of sympathy or even included unwanted exaggerations of parental suggestions that made the parents feel further stressed. In such circumstances, the parents had chosen the path of social withdrawal as a coping strategy to reduce the social stressors they had been experiencing. Fourteen parents in the research had subscribed to this kind of social withdrawal behaviour.

### **8.2.3. Development of Positive Perceptions among Parents**

In my research, parents who had developed positive perceptions of disabilities in their children had adopted a variety of coping strategies, such as connecting to external social and professional support networks outside the family, being associated with parent-based non-governmental NGOs, being connected to or creating community groups in the locality or near vicinity, and participating in various virtual community groups of parents through social media. Engaging themselves in the positive coping strategies mentioned above, parents expressed their agency as a conscious reflection on the life strains and challenges. Interestingly, it was observed that though it was out of the positive perceptions that parents had developed their agency and advocacy for their children, it could not be denied that it was the negative attitude that they had encountered in receiving the required services and interventions for their children at the systems level (macro) that had created the need among them to advocate for their own children.

#### 8.2.4. Impact of Positive Parental Coping on Dealing with Disability

Coping through positive emotional adaptations to the stressful and anxious situations of their lives assisted the parents to look for the positive aspects of their experience. The positive emotional adaptation among parents was observed to have followed the three-dimensional understanding of emotions which was introduced by Folkman & Moskowitz (2000): “positive reappraisal”, “problem-focused coping”, and “creation of positive events”. Many parents (nine) had taken short-term courses or workshops. There were seven parents who worked on their personal growth through professional consultation and psychological counselling to cope with phases of intense stress and frustration. The development of positive perceptions among the parents had contributed significantly to an elevated sense of self, which was surrounded by a maze of negativity during the initial phase of the diagnosis.

#### 8.2.5. Coping Strategies Adopted by Mothers and Fathers

**Table No. 5.5: Coping mechanism adopted by the parents which reflected the development of positive perception towards disability among them**

Coping mechanisms	No. of mothers (32)	No. of fathers (28)	Percentage of mothers (%)	Percentage of fathers (%)
Connecting to networks outside the family	12	7	37.5	25
Connecting to parental groups	25	9	78.12	32.14
Getting associated with NGO	12	4	37.5	14.28
Connecting to local community groups	18	5	56.25	17.87
Joining virtual community groups	8	10	25	35.71
Attending and participating in special programs, courses or workshops	11	8	34.37	28.57
Getting back to their passions like painting, reading books, song or dance etc.	3	4	9.37	14.28
Spending leisure doing things that they love	4	2	12.5	7.14
Connecting to old or childhood friends	6	14	18.75	50

Table No. 5.5 provides a detailed understanding of the coping mechanisms which were adopted by the parents in dealing with the everyday challenges of managing the disabilities of their children.

In households where both parents were employed, professional engagement had contributed to the parents' coping with their life strains. The coping mechanisms differed in households where only fathers were employed and mothers were homemakers. Mothers were exposed directly to the child-related stressors and were observed to have adopted different coping strategies to reduce them. In my research, fathers expressed that talking to their close friends or childhood friends had provided them with positive emotional reinforcement. The fathers sought out positive marital relationships as a coping strategy for the life stress they were experiencing while balancing their roles as caregivers.

### **8.3. Role of Support Systems for Parents: Network Matters**

#### **8.3.1. Lack of Emotional and Social Support: “Nobody Understands!”**

Parents in my research reported a lack of social support systems both at the personal and professional levels. At the personal level, it was observed that contact with friends and relatives faded with time due to a feeling of a “felt stigma” or “perceived stigma”<sup>28</sup> by the parents, which caused them to isolate themselves from such social circles. This further restricted their scope of socializing with people. Support and assistance from other family members have been observed in a very small number of cases where primarily the maternal grandmother of the child and members from the maternal side of the family came to the child's rescue.

Support and assistance from other family members have been observed in a very small number of cases where primarily the maternal grandmother of the child and members from the maternal side of the family came to the child's rescue. Only in two instances, where the parents shared a joint household unit, were assistance and support readily and spontaneously available. Six parents reported that the only caregiver in the family was the mother, who received no assistance from their husband or from any friends or relatives. The lack of assistance from husbands was

observed to be primarily due to the overwork load that fathers had to bear in order to earn more and meet the medical expenses for their children.

Table No. 5.6 presents the information on the different support systems to which the parents had subscribed. Support system networks in the context of Kolkata involved close contacts with family members and extended relatives by kinship, friends, neighbours, and hired care workers who were not specialized or professionals in the field of managing disabled people or children with disabilities.

**Table No. 5.6: Information on the different support systems to which the parents had subscribed**

Type of support systems	No. of parents (60)	Percentage (%)
Family members staying within same household (paternal side)	04	6.66
Family members staying within same household (maternal side)	03	5
Family members staying outside the same household (paternal side)	06	10
Family members staying outside the same household (maternal side)	21	35
Close friends known earlier	06	10
Neighbours	03	5
Hired care worker	15	25
Connecting to other parents having children with difference	34	56.66
Connecting to local community groups	23	38.33
Association with NGO	16	26.66
Connecting to virtual community groups	18	30
Constant touch with professionals and facilitators	04	6.66
Total	60	100

### **8.3.2. Factors Determining the Presence of Support Networks**

Accessing material social support (a hired care worker) required the parents to have affordable monetary resources. Accessing social support that could provide emotional comfort to the parents required the presence of like-minded people or people who could understand the parent's position without having any preconceived notions, prejudices, or judgments about the life context of the parents. Three parents reported that most people in their vicinity could really understand their contexts of life and with whom conversations could be continued on a positive note.

### **8.3.3. Access to Support Groups and Coping of Parents**

Thirty-four parents in my research agreed that they could cope with the anxieties and stress with regard to managing the diversities in their children when they could receive support from other parents who were members of the same support groups. Eleven parents were unable to access the support groups due to the lack of such groups in their locality or within a comfortable commutable distance. Interviews had expressed the need for support groups, which these parents felt were important to receive emotional and informational assistance and support. Instances have shown that some of these parents, who could not access the support groups due to distance or other limitations, chose to form and organize a community of parents among themselves that could provide support to each other.

### **8.3.4. Parent's Access to Virtual Support Groups**

Twenty-four parents reported that the intensive care burden and organizing the household chores at home restricted them from attending programmes that were arranged for the parents in the support groups with which they are associated. Eleven parents had complained that the absence of support groups in their vicinity and their consequent membership in support groups in distant areas limited their frequency of accessing them. In such instances, internet or virtual support groups were found to have facilitated the parents with their requirements. Thirty-four percent of the parents in my interview had subscribed to different virtual, social, and professional networks that could help them to balance their physical tasks of caring for their children and the need for their own emotional peace.

### **8.3.5. Access to Parent Support Groups: “We Care for Each Other!”**

Narratives revealed that parents had received positive emotional and mental support from other parents who also had children with disabilities. Positive emotions emanated due to the sharing of similar social contexts and experiences associated with the diversities of their children. In my research, parents who could manage to contact or access this kind of similar parental network were reported to have gained confidence and strength from each other. Parental support groups and parental community groups have been observed to be the sources from which parental agencies and advocacies find their best and strongest expressions.

## **8.4. Agency, Capacity Building and Advocacy**

### **8.4.1. Organizing Local Level Advocacy by Parents**

Parental narratives and responses reveal active agency on the part of parents in making decisions for their children. This agency included the choice of intervention centers; the kind and duration of interventions that their children could afford (physically and emotionally); time and quality of care to be provided; negotiating with the different stakeholders related to the disabilities (doctors, therapists, medical staff, and care workers); and planning for the children’s future (talking to and listing down names of rehabilitation homes or care centres and trustees, and making insurance and life-coverage plans). Parents who received professional and informational exposure came forward to support other parents, which paved the way for local-level advocacy. Most of these local-level advocacy programmes worked to provide support to parents in dealing with their everyday encounters with disability, and also to overcome and cope with the challenges they encountered as an individual, other than being a parent.

### **8.4.2. Development of Parental Capacity**

Emirbayer and Mische’s (1998, p. 962) conceptualization of agency as iteration or extension of habit, agency as encompassing “projective capacity”, and agency as “practical evaluative capacity” (p. 962) — have been employed and confirmed through the research findings. In my study, parents reflected all three components in their actions to manage their children's disabilities. Parents planned their actions for



the present and the future based upon the past experiences that they had encountered in relation to the diversities of their children. Based on their resources (economic, cultural, and social), parents were observed to have devised strategies to alter their present conditions of strain, which included: getting enrolled in short-term courses or special education programmes in order to gain expert perspective about disability and diversity; getting connected to social support and professional support groups (physical and virtual); getting connected to parents and communities based on similar interests; helping other parents to cope and devise strategies to reduce stress by sharing their own experiences; and thus, developing advocacy. The calculated absence and inefficiency at the system level to meet their children's needs, as well as the social and political reality regarding the services their children had received, compelled the parents to mediate their agency based on the resources they had at their disposal.

#### **8.4.3. Advocacy as a Medium to Access Service**

Interviews revealed that inadequacy and limited accessible resources had been the primary thrust among the parents to develop agency and engage themselves in advocacy. Those parents who were successful in convincing the authorities to bargain out the best service for their children believed that it was through parental advocacy and agency that could provide the required push to authorities to improve the living conditions of their children. Thirty-two parents reported that parental agency was developed to provide improved services and living conditions for their children with disabilities. Parents had expressed the need, which they felt was important to engage them in advocacy to obtain improved services for their children. Diverse activities and negotiations that parents were required to undertake—say while making phone calls to medical practitioners, therapists, and intervention centres for appointments and other related affairs; while taking the children to different special classes and workshops; while playing with and training the children as per the recommendations provided by the experts; while connecting to various government departments to avail disability cards and other related services and entitlements; while discussing the improvement and future course of action, about managing the difference, with the professionals; and while planning for their children's future in the form of saving money, or making an insurance policy for them—was found to have given them the platform to advocate and create agency for them. Parents sometimes had to negotiate

not only with the various stakeholders associated with diversity but also with the one they felt was best for their children.

#### **8.4.4. Parental Involvement in Effective Social Advocacy**

Trainor (2010, p. 40) has classified parental involvement in advocacy into four categories: “intuitive advocacy”, “disability experts”, “strategists”, and “agents for systematic change”. In my study, twenty-seven parents (twenty-two mothers and five fathers) demonstrated intuitive advocacy, agreeing that constant and continuous encounters with diversity had led them to understand their children's various behaviors, expressions, and actions better than anyone else. The parents with “intuitive advocacy” were found to have negotiated with the teachers and the special therapists to receive the best outcome for their children. Mothers were observed to play the role of intuitive advocates in greater numbers as compared to fathers. In my research, fifteen parents (thirteen mothers and two fathers) were observed to have acted as “disability experts”. These parents chose to acquire detailed knowledge regarding disability and had gathered specific information about the respective disabilities their children possessed. The parents had utilized various resources—like becoming members of different support groups, making contacts with disability experts within and outside the city, interacting with different NGOs working in the field of disability, accessing different journals and articles available on the internet, and having detailed conversations with the paediatrician and other disability-related medical and professional experts to illuminate themselves with regard to the diversity present in their children. There were very few parents who could act as strategists and change agents when they extended their agency and advocacy to other parents having children with disabilities.

#### **8.4.5. Advocating for a Wider Cause: Extending Individual Agency for Other Parents**

At the individual level, parents took different measures, which reflected their self-involvement in the decision-making process for their children. In this research, I have mentioned three cases where parents had institutionalized their capacity for agency and advocacy and created organizations that included parents who had children with disabilities—Amrita Mukhopadhaya (founder of “Jagori”), Mr. Goswami (organizer

of local-level initiatives), and Dr. Ranajit Mandal (founder of “Disha” and “Barasat Vision Charitable Trust”).

According to the research findings, a significant number of parents expressed their agency and advocacy as a manifestation of their retrospective capabilities to situations that did not always turn out in their favour. Parents demonstrated agency and advocacy in various episodes of their encounters while negotiating the needs of their children with diverse intuitions, systems, and structures of society.

## **9. Conclusion**

Research has noticed that parents’ perceptions of disabilities and diversity were largely shaped by the existing knowledge of disability, which was nurtured within different social systems and institutions like health, education, infrastructure, family, neighborhood, and community. The existing knowledge of disability was discovered to have a significant impact on how parents react, respond, deal with, manage, and cope with their daily realities related to managing and dealing with their children's disabilities. It was noticed that the medical understanding of disability was central to the way parents had comprehended the diversity in their children and, consequently, they had considered medical rehabilitative procedures and treatments as solutions to the ‘problem in their child’. However, with due course of time, parents have begun to experience their everyday challenges differently and variedly, most of which were beyond the scope of their knowledge. At this juncture, the social model understanding of disability was found relevant in understanding, analyzing, and interpreting the challenges encountered by the parents. Narratives have revealed that parents have adopted diverse strategies to deal with and resist the challenges of raising their children with diversities—like seeking assistance from support groups; taking membership in different professional and non-governmental organizations; providing voluntary services to many groups; disseminating their own understanding and skills to other parents, and forming local level support and community groups.

Parents’ understanding of disability in Kolkata did not reflect strict adherence to any single model or categorization of disability perspectives. While the medical model has explained the needs and requirements of diagnosis, therapeutic and rehabilitative

procedures, it was the social model that could explain that the challenges encountered by the parents were not just because of the disability or diversities in their children, but because of the disabling structural and socio-cultural barriers that had created a disabling environment, which made managing the disabilities challenging for the parents. The cultural model of disability explains how the socio-cultural understanding of disability has led people to accept the given binary constructs of "normality and deviance, self and the other, and familiarity and alterity" (Waldschmidt, 2018), and hence, to comprehend disability in the light of the binary between being abled and disabled. The transactional model has helped in accounting for the interaction of disability with various social agencies, systems (health, education, and infrastructure), support networks, and other transpersonal factors experienced by parents and their children with disabilities. The model had the potential to explain how such interactions shaped their quality of life. The relational model of disability aided the research in understanding how the presence or absence of social networks and relationships impacted the parents. The relational model of disability guided the research in developing a framework to understand how interpersonal, familial, and organizational factors have influenced the experiences of disability, both for children and their parents.

Thus, in gaining a holistic understanding of the parents' reality, their challenges, and stories of resistance, a multi-model perspective was found more appropriate than clinging on a single disability model in analyzing their lived experiences and encounters with disability.

### **9.1. Limitations of the Research**

The research was conducted in Kolkata with sixty parents. Similar research with a broader geographical reach and a greater number of samples would have elevated the validity and reliability measures of the findings. The multilayer approach to reality was hampered by limited access to various government departments and a nonresponsive attitude on the part of the concerned bureaucrats. Expression of unwillingness was witnessed from many potential respondents, particularly fathers, which made the sample selection phase of the research a bit time-consuming and difficult to overcome.

## **9.2. Scopes and Recommendations**

The research has included diverse disability categories to understand how parenting and care intersect with different types and severity of disabilities in an all-inclusive manner. However, in doing so, the realities of parenting and care relating to a single category of disability have not been mistreated. The research has highlighted the gap that exists between the legal promises and the real predicaments. Further critical paradigmatic research can be conducted to unmask the non-existent link. The research has been conducted among parents of children with intellectual and cognitive diversity. The study can be extended to parents having children with physical disabilities in Kolkata.

## Endnotes

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<sup>1</sup> The Rights of Persons with Disabilities Bill, 2011 was approved on December 12, 2013. The bill has covered a large range of issues, from physical disabilities to mental illness and multiple disabilities more comprehensively than before. The Ministry of Social Justice and Empowerment formed a Committee on April 30<sup>th</sup>, 2010. The committee was represented by members from disability groups, NGOs, and experts in drafting legislation that could come as a substitute for the earlier PWD Act of 1995 (Equal Opportunities, Protection of Rights, and Full Participation) because it did not incorporate and recognize many of the rights that were recommended in the UNCRPD. The Act of 2011 was a paradigm shift in the disability discourse with recognition of legal capacity, equality, and dignity. It provided for a 5% reservation in public sector jobs, as well as incentives for private-sector employers to promote the employability of disabled people in their organizations. The bill guarantees the voting rights of the disabled and ensures voter card registration and issuance of the same. The right to fertility has been ensured for women with disabilities and prescribes punishment for instances of forced abortion or hysterectomy. See, Ministry of Social Justice and Empowerment, Government of India.

<sup>2</sup> The Rights of Persons with Disabilities Bill, 2014 was introduced in February 2014. The Bill defined a person with a disability as a person who has been experiencing physical, mental, or any kind of sensory impairment for a long period of time, the existence of which restricts him/her from participating in the normal functioning of life fully and effectively (Narayan, 2014). Mental illness has been defined in the bill as a disorder that causes constraints and limitations in thinking, perceiving, and memorizing; and this affects the person's capacity for judgement and also has an impact on his behavioural outcome. These people often encounter difficulty in meeting the everyday demands of survival. Under this bill, mental illness did include mental retardation, which has been defined as restricted development of the mind, affecting his or her intelligence (Narayan, 2014). The Rights of Persons with Disabilities Bill, 2014 also included health conditions like hemophilia, learning disabilities, and thalassemia within the category of disability (Mandal, 2015). The Bill of 2014 authorizes the District Court to appoint a "limited guardian" for people with mental disabilities who are incapable of taking responsibility for themselves. Provision has been included to appoint a "plenary guardian" who would take all decisions on behalf of the person. A reservation of 5% has been allotted in higher educational institutions and government positions for people with benchmark disabilities. Only 1% of reservations were allotted under the bill for people with autism, intellectual disability, and mental illness combined. See Narayan, 2014, p. 411. Also see Rao, Ramya and Bada, 2016, p. 121.

<sup>3</sup> The Rajya Sabha passed the Mental Health Care (MHC) Bill, 2016 on August 8, 2016. The bill was passed as an amendment to the Mental Health Act of 1987 as it did not fulfil the recommendations made by UNCRPD (United Nations Convention on the Rights of Persons with Disabilities). The Bill was thoroughly designed after Chapter (v) of the UNCRPD on "Rights of Persons with Mental Illness". The bill aimed to protect, promote, and fulfil the rights of people suffering from mental illnesses. The bill marks a shift from psychotic disorders to mental disorders and, hence, from mental hospitals to health centers. The bill put significant stress on the right to access medical treatments for people with mental disorders at

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an affordable cost while not compensating for the quality of services received by them. It is recommended in the bill that the state governments should include provisions to offer treatment-related services to these people and their family members or caregivers (Rao, Ramya and Bada, 2016, p. 121).

<sup>4</sup> The word "normal" is a value-based term. Amundson (2000) provides a clear distinction between normal and abnormal. He shows that the concepts of normal and abnormal are social judgments of what conditions, actions, and roles are considered to be acceptable biological variations and functioning and what is not. These value judgments about the standards of normal and abnormal are used to justify the advantages and exclusions that people with disabilities confront in society (Pfeiffer, 2002, p. 3-23). See also Amundson (2000, p. 33-53). The word 'normal' was introduced in the English language resource around the 1840s, as a parallel term to "constituting, conforming to, not deviating or different from, the common type of standard, regular, and usual". Likewise, the word "norm", in the modern sense, has only been in use since around 1855, and "normality" and "normalcy" appeared in 1849 and 1857. See Davis, 2013, p. 2. The graph of an exponential function, variously known as the astronomer's "error law", the "normal distribution," the "Gaussian density function", or simply "the bell curve", became the yardstick against which the majority of the population was pinned down to measure the "norm". Any bell curve has its extremes that do not fall under the norm, and hence the concept of deviance sets in. Hence, with the norm, the concept of deviance entered the context. With regard to bodies, societies that accept the rule of norms thus portray people with disabilities (different bodies and minds) as deviants (Davis, 2013). Also see Shakespeare (2007), Pp. 51-59. The concept of 'normative' is often used confusingly and has become a 'synonym for 'normal', 'normate' or 'standard' in disability studies' (Shakespeare, 2007).

<sup>5</sup> See Illich (1976), p. 13–43. In "Medical Nemesis" Ghosh (2016, p. 03) has adopted this term to denote that medical definitions impose a presumption of biological or physiological inferiority upon people with certain disabilities. In doing so, it inhibits the possible sources of discrimination from societal and structural inequality faced by these people. To him, the medicalization of life results in the "destruction of people's capacity for self-care and self-responsibility" (Barnes, Mercer and Shakespeare, 1999, p. 59).

<sup>6</sup> Discipline and Punish: The Birth of the Prison (1975/1991) conceives of disciplinary power as distributive power and operates in a network of relationships with power inequalities between those who possess power and those who are made subject to it. The disciplinary means through which this happens include the normalization of judgements (Foucault, 1975, p. 170). Foucault (1975) argued that today's modern society is characterized by a "disciplinary society" (p. 209) where different disciplinary means are adopted to exercise power in order to regulate individuals' actions, thoughts, and knowledge to reflect a centralized dominant discourse. This is done through different institutions like schools, hospitals, military training, prisons, and so forth. The parents and the children with diversity are put under this disciplinary gaze through the different interventions, therapeutic sessions, clinical consultations, and recommendations for special schools for these children, where they will be trained and made to learn the expected social norms for conducting and presenting themselves based on certain (bio) normative standards.

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<sup>7</sup> The idea of the “panopticon” was originally introduced by English philosopher Jeremy Bentham as an “idea in architecture” (Bozovic and Bentham, 1995, p. 1) by which the minds of individuals are/can be controlled by the minds of the one who controls it, and the one who controls the architecture becomes the possessor of power over the subjects who reside within such a panopticon (Bozovic and Bentham, 1995, p. 01). In 1975, it was adopted by Foucault in his analysis and descriptions of the functioning of power and surveillance in institutions like hospitals, mental asylums, and prisons. For Foucault, being within a panopticon allows control over the thoughts and actions of the inmates, thereby assuring “automatic functioning of power” over them by those who hold the power (Foucault, 1991, p. 201). The panopticon, thus, can be comprehended as a gaze that regulates the functioning of power and dispersion of knowledge by those who are in the position of power. The parents are observed to reside and manage their actions with regard to the difference, being within a gaze or panopticon created by the medical professionals by virtue of their power of knowledge.

<sup>8</sup> Roberts (2005, p. 34-35), in his work “The Production of the Psychiatric Subject: Power, Knowledge, and Michel Foucault,” has used the concept of “made subject” to describe how people are subjected to following dominant knowledge through the dispersion of power and how this knowledge yields power in turn. Foucault first used the concept to show how, throughout Western history, human beings have been subjected to or “made subjects to” (Foucault, 1982, p. 212) others through “control and dependence” (Foucault, 1982, p. 212) and, secondly, they are made subjects by the specific subjective identity which they derive from their knowledge of self (Foucault, 1982, p. 212). In this research, I have attempted to look at how parents are made subjects to the power and knowledge of medical professionals with regard to the diversities in their children, and through the use of such power, how the parents’ conceptualization of disability is framed and nurtured, giving rise to a dominant discourse of disability with its affiliation towards the medical model of looking at diversity.

<sup>9</sup> As Oliver maintained, there are two fundamentals that need to be considered while understanding the individual model of disability—firstly, that the ‘problem’ of disability lies within the individual; and secondly, that this ‘problem’ stems from the psychological losses and functional limitations arising from disability (Barnes, Barton and Oliver, 2002, p. 32). The medical paradigm has asserted that “disability arises from physical flaws within a person”. It does away with the possibility that an unadaptive environment or society plays a vital role in creating disability and a disabled social context for these people. The medical model believes that, since the problems of disability reside in and arise from the individual, the solutions to these problems or difficulties “must be sought primarily through individual rather than collective efforts” (Ghosh, 2016, p. 3).

<sup>10</sup> “Caring masculinities” (Elliot, 2016) refers to those masculine identities who consider the values of care to be an integral part of their human nature. People with such masculine identities tend to embrace values that are closely related to care and that generate feelings of “positive emotion, interdependence, and relationality” (p. 240) within the care relationship.

<sup>11</sup> Erik Erikson (1950, 1982) introduced the concept of “generativity” to refer to the care activities performed by adults towards their next generations. Based on the concept given by Erikson, Dollahite, Hawkins and Brotherson (1997) have proposed the concept of the “conceptual ethic of fathering as generative work” (Dollahite and Hawkins, 1998, p. 110).



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The conceptual framework of generative fathering holds that i) fathers have ethical responsibility and capacity to meet the needs of the next generations, and ii) generative fathering work benefits both children and fathers to grow and evolve in their respective roles and responsibilities. Read Dollahite and Hawkins (1998), pp. 109-113.

<sup>12</sup> The idea of “habitus” is central to Bourdieu’s theory of field, philosophy, and thought of practice. Bourdieu has defined habitus as a characteristic property that every individual carries within them, which is shaped by their past experiences, thoughts, and knowledge, and based on that, the individuals shape their present and future disposition of actions, thoughts, and behaviors. Habitus is a process by which individuals within society construct their knowledge of things they encounter in reality and are capable of understanding reality in relation to the experiences they have encountered in the past (Grenfell, 2008, p. 50). According to Foucault, the habitus is structured by the material conditions of existence of the individuals and their perceptions, understanding, thoughts, knowledge, and feelings are generated based on those patterns, regularities, and structures (Grenfell 2008, p. 51). According to Foucault, habit is structured by an individual's material conditions of existence, and their perceptions, understanding, thoughts, knowledge, and feelings are generated in response to those patterns, regularities, and structures (Grenfell 2008, p. 51). The parents of disabled children are embedded in a social context defined by specific characteristics of their class, education, age, and so on, which causes them to internalize disability in the same way that their wider social-cultural context has (for example, disability is a personal tragedy, disability is associated with permanent grief, and so on). The medical professionals, on the other hand, possess a definite knowledge of disability and difference which is nurtured and shaped by a biological understanding of disability followed by the medical model and which they acquire via long-term training in the field. In the separate fields or contexts of the parents and the professionals, different conceptualizations of the differences in the children are produced, which, though in most cases, turns into peaceful negotiation because the parents tend to obey the medical directions and remain subject to the medical supremacy, in some instances, this generates clashes when the parents reflect their own perceptions over the recommended prognosis. Habitus focuses on the ways of acting, feeling, thinking, and being (Grenfell, 2008, p. 52).

<sup>13</sup> Pierre Bourdieu (1986) defined capital as “accumulated labour” accumulated in the form of materialized or embodied manner (p. 81). According to him, when people in society as individual agents acquire capital, they accumulate social energy. The accumulation of this social energy places individuals in positions of advantage or disadvantage. Thus, accumulation and acquisition of capital influence the potential capacity of individuals to dispose of and predispose things and events at their disposal. Parents’ capacity to cope and act was observed to be significantly influenced by their acquisition and possession of capital, which they could manipulate for the betterment of their living conditions. Bourdieu classified capital as economic capital, cultural capital, and social capital. Economic capitals are those which are directly exchanged with money (p. 82), like property, land, material or precious assets, etc. Parents’ income, property, and capability to have direct access to services or facilities that are directly exchanged with money constitute their economic capital. Hiring a care worker, and paying fees to doctors or professionals, and fees for special education and therapies, all comprise the parents’ financial capacity. Cultural capital is the embodied or institutionalized form of the “long term disposition of mind and body” (p. 83). Cultural

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capital is initially acquired by individuals through the process of socialization within the family. Cultural values, morals, ideology, internalization of expected social norms, and norms are the primary foundations based on which individuals acquire further cultural capital in the form of education and acquire certain skills through long-term training. Instances were not rare in my research where parents underwent training or gained admission to special education courses based on their previous educational qualifications. Some parents could teach singing or dancing to the children with differences in different parental community groups based on their previously learned skills. Social capital refers to the network of relationships that people accumulate over long periods of time or even generations of investments in creating social networks. For Bourdieu, social capital is acquired when social actors consciously or unconsciously invest in social relationships for the short-term or long-term exchange of social benefits (p. 87). Parents' previous social networks and the new social networks formed by them comprised the long term social capital. The parents associated with the professional and community support groups and parental community groups and connected with parents of other children with differences formed their social capital, based upon which they coped with their stressors.

<sup>14</sup> "Field" refers to the context in which people live and from where the individual disposition of thought, feelings, and knowledge emanates and gets structured (Bourdieu & Wacquant 1992, p. 127). The parents of the children with diversities and the professionals are situated in their respective fields (which are separate) from where their respective habitus have evolved. Their social positions in different fields, as well as the resulting habitus formations, position them to perceive separate realities and expose them to different lived experiences of the same phenomenon—disability and difference in children.

<sup>15</sup> Following Goffman, when the stigma of the stigmatized individuals is transferred or passed on to people who are associated with him/her, it is called a 'courtesy stigma' (Goffman, 1963).

<sup>16</sup> Erving Goffman (1983, p. 4-5) made a distinction between the "discredited" and the "discreditable" based upon the perceptions and experiences of the stigma that individuals feel and encounter, respectively. Those people are accorded the status of "discredited" whose stigmatizing attributes are apparent or visible, while those with the most obvious stigmatizing characteristics are labelled as discreditable. Parents who have children with disabilities do not possess any stigmatizing attributes that are visible or apparent. But due to the development of courtesy stigma, often they are labelled as having attributes that are discreditable. See Goffman, 1983.

<sup>17</sup> The Rights of Persons with Disabilities Bill, 2011 was approved on December 12, 2013. The bill has covered a large range of issues, from physical disabilities to mental illness and multiple disabilities more comprehensively than before. The Ministry of Social Justice and Empowerment formed a Committee on April 30<sup>th</sup>, 2010. The committee was represented by members from disability groups, NGOs, and experts in drafting legislation that could come as a substitute for the earlier PWD Act of 1995 (Equal Opportunities, Protection of Rights, and Full Participation) because it did not incorporate and recognize many of the rights that were recommended in the UNCRPD. The Act of 2011 was a paradigm shift in the disability discourse with recognition of legal capacity, equality, and dignity. It provided for a 5% reservation in public sector jobs as well as incentives for private-sector employers to promote

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the employability of disabled people in their organizations. The bill guarantees the voting rights of the disabled and ensures voter card registration and issuance of the same. The right to fertility has been ensured for women with disabilities and prescribes punishment for instances of forced abortion or hysterectomy. See, Ministry of Social Justice and Empowerment, Government of India.

<sup>18</sup> Arlie Russell Hochschild (1983) developed a model to show how people display emotions before others and in a specific social setting with regard to specific social interactions they encounter. In explaining her model, she introduced the concepts of ‘deep acting’ and ‘surface acting’. In surface acting the individuals displays the expected feelings which they sense to be appropriate for a given social setting or a social interaction situation, irrespective of what he/she actually feels in the given situation or social setting. For Hochschild, the surface acting displayed by individuals is an “insincere performance” of displaying their emotions which they think to be convincing for others in social interaction situations or any given social context (Michelle Addison, 2017, p. 10).

Surface acting is thus to know which feelings are appropriate and which are not in a given social interaction situation (Hochschild, 1983:48). And the appropriateness of the emotion with regard to a situation is shaped by the ‘feelings rules’ and which are guided by ‘framing rules’. For Hochschild, individuals [should] feel according to certain socially guided rules about the appropriate and inappropriate behaviours in specific situations. Hochschild called this ‘feeling rule’ which is based on a certain socially shared understanding of situations and the accompanying feeling one should have or want in such a situation, and that most of these feelings and emotions are latent in nature. However, in reality, people find themselves oscillating between the ‘feeling rule’ (what one should feel in a given situation) and ‘emotion work’ (what the person tries to feel). The feeling rules are embedded within a wider ideological framework through which individuals perceive a given social context or situation and attach meaning and definition to the situation or context. This ideological framework guides how a person should feel in that given situation. Hochschild named this ideological framework ‘framing rules’. Thus ‘feeling rules’ are always backed by ‘framing rules’. Framing rules provide the framework through which people develop feeling rules in any given situation. It is important to note that the framing rules by which a person measures and assesses a given situation and accordingly assumes certain feeling rules to react in that situation, might get altered once the ideological framework of comprehending the situation changes. With a different set of ideological frameworks for a given situation the framing rules and the feeling rules of the individual change. In Hochschild’s words "when an individual changes an ideological stance, he or she drops old rules and assumes new ones for reacting to situations, cognitively and emotively" (Hochschild, 1979: 567). Individuals defy ideological framework by adopting different emotion work or my refusing to manage emotion in the manner it is expected to be worked upon by the widely shared official frame of feeling rules and emotion work.

<sup>19</sup> Leo Kanner (1943) introduced the term “refrigerator mother” (Joseph, 2018, p. 01), while explaining that autism in children is a result of the interaction between the social-physical environment and wrong mothering practices. According to Douglas (2014, p. 95), the “refrigerator mother” is at the center of larger social-cultural contradictions in which medical discourse on autism encounters with contradictory femininity has begun to assess and regulate

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good and bad mothering practices in a new way. In my research, I have adopted the concept of showing how mothers are blamed by their family members and relatives for being responsible for the difference in their children.

<sup>20</sup> “Cultural capital” can be defined as attributes that individuals possess by virtue of their skills, knowledge, education, or any vocational qualities that have cultural elements that require training and learning or that individuals might gain due to the possession of any cultural artefact (Bourdieu, 1986, p. 17-21). The professional’s expertise and knowledge form their cultural capital, which is acquired in the context of a specific social field and which forms their habitus. For the parents, their possession of attributes in the form of cultural capital, along with the different fields and habitus, creates a completely distinct life world from that of the medical professionals. The field, habit, and capital create a rule of the game in which professionals (via their practice (habitus, field, and cultural capital) hold power over the parents, who are forced to follow the directions and accept the reality as shown by the doctors regarding disability, which frequently contradicts what the parents actually experience.

<sup>21</sup> Bourdieu used the word “game” as a metaphor to make sense of social life. By using the word, he tried to convey the way in which players remain intensely involved in a game; their commitments to their roles in the game; the mutual understanding with the other players; their understanding of their own limits and that of the other players; and the understanding of the competition involved- all are characteristics which are present in social life. Like a player, a social individual lives in a society with others, accepting the norms of cooperation, competition, and assimilation. Individuals in society also understand their own and others’ limitations in social interactions and communication. This generates an invisible thread of rules which are consciously and unconsciously accepted and understood by the people in a society. This is what Bourdieu called the “rule of the game”. Sometimes we accept the rules learned through predispositions and socialization and sometimes we challenge them using our present dispositions; thus building agency. The field, habitus, and capital are taken together to generate a rule of the game in which professionals (by their practice (habitus, field, and cultural capital) hold power over the parents, who are forced to follow the directions and accept the reality as shown by the doctors with regard to disability, which frequently contradicts what the parents actually experience. It is through this rule of the game that people in society understand, evaluate, and act according to their social, economic, and cultural positions. In this research, the concept has been used to understand the perceptions and modalities used by doctors in their encounters with a disability, which are far different from the ones encountered by the parents of children with disabilities. See Calhoun (2003), pp. 274-309.

<sup>22</sup> In her work “The Second Shift” (1989), Arlie Hochschild maintained that gender ideologies frame the feeling rules among the individuals in society. With the aid of her classification of ideologies into traditional, egalitarian, and transitional (Hochschild, 1989, p. 16), she tried to explain how men and women adopt different feeling rules and place themselves accordingly in different social contexts to justify their placement within them. The kind of gender ideologies they adapt have a significant impact on the placement they justify for themselves with regard to the household division of labor and care activities of the children. Thus the ideology that the individuals in a family adopt frames the family’s emotional culture

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(Gretchen Peterson, 2006, p. 118-120, in “Handbook of sociology of emotions”). According to the traditional gender ideology, men should identify themselves with the labor they perform in the workplace and their passive role in the household and care activities are justified both by him and within the family. According to this ideology, men should be playing a supporting role in the family providing for the financial and mother's material security. See Gretchen Peterson (2006) pp. 118-120.

<sup>23</sup> The concept of “hegemonic motherliness” has been given by Patrick Ehnis (2008) by deriving the idea from the hegemonic masculinity of Connell. Through this concept, he has tried to express how mothers perceive and believe their role to be the dominant one in performing care work for their children. With such a perception, mothers don't trust anyone other than themselves to share the care work of their children, even with their husbands. See Ruby and Scholz (2018), pp. 77-78.

<sup>24</sup> “Intensive mothering” was coined by Sharon Hayes in her work “Contradictions of motherhood” (1996). Intensive mothering is an ideological construct that holds that mothers are and should be the sole caregivers for their children, regardless of what other identities they hold. Hayes explained that intensive mothering considers mothers to devote all their time, energy, and resources (both material and emotional) towards providing care to their children, even though it comes at the cost of leaving a paid job (O'Reilly, 2004, p. 5). Conversations with the mothers in my research reflected a similar ideology of motherhood, stereotyped by gender norms and exercised by patriarchal ideology. In most instances, mothers have internalized this ideology, and sometimes because they have been put under an invisible gaze that compelled the mothers, though passively, to adopt the motherhood ideology of parenting, where mothers are central to the caregiving role for children.

<sup>25</sup> Bruhn & Rebach (2014) talk about the “male breadwinner/female caregiver model” and the “dual breadwinner/female caregiver model” (2014, p. 19) to put the realities of balancing home and work before men and women amidst the evolving socio-economic context of urban industrialization in mid-nineteenth-century America. I have used these two models to reflect on the realities of the parents in Kolkata and to understand how these parents deal with the burden of balancing both household chores and the care work of their children with disabilities. According to the first model, the appropriate role of breadwinning has been accorded to men, while women's role and responsibility in performing domestic chores and child care work remain primary. According to the second model, even if a woman works in a paid labour sector, it will not be considered their primary job according to their gender identity. Women are encouraged and expected to work in paid jobs in this model, but their responsibility for domestic chores and child care remains the same. Thus, in both cases, the men refrain from sharing the burden of chores and care. In the case of women, they are expected to perform the role of caregiver, irrespective of whether they are committed to working outside or not. See “The Sociology of Caregiving”, 2014, Pp. 20–24

<sup>26</sup> The concepts of “misfits” and “misfitting” have been presented by Rosemary Garland Thomson (2011, p. 592) to highlight how disability in its embodied form interacts and counteracts with the external physical environment. Her concept of “misfittin” goes hand in hand with “fitting,” as she considered them to operate together, taking either a harmonious form or as a disjunction to each other (Thomson, 2011, p. 592–593). Garland has been

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critical of how people with disabilities are perceived as misfits, and she investigates how these people are made to misfit not only socially, but also in material terms, such as access to roads, public buildings, and transportation. There are many accounts in this research where the parents and their children with diversity have encountered similar challenges when they could not attend school just because the buses did not have a ramp, or when they could not visit the local park because the roads were not smooth enough to run a wheelchair.

<sup>27</sup> The chapter has attempted to see how parents' possession of cultural, social, and economic capital shapes their habitus within the context (field) and reality in which they received their socialization. It was observed that, depending upon their habitus, parents adopted diverse coping strategies, which for some parents developed positive emotions, and for some parents resulted in negative emotional arousal and perceptions. Thus, the capital, habitus, and field of a person determined the kinds of perceptions they developed while coping with the life strains with regard to the differences in their children.

<sup>28</sup> Perceived stigma, also known as felt stigma, occurs when people believe that other people possess certain judgments about them. People who develop perceived stigmas about themselves evaluate themselves in the eyes of others and believe they may have possessed some of the characteristics that are stigmatized. People who perceive themselves as having stigmatizing attributes are prone to developing self-stigma. Refer to Hing, Nuske, Gainsbury, and Russell (2016), pp. 32–35. Perceived stigma is the personal feeling of stigma. Parents of children with disabilities develop perceived stigma when they feel the stigma associated with the disability of their children. See Gray, 1993, pp. 114-116. Perceived stigma is thus closely attached to developing courtesy stigma. Following Goffman, when the stigma of the stigmatized individual is transferred or passed on to people who are associated with him/her, it is called a “courtesy stigma” (Goffman, 1963).

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