# PARENTING CHILDREN WITH DISABILITIES: A SOCIOLOGICAL EXPLORATION IN KOLKATA

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**By**

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# Certified that the Thesis entitled

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

submitted by me for the award of the Degree of Doctor of Philosophy in Arts at Jadavpur University is based upon my work carried out under the Spervision of

**Dr. PIYALI SUR**

And that neither this thesis nor any part of it has been submitted before for any degree or diploma anywhere/elsewhere.

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# ABSTRACT

In India, the discourse around disability has been observed to remain embedded within the cultural, ideological, and social history of the country on the one hand, while on the other hand, the state was found to have adopted provisions and devised laws 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 cultural understanding of disability, which looked at disability as a personal tragedy and hence, undesired. The policies and legislation, thus, focused on the prevention of disabilities and rehabilitation, which essentially required medical intervention. With a long history of marginalization within the larger disability discourse, issues of mental health and intellectual diversity have received their due attention in India in the Disability Bills of 2014 and 2016. Although the importance of parents, family, and home in caring for children with intellectual disabilities was highlighted in the bills of 2014 and 2016, the contribution of family members and the caregiving challenges, which are often associated with isolation, stigmatization, violence, and frustration, remained unattended.

In the above context, the current research has tried to explore the different trajectories through which parents were observed to navigate while parenting their children with intellectual, In India, a family has been found to have emerged as a primary site of care for children with intellectual and cognitive diversities. Thus, "caring and receiving care becomes a paradoxical experience of enabling/constraining, love/duty, agency/dependence" (Ghosh, 2017, p. 03) for the parents, where the so-given situation gets further jeopardized by varying acquired and accessible social, cultural, and economic resources for the parents.

Reviewing the literature has revealed that the existing plethora of works regarding disability has helped only 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. 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.

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.

A qualitatively inclined mixed-method research design was understood to be relevant for the research. The study has employed a partially mixed concurrent dominant status design where the qualitative dimensions and methods dominate the entire research process, with quantitative methods being used only as a supplementary aid to ease the presentation of the findings. 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. The broader theoretical perspectives which have been used to contextualize and ground the research include perspectives from symbolic interactionism, sociology of emotions, sociology of care, feminist perspectives on gender and care, general disability, and critical disability perspectives.

Findings of the research have unearthed that parents remain primary caregivers and act as a bridge between children's needs (educational, health, social, and public participation) and the fulfilment of their diverse requirements. This is where the primary challenge for parents emanates from. The reactions of the parents to the knowledge of the disability of their children were analyzed sociologically, engaging different theoretical perspectives of the sociology of emotions to look into how parents' reactions and expressions were part of the larger emotional culture of a society. Parents' reactions to the disability of their children were a product of such constructions through which disability was comprehended by them and generated consequent emotional reactions. The research has adequately accounted for and analyzed the gendered dimension of care, the balancing of child-care and household responsibilities by parents, and the impact of the care burden on parents. The research was desperate in highlighting the gaps that were evident between the policy frameworks on paper and their real-life implementations in the lives of children with disabilities. This had a far-reaching impact on the parents of these children, who used to be their primary care-giver. With regard to different disability models, parents' understanding of disability in Kolkata did not reflect strict adherence to any single model or categorization of disability perspectives. It was, however, noteworthy that, though parents had expressed their immense challenges, stress, and stigma, it was part of their lived experiences and should not be understood as an end in itself. There were instances where parents chose to challenge the dominant discourse on disability by forming an agency to speak for themselves and their children.

Key words: Intellectual and cognitive disability, care, care-giver, challenges, agency

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| | | |
|---|---|---|
| **ADD** | : | Attention Deficit Disorder |
| **ADHD** | : | Attention Deficit Hyperactivity Disorder |
| **ASD** | : | Autism Spectrum Disorder |
| **ASWB** | : | Autism Society West Bengal |
| **BVCT** | : | Barasat Vision Charitable Trust |
| **CP** | : | Cerebral Palsy |
| **CRS** | : | Congenital Rubella Syndrome |
| **DS** | : | Down Syndrome |
| **DSM- IV** | : | Diagnostic and Statistical Manual of Mental Disorders 4th Edition |
| **DSM-5/ DSM-V** | : | Diagnostic And Statistical Manual of Mental Disorders,5th Edition |
| **ENT** | : | Ear, Nose and Throat Doctor |
| **IASSID** | : | International Association for the Scientific Study of Intellectual Disability |
| **ICD-11** | : | International Classification of Diseases |
| **ICF** | : | International Classification of Functioning, Disability and Health |
| **ICIDH** | : | International Classification of Impairment, Disability and Health |
| **ID** | : | Intellectual Disability |
| **IDD** | : | Intellectual Developmental Disability |
| **IDEA** | : | Individuals with Disabilities Education Act |
| **IQ** | : | Intelligence Quotient |
| **MR** | : | Mental Retardation |
| **NIMHANS** | : | National Institute of Mental Health and Neurosciences |
| **OCD** | : | Obsessive Compulsive Disorder |
| **SSKM** | : | Seth Sukhlal Karnani Memorial Hospital |
| **SLD** | : | Specific Learning Disorder |
| **SUPW** | : | Socially Useful Productive Work |
| **UNCRPD** | : | United Nations Convention on the Rightd of Persons with Disabilities |
| **UNESCO** | : | United Nations Educational, Scientific and Cultural Organization |
| **WHO** | : | World Health Organization |

# Chapter- 01

## Parenting, Disability and Care in Context

> **“Society is understood in terms of an ongoing dialectical process composed of the three moments of externalization, objectivation, and internalization”**
>
> **-Peter L. Berger and Thomas Luckmann (1966, p. 149)**

### 1.1 Introduction

For a major period, the global discourse on disability was dominated by a western understanding of disability that was specific to the experiences of western societal realities. It was only since the 1980s that non-western societies began to develop their own understanding of disability based on their own historical, cultural, economic, political, and social realities. Gradually, the global discourse surrounding disability has begun to be conceptualized differently for western and non-western societies. This has given rise to a kind of disability discourse that is specific to the social contexts and realities of the global north and global south.

In India, the discourse around disability has been observed to remain embedded within the cultural, ideological, and social history of the country on the one hand, while on the other hand, the state was found to have adopted provisions and devised laws 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 possessed by society, which looked at disability as a personal tragedy[1] and hence, undesired. The policies and legislation, thus, focused on the prevention of disabilities and rehabilitation, which essentially required medical intervention. Closer scrutiny of the attitude of the Indian state has revealed that the laws that were devised before 2005 were primarily informed by a medical model of understanding disability. Following such a model, disability was constructed as a dependent social category, the measurement of which was performed against the medically defined yardsticks of 'biological normativity'[2]. Before 2005, the general understanding of disability in India was such that it was considered a problem, and the (bio) medical model was believed to possess the capacity to solve the problem it created. The solution, consequently, lay in the prevention, cure, correction, and rehabilitation of the disabilities. Viewed in this manner, people with disabilities have come to be considered dependents and non-productive individuals in society. Consequently, their potential and capability in formal employment and education have raised questions among many. People with disabilities were turned into a social category that was dependent and had been taken for granted to be eligible to become state beneficiaries (Jeffery & Singal, 2008, p. 23). It was after the United Nations Convention of the Declaration of the Rights for Persons with Disability (UNCRPD) in 2006 that the Indian state amended its disability policy to keep its provisions in tune with what was mentioned in UNCRPD, 2006. The UNCRPD (2006) was a clear expression of the shift in the understanding of disability, which had focused on the socially disabling environment. Thus, it was the role of the socially disabling environment that was significant in producing disability. The angle of social oppression and marginalization was then adopted as a conceptual medium to contextualize the lives, experiences, and realities of people with disabilities. It was a sharp break from the hegemonic medical model of disability. However, this shift in international policies was the result of different actions and campaigns undertaken by the international disability rights movements across the world. In India, though the laws of 1995[3] and 1999[4] made provisions for education, employment, and receiving other services for living a life and fulfilling basic needs, those too came with the eligibility requirement of proving that the extent of disability had reached the minimum qualifying range of 40%, and this was essentially required to get certified by a state-approved medical panel.

It was in 2011 that disability discourse in the Indian state shifted from its charity model to a rights-based model, where dignity and independent living were highlighted more, than providing them with charity and welfare. The Rights of Persons with Disabilities Bill 2011[5] was written with the central themes of the disabled person's legal capacity, equality, and dignity in mind. The ideas of "inherent dignity, individual autonomy, equal opportunity, accessibility, respecting diversity, acceptance for all, and evolving capacities of children with disabilities" were emphasized in this new bill (Ghosh, 2016, p. 13). The Disability Bill of 2011 required the government to make provision for free and appropriate education that could be accessed by every child with a disability up to the age of eighteen years. The act aimed to promote integration. It was designed to keep the need for inclusion of children with disabilities at the fore in regular schools, with specific provisions for special schools for those who required such facilities. Provision for accessible transportation and infrastructure was also considered under this Act to facilitate the accessibility of these children to regular schools.

In the context of the global north, the emergence and dissemination of the ideas of the social model were observed to have helped the way disability was understood and comprehended in the light of social construction. In this light, disability was comprehended as a social creation; created by the disabling and oppressive social conditions existing within wider social institutions, structures, and interactions. In the global south, which also includes India, disability discourse has begun to be conceptualized as a heterogeneous social category, which stands across diverse intersections among class, gender, caste, age, religion, and even geographical locations (urban-rural divide). Different models of understanding disability, thus, have emerged in India based on charity, religion, development, culture, and kinship (Mehrotra, 2011, p. 66). In India, disability has been identified as a socially repressive category in which people with disabilities are discriminated against and denied access to education, employment, and other human rights protections to which they are entitled.

Within this larger and general discourse surrounding disability, specific understanding, discussions, and research on intellectual disability and developmental disabilities (which come under the umbrella term of "intellectual and cognitive diversities") has remained a limited venture (if not an untouched endeavor) within the larger disability scholarship and literature. Disability, viewed as a homogeneous social category, has been well reflected in the policies, provisions, and benefits that have been extended by the state for people with disabilities. Different needs and issues, experienced by the people specific to their diverse kinds and extent of disability, have never been emphasized in their respective terms. Moreover, the heterogeneity of disability as a social category, which cuts across various other social intersections of class, caste, gender, age, geography, and types and extent of disability, has not been adequately featured in the existing disability discourse centering on the global south, including India. The heterogeneity and diversity of the kinds and extent of disabilities were found to have received partial or no attention. Thus, the experiences and challenges of people with intellectual and developmental disabilities have continued to remain a marginalized field within disability studies. The number of people and children with intellectual and cognitive disabilities has also remained under-represented in large-scale surveys and national databases (Kishore & Nagar, 2011).

In India, the Rights of Persons with Disabilities Bill, 2014[6] and the Mental Health Care Bill, 2016[7], have placed a premium on mental health and intellectual diversity. In these bills, family and care agencies were charged with the responsibilities of caring for children with diverse needs. 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.

In the above context, the current research has tried to explore the different trajectories through which parents were observed to navigate while parenting their children with intellectual, developmental, and cognitive diversities[8]. Talking about diversity and disabilities among children with certain types of intellectual, neuro-motor, psycho-motor and cognitive functionality, the responsibility of care and rehabilitation has been found to have been inflicted upon the family and parents as the primary caregivers. But, at the same time, their (parents and family members') indispensable role in caregiving has remained invisible in the state policies related to intellectual, psycho-motor, neuro-motor, and developmental diversities among children and adults (Sen, 2016, p. 73). In India, a family has been found to have emerged as a primary site of care for children with intellectual and cognitive diversities. Thus, "caring and receiving care becomes a paradoxical experience of enabling/constraining, love/duty, agency/dependence" (Ghosh, 2017, p. 03) for the parents, in which the so-given situation gets further jeopardized by varying acquired and accessible social, cultural, and economic resources they have at their disposal.

## 1.2. Rationale of the Study

For a long time in the history of human civilization, disability has been portrayed as a “problem” (Titchkosky & Michalko, 2017, p. 127-128). Viewing disability as a “problem" has kept disabled people outside of the mainstream social, cultural, and intellectual world and thus excluded them from participation in social activities, resulting in marginalization in education, employment, political participation, and social activities. “Problem” is the definition of the situation of disability (Titchkosky, 2000, p. 198). 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. This was consequently furthered by the production and creation of knowledge about the social reality relating to disability. Hence, disability was produced and created through the “social production of knowledge” (Titchkosky, 2000, p. 198). The attachment of the problem dimension to disability—which has been produced, recognized, and patterned through socio-cultural production and dissemination of knowledge—has represented disability as a social problem (Titchkosky, 2000).

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 1980’s brought in a shift in the disability discourse, putting much emphasis on the social creation and cultural reproduction dimension of disability. Thus, the problem dimension was shifted from the individual to the social. After the emergence of the social model, disability came to be understood as a social creation resulting from a socially disabling environment.

The meaning and understanding associated with disability 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 that rested on a systematic change in the social, cultural, political, and economic dimensions that created disability (Hughes, 2004, p. 45). The widespread dissemination of the social model perspective on disability has spurred the development of activism and the consequent emergence of the specialized interdisciplinary field of disability studies was witnessed, both in the UK and worldwide. Different countries have adopted the social model framework to shape and conceptualize disability according to their national context and culture. In the UK, British disability researchers have adopted the social model perspective to illuminate the role of social barriers in leading to the social oppression of disabled people. In America, disability has gained its conceptual commitment from a minority perspective that was central to the representation of disabled people as a minority group both within cultural representation and meaning. The Nordic countries have emphasized disability welfare services, conceiving them from a relational perspective to gain disability insights. Thus, research across the global north has conceptualized disability as a social construction; as the "social creation of the disability problem" (Shakespeare, 2008, p. 12).

Within sociological discourse, disability has been conceptualized, drawing sources from two different fields of inquiry—disability studies and medical sociology. Chronic illness and disability were viewed as social pathogens in the 1950s (Goodley, 2011, p. 48), and disability was associated with various sociological concepts such as sick role (Parsons, 1951), social exclusion (Alcock, 1997), and social deviance (Durkheim, 1964; Cockerham, 2013). However, it was in the 1970s that one could notice the emergence of a new perspective in the sociology of disability that negated the earlier tendencies of relating disability with deviance; tendencies that evaluated disability against the yardstick of normativity. Disability studies are a relatively new field of study that emerged and established itself in the 1980s and is still fostering sociological investigations and work on disability today. Since the 1980s, different sociological works have been published that have observed and theorized disability, focusing on its social construction dimension. Phenomenological approaches have begun to take the front seat in analyzing and conceptualizing disability. Oliver (1990) has pointed towards the social restrictions and social barrier perspective, which believes that disabled people's social participation to their full potential, is limited by social environmental constraints. 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. B.S. Turner (2001) has given a phenomenological account of the lived experiences of disabled people. Len Barton (2018) has shown that the process of social differentiation and categorization has a discriminating impact on disabled people, based on their socially evaluated inabilities, leading to the consequent generalization and legitimization of their socially created unexpected, undesired, and inferior aspects.

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. People with intellectual disabilities or mental illnesses are also underrepresented in the disability movements (Reid and Knight, 2006; Morgan et al., 2015).

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.

## 1.3. The Research Objectives

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

1. The first objective of the research has been to explore how parents have confronted the reality that their child has been detected with a disability.

The research has attempted to understand how parents reacted when they discovered that their children were being identified with certain intellectual, developmental, psychomotor, and cognitive diversities. Attempts have been made to understand whether and to what extent the dominant bio-normative discourse on disability has influenced parents' reactions.

2. The second objective of the research has been to reveal the challenges that parents have encountered in raising their children and managing their disabilities.

An attempt has been made under this objective to uncover the diverse range of experiences, encountered by parents in raising, nurturing, and providing care to their children with disabilities with regard to their intellectual, developmental, cognitive, psychomotor, or neuro-motor functionality of the body and mind. The purpose of this objective has been to explore whether parents have encountered any kinds of challenges in caregiving and to look into the different facets of such challenges that parents have encountered in raising their children and dealing with their diversity. The goal has been to observe how parents have encountered parenting at both the micro and macro levels of social interaction. An attempt has been made to see whether parents have encountered any difficulties in their interactions with friends, family members, neighbours, and other individuals, whom they have met in public spaces, concerning the diversity of their children. At the macro level, the objective has tried to observe whether and how interactions at the systems level—medical, legal, and education—have raised challenges for parents in caring for their children with exclusive and diverse needs.

3. The third and final objective of the research has been to look into the diverse coping mechanisms that the parents have devised and adopted to overcome the life strains caused by their constant exposure to the challenges of parenting and caregiving.

Through this objective, it has been attempted to explore whether the parents had given in to the dominant 'bio-normative' discourse or whether they had resisted the conventional understanding of disability and perceived their children as able and active social actors. The objective, thus, was intended to observe whether parents had opted to parent, conforming to the dictates of the bio-normative medical model, or whether parents had accepted the disabilities of their children as a part of biological diversity. The goal was to investigate how and to what extent parents exercised their agency and developed their advocacy based on the resources they possessed in the past, acquired in the present, and accumulated for the future.

## 1.4. Description of the Field

Before moving into details about the methodology of this research field, I would like to conceptualize what I mean by the word "field". For conceptualization, I have adopted the definition of "field"[9] as it has been understood and explained in Pierre Bourdieu's theory. According to Bourdieu, for understanding interactions between people or explaining social phenomena or events, it is not enough to just look, know, or listen to mere facts about what was said or what did happen. To get a better understanding of the reality under study, one needs to delve into the social space within which such interactions and events have occurred (Thomson, 2008, p. 67). Any discussion or description of the 'field' of research refers to a setting within which social agents and their social positions are located. The position of the agents within the field reflects the interaction between the field, habits, and capital of the agents.

The research would attempt to analyze and explain interlinks among all of them for a better grasp of knowledge about the relations between the social positions and actions of the agents in the field. I am using the word "field" to denote the physical, social, cultural, and emotional (induced by socio-cultural ideological frameworks one develops and reproduces through social interactions) social space within which primary data was retrieved using a face-to-face interview method.

The description of any field for research must include two major dimensions: geographical and socio-cultural, which remain embodied and inseparable from the field. The description of the geographical dimension reflects the physical-social environmental characteristics of the field within which individuals think, act, and encounter diverse social structures. In this research, Kolkata has been selected as the geographical dimension of the field, which takes certain physical characteristics under consideration, like the economy and infrastructural characteristics, and incorporates all the related physical demographic characteristics of the field.

The Kolkata metropolitan area was covered as the field for the current research. It is located in the eastern Indian state of West Bengal. It is the administrative capital of West Bengal and has been ranked as the 14th largest city in the world (Colenbrander et. al., 2017, p. 141). The Kolkata metropolitan area covers an area of around 1,886.67 $km^2$ and comprises four municipal corporations, thirty-seven local municipalities, and twenty-four panchayat samitis (Awaruzzaman & Biswas). Respondents (parents of children with intellectual, cognitive, and developmental diversities) of the research were well distributed among the city of Kolkata and its adjoining northern areas like Dum Dum, Barasat, Barrackpore, and New Barrackpore, which also come under the jurisdiction of Kolkata as a metropolitan structure[10]. From the southern part of Kolkata, respondents were chosen from areas like Alipore, Dhakuria, Kasba, Ballygunge, Santoshpur, Bhawanipur, and Behala. From northern Kolkata, data was gathered from respondents residing in areas like Ultadanga, Shyambazar, and Baranagar.

According to 2011 National census reports, Kolkata has a population of 4,496,694 with a population density of 24,252/$km^2$. According to the census report of 2011, the sex ratio of the region is 899 females per 1000 males. The literacy rate of the region has been estimated to be 87.14% which is 74% above the national average. The dominant working language among the people of Kolkata is Bengali. Thus, the interviews were conducted in Bengali as the respondents were found to express themselves comfortably in their mother tongue. According to the census 2011 report, there were 20,17,406 people with disabilities in West Bengal, which comprised 2.21% of the total population of West Bengal. As per Kolkata is concerned the total number of disabled people is 1,21,410 out of which 7652 people have mental retardation, 5297 have multiple disabilities, and 27874 people fall under the category of other intellectual and cognitive disabilities which includes other developmental and neuro-motor and psychomotor disabilities[11].

Kolkata has been conferred with the label of being the commercial and financial hub of East and North-east India. Economic operations in Kolkata have been characterized by a flexible production structure and are run by an informal economic sector of production. More than 40% of the labor force is engaged in these informal employment sectors. The informal sectors have been growing in size and proportion over the past three decades and cover a good proportion of the total workforce of Kolkata (Shaw, 2016). This explains the competition in the job sector experienced by the respondents, and the kind and extent of job-related pressure have been well reflected in their narratives. This has also helped the research to analyze how job-related competition and pressure, sustained by these parents, have compromised their time for care and management of their child's disability within the household. For mothers, this compromise sometimes went to the extent of leaving their full-time jobs to balance and compensate between care and chores. The expansion and spread of informal labour sectors had a dual impact on mothers. On one hand, the proliferation of informal sectors indicates a shrinkage of work opportunities in the formalized job sectors, creating excessive competition and work pressure for employees in the informal sectors. The excessive and special demand for care required for managing and dealing with the disabilities of their children has left many mothers unable to return to their earlier employment status. On the other hand, access to informal sectors was found to be an accessible choice for these mothers who had left their earlier full-time jobs with a long career break (this has been discussed extensively in chapter 4).

Kolkata is a well-connected city by rail, road, water, and airways. The suburban railway network system connects the city and suburbs very well. Public transport facilities are provided by Kolkata Suburban Railway, metro railway networks, trams, buses, taxis, auto-rickshaws, and hand rickshaws. Public transportation still remains the dominant mode of the transportation system in Kolkata. According to a survey conducted by the International Association of Public Transport in 2013, Kolkata has topped the list among Indian cities in terms of its extensive network of public transport systems (Phanikumar & Maitra, 2006). Owning a private vehicle was found not to be very common among the people of Kolkata when compared with other Indian cities. Buses are the most commonly used transportation mode in Kolkata. The extensive network of bus transportation systems covers every part of the city. However, keeping in mind the population density and daily urban mobility, the existing services are inadequate in meeting the regular demands of public conveyance. Decreased public space and difficult urban mobility have affected the "city's environment, health, education, employment, and internal security", which in turn has affected "the city's overall socio-economic liveability, sustainability, and vibrancy" (Haque, Mehta & Kumar, 2019: 18). The dominance of public transportation mechanisms (most of which, if not all, have no ramps and are non-spacious to accommodate wheelchairs) coupled with the non-owning of private vehicles explains the misery experienced by parents and their children with disabilities in moving from one part of the city to another for different purposes, ranging from attending schools (regular or special) to attending doctor's or medical practitioner's chambers, hospitals, or clinics.

Kolkata has 48 government hospitals, which mostly function under the Department of Health & Family Welfare, the Government of West Bengal, and 366 private medical establishments[12]. According to the National Family Health Survey, more than 78% of people had been relying on the private medical health care sector over the public facilities. The main reason for such reliance on private medical services has been the lack of nearby public health facilities and overburdening of the public hospitals and health facilities leading to long queues and excessive waiting time This kind of situation in relation health care system in Kolkata has helped in explaining the challenges parents had encountered while receiving disability cards from government hospitals or while consulting medical practitioners for their children. Regarding the presence of the early detection and intervention center, only one government hospital (Seth Sukhlal karnani Memorial Hospital, SSKM) in Kolkata has such facilities. Most of such interventional services and facilities are provided by different non-governmental organizations. Most of such non-governmental centers are located in the heart of the city and incur a high cost for the services they provide for children with intellectual disabilities. High expense and infrastructural limitations in conveyance have left many parents and children to remain outside the periphery of accessing such services.

Apart from the physical demographic characteristics of the field, the social and cultural demographic factors were observed to have contributed to the formation of the habitus[13] and field of the social agents. In Kolkata, one can notice a culture of closed community neighborhood bonds characterized by a strong sense of community among the residents. The presence of such closed community neighbourhoods called “paras” (Mitra & Roy, 2021, p. 25) gives the city its unique cultural identity. In this research, the significance of such neighborhood community bonding and networks was evidenced when parents of children with diverse needs received support from such ties whenever it was needed. However, stories, in contrast, were also present when such closed community circles became the primary locus of stigmatization and taboo related to disability and have been discussed in detail in the following chapters. The possession and acquisition of capital by parents—economic, social, and cultural capital—was viewed as an important tool for analyzing their beliefs and actions, as well as their daily encounters with disability.

## 1.5. Conceptualizing Intellectual and Cognitive Diversity

In this research, I interviewed sixty parents of children with intellectual and cognitive diversity. Under this banner of “intellectual and cognitive diversities”, the research has included children who were detected to have diversities 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). The study used sixty parents as samples to better understand the parenting experiences and challenges that parents face when raising their disabled children and managing their diversity. To provide a better understanding of their experiences and to aid in a better conceptualization of the research problem, I have included certain information regarding the children with disabilities, the parents of whom were included in the research as samples.

Detailed information regarding the disabilities of children of the respondents has been provided in tables 1.1-1.4. Although children with disabilities are not directly related to the research, to understand parents' everyday challenges and experiences with managing the disabilities of their children, it was found relevant to provide information related to the sex, age, and kinds of disabilities that their children were detected with. For the parents, including such information was thought to demonstrate the reality of care demanded by the children with disabilities.

**Table No. 1.1: Sex of the children with disabilities**

| Categories (sex) | No. of children | Percentage (%) |
|---|---|---|
| Male | 43 | 71.63 |
| Female | 17 | 28.32 |
| **Total** | **60** | **100** |

Table No. 1.1 shows that out of the sixty children involved in the research, forty-three were males and seventeen were females.

**Table No. 1.2: Age of the children at the time of the interview**

| Age of the children in years | No. of children | Percentage (%) |
|---|---|---|
| **Below 4** | **0** | **0** |
| **5-9** | 15 | 46.87 |
| **10-13** | 11 | 34.37 |
| **14-17** | 6 | 18.75 |
| Total | **32** | **100** |

Table No. 1.2 shows the age distribution of the sixty children with disabilities involved in the study at the time when the interviews were conducted with their parents. The children included in the research ranged between four and seventeen years of age. Parenting for children with disabilities in such ranges of age becomes more demanding because children at these ages are dependent on their parents for care and to manage their disabilities. Information on the age distribution has been included in the research to understand the dependability of the children for care and management of their disabilities by the parents.

**Table No. 1.3: Age at which disability was detected among the children**

| Age Distribution (In years) | No. of children | Percentage (%) |
|---|---|---|
| At birth | 9 | 28.12 |
| 0-4 | 13 | 40.62 |
| 5-9 | 8 | 25 |
| 10-14 | 2 | 6.25 |
| **Total** | **32** | **100** |

Table No. 1.3 shows the distribution of ages of the children at which their disabilities were detected. According to the distribution, most of the children were detected with a disability when they were less than four years of age. Thus, most of the disabilities were detected in their formative years of development. And for nine children, their disabilities were present from birth. For other children, the disabilities were detected in the later years.

Intellectual disability is defined as a condition of restricted intellectual and adaptive functioning. People with intellectual disabilities have been found to experience functional limitations in the sphere of conceptual, social, and practical adaptive skills. People who have intellectual disabilities encounter delayed intellectual growth and limitations in social communication and self-help skills (Kalgotra & Warwal, 2017, p. 15). The issues with intellectual development are manifested during the developmental period of mental and physical growth; during the formative years of development in one’s life course. Intellectual disability is a condition that causes delayed intellectual and cognitive growth in children.

Table No. 1.4 shows the information on the kinds of disabilities and diversities that the children included in the research have been detected with. All the categories of the disabilities mentioned in the table have been conceptualized in this research under the umbrella term of “Intellectual and cognitive diversities”.

**Table No. 1.4: Information on the kinds of disabilities detected in the children**

| **Categories** | **No. of children** | **Percentage (%)** |
|---|---|---|
| Down Syndrome | 9 | 28.12 |
| Autism Spectrum Disorder | 7 | 21.87 |
| Attention Deficit Hyperactive Disorder (ADHD) | 4 | 12.50 |
| Rubella Syndrome | 2 | 6.25 |
| Learning Disability | 4 | 12.50 |
| Cerebral Palsy | 4 | 12.50 |
| Multiple Disability | 2 | 6.25 |
| **Total** | **32** | **100** |

The term “intellectual disability” carries a chronological journey from being defined as mental retardation to ultimately earning the term "intellectual disability." The terminological evolution of the term "mental retardation" to "intellectual disability" was a reflection of the journey traversed by the disability perspective, from its individual medical model to a model of social construction. According to the definition provided by the American Association on Mental Retardation (2002), MR has been identified as having limitations on intellectual functioning and adaptive behaviour. The accurate diagnosis of MR was based on the evaluation of IQ, determining the limitations in adapting social, conceptual, and practical skills originating before the age of eighteen. The American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) has also defined mental retardation as a dysfunction of the central nervous system that produces an IQ of below seventy and causes deficiencies in life skills like "self-direction, academic skills, social skills, communication, health, and work" (Kalgotra & Warwal, 2017, p. 16). In both of the above definitions, intellectual disability (earlier known as mental retardation) has been explained and measured in terms of 'deficits' (of certain skills) and IQ scores (of or below seventy) respectively. Focus on 'measurement' and 'deficits' in measuring intellectual disability was later reviewed. The 'needs' dimension was perceived to be compromised by the use of words such as 'deficits', and IQ measurement was perceived to be more of a dependent category based on the evaluator's decision rather than the intellectual tests (Salvador-Carulla, Rodríguez-Blázquez, & Martorell, 2008, p. 144). As a result, it was thought important to include the social and cultural context of age, peers, social networks, available social supports, linguistic diversity, and differences in behavioral, motor, and sensory aspects of the people with intellectual disabilities while defining their functional limitations. Thus, "the dimension composed of participation, interaction, and social networks" (Katz & Lazcano-Ponce, 2008, p. 133) was included in the definition of intellectual disability.

This way of defining intellectual disability (ID) that takes the socio-cultural environment of the people into account was found to be in tune with the International Association for the Scientific Study of Intellectual Disability (IASSID) and the World Health Organization's International Classification of Functioning, Disability, and Health (ICF)'s most recent definition of intellectual disability. Thus, in the tenth revision of the WHO, ID was defined as a disorder that results from "incomplete or arrested mental development" (Katz & Lazcano-Ponce, 2008, p. 133). As per their definition, ID is characterized by the "deterioration of concrete functions at each stage of development" of an individual. The presence of such conditions affects the level of intelligence a person has. This includes the cognitive, language, motor, and communicative skills of an individual, affecting their overall adaptability to the environment (Katz & Lazcano-Ponce, 2008, p. 133).

The term intellectual disability has been adopted by the International Society for the Scientific Study of Intellectual Disabilities and the WHO to bring a range of conditions, resulting from delayed or arrested development of cognitive, intellectual, and developmental functioning, under a single umbrella term. According to the American Association on Intellectual and Developmental Disabilities (2009), ID is characterized by limitations in both "intellectual functioning and adaptive behaviour"[14] of a person. Limitations in intellectual functioning imply arrested mental capacities of learning, reasoning, and problem-solving. While limitations in adaptive behaviors indicate constricted "conceptual, social, and practical skills", which people learn, acquire and implement in their everyday tasks"[15]. These include delayed development of- language and literacy skills, conceptions of money, time, and number, interpersonal and communication skills, occupational skills, understanding of social responsibility, understanding and conforming to social norms, and other domains of intellectual growth. Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (American Psychiatric Association, 2013 DSM-5), has defined ID as a neurodevelopmental disorder, the presence of which causes people to struggle in conceptualizing and performing the social, cultural, and normative practices of everyday life.

A similar shift in conceptualization was witnessed when WHO's ICIDH (International Classification of Impairment, Disability and Health) was changed to ICF (International Classification of Functioning, Disability and Health) in 2001. The definition of disability, as provided in WHO's ICIDH, was in general questioned on the ground that it had little (if any) scope for considering the role of the environment (including the socio-cultural context) in the creation of disability. And as such, the focus of such a definition remained on individuals as "the locus of intervention rather than the environment as reflected in society and social organization" (Schneidert, Hurst, Miller & Üstün, 2003, p. 590). Disability movements and various social groups began to cherish the perspectives fostered by the social model of disability, prompting harsh criticism. Michael Oliver (1990) took a critical stance in this regard when he mentioned that ICIDH could not get away with its medical affiliation in approaching disability and that the focus of discussion remained on the individual rather than the environment, situation, or context. For him, the medical approach has produced disability definitions that have been partial in their scope to define disability from all aspects. Oliver has criticized ICDH’s conceptualization of defining "disability as a static state" which "violates its situational and experiential components." (1990, p. 05). Thus, ICIDH has failed to recognize the intrinsic role of the environment in disability. It has thus disregarded the importance of the physical, social, cultural, and policy environments in which disabled people live and continue to function (Schneidert, Hurst, Miller & Üstün, 2003). In 2001, WHO’s ICIDH was changed to ICF, which was recognized as an international standard against which health and disability were required to be explained and evaluated. The environment was accounted for as an independent and principal component of defining and classifying disability. This shift in the conceptualization of disability has recognized that disability is an outcome of the interaction between people with disability and the environment. Thus, the significance of the environment, socio-cultural context, and social interactions in defining and comprehending the context of intellectual disability found its expression in ICF.

The terms "cognitive disability" and "intellectual disability" have often been used interchangeably in many kinds of literature, articles, and documents related to intellectual disability (Baldry & Dowse, 2013). Papers and academic resources which have focused their discussion on people with cognitive disabilities have most often referred to people with intellectual disabilities (Douglas, Bigby, Knox & Browning, 2015). People, who have intellectual disabilities, also often have cognitive impairments and hence, often experience difficulties related to cognitive functions (Baldry & Dowse, 2013, p. 220). Thus, in many instances, intellectual disabilities cause individuals to develop arrested cognitive functions with difficulties in communication, executive function, and self-direction (Douglas, Bigby, Knox & Browning, 2015). It is important to note that though people who have intellectual disabilities often develop difficulties in cognition. However, it is not necessary that people with cognitive disabilities will definitely have traits of intellectual disability. Cognitive disability has been understood more as a developmental disorder that fundamentally requires professional care (Katz & Lazcano-Ponce, 2008, p. 133). Thus, cognitive disability has been defined as a condition that affects the development of cognitive ability within individuals. Cognitive disability is a broad concept that comprises intellectual and cognitive limitations, including intellectual disabilities (that can be too mild to qualify as ID). In functional terms, cognitive disabilities can show features of intellectual disabilities and vice versa. In clinical terms, however, the detection and diagnosis of cognitive disabilities includes autism, Down syndrome, attention deficit disorder (ADD), and learning disabilities.

Intellectual and cognitive disabilities come under a broad purview of disorders that are characterized by diminished adaptive and cognitive development, and this also includes certain developmental disorders. The diagnostic term of intellectual disability that has been used in the DSM-5[16] has been named intellectual developmental disorder in ICD-11[17] (American Psychiatric Association (DSM-5), 2013, p. 33). Developmental disability refers to a group of conditions that begin in childhood and continue through adulthood. People with a developmental disability may show features of arrested intellectual development, but not always. For example, though cerebral palsy is a clear case of developmental disability, it might not necessarily be accompanied by cognitive disability. DSM-5 has defined intellectual developmental disability (IDD) under the bigger canopy of neurodevelopmental disorders, which are characterized by limitations in intellectual and adaptive functioning (Munir, 2016). The DSM-5 has referred to neurodevelopmental disorders as a group of conditions that are manifested during early developmental periods and express constraints in "personal, social, academic, or occupational functioning" (American Psychiatric Association (DSM-5), 3013, p. 31). The neurodevelopmental disorder often co-occurs with other developmental delays, affecting both cognitive and intellectual delays—like in the case of children who have ASD or ADHD, who may also develop traits of Specific Learning Disorder (SLD) (American Psychiatric Association, 3013).

The American Psychiatric Association’s Diagnostic and Statistical Manual of Mental Disorders (DSM-5, 2013) has defined ASD as a “neurodevelopmental disorder” that has underlying cognitive traits (Lord et al., 2020, p. 03) and is found to co-occur with other conditions. While conducting my research, I came across parents who had children with ASD accompanied by ADHD. Likewise, traits of intellectual disability were found to be very common in children who had ASD.

Down syndrome (or Down’s syndrome) is a chromosomal condition often associated with an intellectual disability accompanied by other clinical findings (Bull, 2020, p.

2344). Children with Down syndrome show delays in neurological development, which are often manifested in arrested intellectual development (Bartesaghi, Haydar, Delabar, Dierssen, Martnez-Cué & Bianchi, 2015). Thus, children with Down syndrome fall under the wider category of intellectual disability, the presence of which affects their social skills, communicative ability, and reasoning.

In DSM-5 (2013), attention deficit hyperactivity disorder was placed under the discussion of neurodevelopmental disorders. According to DSM-5 (2013), ADHD is characterized by "impairing levels of inattention, disorganization, and/or hyperactivity-impulsivity (p. 32). ADHD is a condition that often accompanies other intellectual or intellectual developmental disorders (Munir, 2016).

According to the classification provided in DSM-5 (2013), specific learning disorders (SLD) are a kind of neurodevelopmental disorder. The presence of SLD in children hinders their learning ability and restricts them from learning specific academic skills like reading, writing, and arithmetic, which are integral parts of formal learning. In SLD, other aspects of development appear to be fine, and the early signs of troublesome development are noticeable in the preschool years (Tannock, 2014). SLD can happen in children who have been identified with intellectual disabilities (American Psychiatric Association, 2013). Assessment and diagnosis of SLD are highly connected to the measurement of the intellectual capacity of children. Thus, children with intellectual disabilities may show signs of SLD in their pre-school and school-going years.

Children with cerebral Palsy (CP) have been defined as a neuro-developmental condition that begins in the formative years of development in children and continues throughout their lifetime (Rosenbaum et al., 2006). Children with CP frequently develop motor disorders that are accompanied by difficulty in perception, cognition, communication, and behavior, thus showing signs of cognitive disability. Intellectual disability is present to a significant extent in children with CP, which affects their everyday activities and impacts on their overall quality of life. Research has shown that two-thirds of patients who have CP are dfound to possess intellectual impairments to a certain degree (Krigger, 2006).

In my research, I had two children who were detected with multiple disabilities. The Individuals with Disabilities Education Act's (IDEA) defined multiple disabilities as the presence of one or more impairments at the same time. The presence of more than one disability in children has often been found to have caused difficulty in adapting to the immediate physical and social environment, difficulty in cognition, communication, and even intellectual capacities.

Congenital Rubella Syndrome (CRS) results when a group of abnormalities develop in children during the gestation period. CRS is a condition that results when the mother gets affected or exposed to the rubella virus during her gestation period. Getting infected with the Rubella virus often results in foetal death or the birth of a child with congenital birth defects (Robertson, Featherstone, Gacic-Dobo and Hersh, 2003). Children born with CRS often experience multiple disabilities where more than one developmental, intellectual, or congenital difficulty remains dominant. CRS in children causes blindness, deafness, and even mental retardation. Research has proved that the rate of mental retardation has been as high as 42% among children with CRS. Moreover, 4.12–7.3% of children with CRS show signs of autism (Hwang and Chen, 2010). In children who have CRS, a high rate of impulsivity and behavioural issues like "aggression, self-injury, emotional outbursts and tantrums" have been observed (Hwang and Chen, 2010, p. 104).

All the categories of disability that have been considered for this research, in one way or the other, remain connected and fall under the wider classification of intellectual, developmental, or cognitive disabilities. Moreover, disabilities 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) do not have any fixed assessment criteria, nor is there any standard evaluation method for measuring the type and extent of disability present. Most of these conditions are symptom or sign based, and the evaluation of which depends more upon the evaluator and context of evaluation, and more often the symptom overlap with other disability categories. Since there are no available standardized or reliable biomarkers to measure these disabilities, diagnosis, and detection of them are made on the basis of behavior. Thus, developmental disorders vary from difficulties in learning and functional control to developing constraints in social skills or intelligence. Again, neurodevelopmental disorders like autism spectrum disorder often co-occur with an intellectual developmental disorder. Children who have ADHD may also show signs of SLD to varying degrees. A recent study has shown that about 45% of children with ADHD develop signs of learning disability (Kałdonek-Crnjaković, 2018, p. 216). With this context at hand, the research has employed the umbrella term “intellectual and cognitive diversity” to cover all the disability categories mentioned above.

In this research, I have used "intellectual and cognitive diversities" as an umbrella term to bring in all the intellectual, cognitive, developmental, and neurodevelopmental diversities under a single conceptual banner. This research has included parents of children with diversities like Autism Spectrum Disorder (ASD), Down Syndrome (DS), Attention Deficit Hyperactive Disorder (ADHD), Specific Learning Disability (SLD), Cerebral Palsy (CP), Multiple Disabilities, and Congenital Rubella Syndrome (CRS). The choice of the term "intellectual and cognitive diversities" as a single term in denoting all the diversities included in the research was backed up by the technical information and general explanation provided in DSM-5 (APA, 2013). All the diversities mentioned above and included in the research were found, in some way or the other, to have been connected with intellectual, cognitive, developmental, and neurodevelopmental delays. Hence, the term "intellectual and cognitive diversity" has been used as a conceptual category to refer to all the disability categories included in the research.

## 1.6. Research Methodology: Design, Methods and Parameters

### 1.6. 1. Ontological, Epistemological and Theoretical Standpoints of the Research

The research methodology in any social research is shaped by its ontological and epistemological underpinnings that remain embedded in the way the research has been designed and are well reflected throughout the research process. The ontological, epistemological, and theoretical frameworks that a researcher utilizes in his/her research at hand provide a structure for the research and shape the theory building of the research. Hence, the ontological and epistemological considerations of the researcher are conducting research that stimulates the choice of theoretical perspectives to be included in the research. The ontology of research is concerned with the fundamental nature of reality. And epistemology directs how this reality can be known. W. Lawrence Neuman (2014) has mentioned realist (with a subgroup of a critical realist) and nominalist (with subgroups of moderate and extreme nominalist) viewpoints about the nature of reality. The critical realist view looks at reality as highly influenced and affected by "pre-existing ideas, subjectivity, or cultural interpretations" and recognizes the subjectively woven interpretations that nurture the understanding and experiences of reality (Lawrence Neuman, 2014, p. 94). A moderate nominalist perspective also highlights the importance of subjective-cultural components in framing our experiences of the physical and social world (Lawrence Neuman, 2014, p. 94). I took a critical and moderate nominalist approach to understand how disability as a social category exists in social reality and how existing knowledge about disability in general, and intellectual and developmental disability in particular, has been created, constructed, and reconstructed along the social, cultural, economic, political, and historical continuum. Thus, a social-constructionist lens of understanding the nature of reality was found relevant in understanding that parents' perceptions, reactions, and responses to disability were products of social constructions; and since these were socially constructed, the research has attempted to see whether such constructions were re-constructed and re-produced when the parents had encountered various challenges living with the past constructions they had developed earlier. Social constructionism, which is typically associated with qualitative research, holds that knowledge is formed as a result of human interactions and shared experiences of the individual. The constructionist approach to knowing and understanding reality emphasized the role of context in knowledge construction and accumulation. Hence, truth and knowledge vary because they are socially and culturally constructed (Berger & Luckman, 1966). Because the parents' understanding and experience of the diversities in their children were found to be varied due to their diverse and subjective demographic positions, which were reproduced through their interaction across diverse individual, institutional, and structural boundaries, I preferred the constructionist paradigm to investigate their experiences in raising their children with disabilities.

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. Interpretivism opposes the positivist methods of knowing reality. The term itself stands in opposition to positivism and "denotes an alternative to the positivist orthodoxy" (Bryman, 2012, p. 30). Conducting research by adapting an interpretivist epistemological device requires the researcher to get hold of the subjective meanings of reality. For this research too, methods of knowing reality were thus chosen, which allowed scope for the researcher to interpret the findings in their subjective contexts of reality. Hence, the methods of sample selection, data collection, and choice of tools for conducting interviews, data coding, and analysis were so chosen that they could meet the needs of the research designed along the interpretive epistemological lines.

Many researchers (Hesse-Biber, 2010b; Lawrence Neuman, 2014; Creswell, 2014) have recognized that the critical paradigm approach has attempted to demystify multiple levels of reality experienced by individuals, which in turn shape their understanding of reality with multiple meanings associated with it. Hence, to understand reality, it is important to take into account the multiple realities and experiences that might have existed around the different social phenomena. Thus, critical disability perspectives were employed in this research to complement the research gap that would have existed if only the constructionist perspectives would have been employed. The micro-level, subjective, and relative understanding of reality from the constructionist angle, often limits the scope of understanding the same reality in the presence of actual conditions of life, thus ignoring the broader structural conditions that might have generated conditions of marginalization and discrimination for the individuals (Neuman, 2014). To understand the challenges encountered by the parents, a meso-level understanding has been attempted in the research which would include both micro and a macro level perspective, without taking the extreme standpoints of either the micro or the macro level. Hence, while parents' perception and understanding of disability (in general and about the diversities in their children) was taken into account, and the institutional (law, education, special schools, medical and clinical professionals, psychological counselors) viewpoint was also considered as an important source in reflecting upon the reality, thus known. I have thus adopted approaches of critical disability theories to frame the understanding of disability in the Indian context; to situate Indian disability discourse within Indian social, cultural, political, economic, and historical reality. Few feminist approaches were employed to explain the parenting realities of balancing care and chores. The gendered dimension of caring for children with disabilities and managing their diversified needs has been understood under a general feminist theoretical lens. Thus, the research has been designed along a qualitative paradigm that has considered social constructionism as its ontological position and interpretivism as its epistemological device. The theoretical approaches and conceptions which were employed and engaged in the research were so chosen that it could satisfy the needs for using such ontological and epistemological considerations. Thus, 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 generalization that remained limited within the scope of samples included in the research.).

### 1.6. 2. Design of the Research

The current study has been planned in conjunction with mixed methods strategies to comprehend how parents have perceived disability; to comprehend the challenges that parents have encountered in their daily interactions both at micro and macro-societal levels; and to investigate how parents have reflected on the existing legal and social security about the diversity (disabilities) in their children. It has often been termed a third research paradigm after the qualitative and quantitative paradigms and has often acted as a bridge connecting both (Onwuegbuzie & Leech, 2004). Teddlie and Tashakkori (2011, p. 285) called the development of mixed-method research the "third methodological movement" that has resulted from the "paradigmatic debate" between quantitative and qualitative methodological approaches. Mixed method research is a type of research in which the researcher employs components from both quantitative and qualitative approaches at different stages of the research, ranging from data collection, analysis, and inference techniques to accomplish the intensity and depth of the research (Johnson, Onwuegbuzie, and Turner, 2007, p. 123). The mixed-methods approach has the potential to include the elements of both the qualitative and quantitative approaches, which the researcher feels are relevant to employ in his/her research (Bryman, 2012, p. 638). Mixed method design has been used as an "umbrella term" to designate the several ways in which multiple methods of research can be employed and integrated (Creswell, 1999).

The current research employs a qualitatively driven mixed-method design. However, there is no denying the fact that it has been a very difficult journey for the research to decide upon how, when, where and to what extent it should engage and mix qualitative and quantitative dimensions. This was mainly because mixed-method studies incorporate as much variety as possible—mixing different methods, at different points, and to a different extent than categorizing any research according to a single typology becomes a difficult job for the researcher. Thus, the diversity of the existing typologies of mixed method design is so vast and variously classified, that any research can hardly engage any single typology that can adequately fit the research design of the given research. "The actual diversity in mixed methods studies is far greater than any typology can adequately encompass" (Maxwell and Loomis 2003, p. 244). As far as mixed-method designs are concerned, a plethora of typologies and kinds of mixtures exist per the mixed-method designs. Keeping such context at the fore, I have adopted a typology of mixed methods design which has been introduced by Leech and Onwuegbuzie (2009) in their work "A typology of mixed methods research design". They have introduced a three-dimensional typology based on which qualitative and quantitative approaches could be mixed at all or different stages of the research (Leech & Onwuegbuzie, 2009, p. 268). The three dimensions are:

1. The extent of mixing (based upon deciding whether qualitative and quantitative dimensions are to be mixed partially or fully).
2. Time of mixing (based upon the point of time when the quantitative and/or qualitative dimensions are to be employed). They can be mixed simultaneously (concurrent) or subsequently (sequential)).
3. Emphasis on mixing approaches (based upon deciding whether quantitative and qualitative approaches are employed with similar priority (equal status) or if one approach is to be given greater priority over the other (dominant status).

Considering all possible kinds of mixtures from the three-dimensional typologies above, the current research has adopted the partially mixed concurrent dominant status design (Leech & Onwuegbuzie, 2009, p. 273). With this design of mixed-method, qualitative and quantitative approaches are simultaneously mixed but partially, with the qualitative dimension given a greater weightage. Thus, be it the extent of mixing, time orientation, or emphasis of mixing approaches, the qualitative dimension (QUAL) has played a dominant role as compared to the quantitative (quan) one. The qualitative dimension of the design has been employed at all stages and methodological considerations of the research, ranging from its ontological grounding (social constructionist) to epistemological tools (interpretivism); from sampling technique and data collection to analysis and interpretation of the data. The quantitative dimension, however, was employed in the research in preparing and analyzing the demographic data of the respondents, which also acted as a complementary aid to the qualitative interpretation of the same.

Denzin and Lincoln (1998) have provided three variations in approaching research from a qualitatively driven angle (Hesse-Biber, 2010, p. 102). The first one is related to a constructionist approach that I have employed in this research that observes how disability is socially constructed and associated with subjective meanings that individuals or parents (of children with disabilities) attach to it. The second one, which is also a qualitatively driven paradigm, is the critical approach, which believes that social reality is formed and shaped through power, social control, and dominant ideological underpinnings. This study took a critical approach to understand Indian social reality, taking into account the various intersections of class, age, and gender to reflect on a reality centered on disability. The third variation argued by them is the feminist perspective (gathering relevant data and information through narratives and lived experiences, which is the preferred method in disability-related qualitative research), which focuses on the lived experiences of women and other groups having experiences of marginalization. Using a feminist theoretical lens, the research has attempted to trace the link between gender ideology possessed by the parents and the caring role they have adopted for their children. In this research, I have used all three qualitatively driven approaches to understand disability in the Indian context, especially for parents having children with intellectual and cognitive diversity.

This research has attempted to study the experiences of parents in raising their children with disabilities (Autism Spectrum Disorder (ASD), Down Syndrome (DS), Attention Deficit Hyperactivity Disorder (ADHD), Specific Learning Disability (SLD), Cerebral Palsy (CP), Multiple Disability, and Congenital Rubella Syndrome

(CRS); to observe how their interaction with the wider social world, both at the micro and macro level of interaction, has shaped their perception and understanding of disability; and to see how the parents have reflected on the existing disability discourse at the social, cultural, political, and economic level. For a better and in-depth understanding, the research has tried to explore multidimensional and multifaceted layers of social experiences and the lived realities of the parents to get a complete picture of the research problem in question.

Jennifer Mason (2006, p. 13) in her work “Mixing methods in a qualitatively driven way” has extended three reasons that could help a researcher apply a mixed-method approach to his/her study: Firstly, it facilitates "Outside the Box" interpretation by allowing one to travel through the multiple layered experiences of people and to reveal the interconnections and interdependence (if any) among the different dimensions of reality. Secondly, it encourages the researcher to develop his/her “capacity for theorizing” (p. 14) across the continuum of the micro and macro levels of interaction and encourages the recruitment and deliberation of "theoretically driven empirical research" (p. 14). Finally, the application of a mixed-method strategy in qualitatively driven research prepares a strong platform for extending the logic of using a qualitative approach in research. In doing so, mixed methods assist the researcher to observe, conceptualize, comprehend, and explore the contextual understanding of the reality under question.

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 utilized only as a part of understanding the demographic status of the respondents (parents of children with disabilities). Approaching research from a qualitative standpoint expands the possibility of an in-depth understanding of social reality within a specific socio-cultural context and among a small number of samples encountering multiple dimensions of reality. Understanding realities, which contain multiple subjective elements, is recognized as an important source of knowledge building in the concerned research arena by qualitative methodologies (Hesse-Biber, 2010, p. 16). The qualitative approach facilitates the researcher to observe the social world and its consequent knowledge building through the standpoint of the respondents or samples covered under the study (Bryman 2012, p. 399). The social constructionist dimension of knowledge, about the wider social reality, is thus presented before the researcher comprehensively.

Within the mixed-method strategy, a qualitatively driven inquiry is committed to putting a qualitative approach as a central guiding star for the entire research design. At all different stages of this research, a qualitatively driven dimension of understanding the research problem and contextualizing the same in the wider social reality has been reflected. The epistemological and methodological underpinnings of the entire research thus, manifest a qualitative inclination and commitment towards the research. Here, quantitative dimensions have been recognized in their secondary role. The use of quantitative methods in data interpretation served as a supplement to the core qualitative paradigm (Hesse-Biber and Johnson, 2015).

The research, thus oriented towards a qualitatively driven mixed-method strategy, has provided immense scope for an in-depth understanding of the social reality of disability; it has also left the room to gain deeper insights from the lived experiences expressed by the parents (of the children with differences) by narrating their stories and experiences relating to their children's disability. For a clearer and better understanding of their experiences and also as a means to verify the validity of the narrations and responses by the parents, I have supplemented the qualitative analysis with certain quantitative data. The core design of the research thus remained qualitative with a few quantitative dimensions attached in the form of numbers, tables, figures, and percentages to supplement my research analysis and findings.

### 1.6 3. Methods Employed in the Research

In this research, I have adopted research methods of sampling, collecting, and analyzing data that are associated with the qualitative research strategy. Research from a qualitative angle requires studying people in the social and cultural context of which they are a part. It seeks to examine how these social, cultural, economic, political, and physical contexts shape their experiences and behaviours in the social world in which they live; and in doing so, it attempts to interpret the social world in relation to the subjective meaning people place on it (Hennink, Hutter, & Bailey 2020, p. 10).

This research has been espoused by what is called abductive reasoning. Abductive reasoning leads the researcher to ground his/her theoretical understanding of the research in the context and people he/she is studying and to comprehend the meanings, perceptions, and perspectives that shape their knowledge of social reality. Through abduction, the researcher interprets the social world from the perspective of the respondents or samples, goes on to theorize based on the interpretation and understanding of the same world, and finally provides a social scientific account of the reality seen from those perspectives (Bryman, 2012, p. 401). In abductive reasoning, the theoretical accounts provided by the researcher reflect the worldview of the respondents. In this study as well, I used abductive reasoning to theorize and understand disability from the perspective of parents who have children with various disabilities. Parents' perception of disability was found to have a strong association with the existence of disability as an objective reality. Parents' subjective experiences and encounters with such objective reality helped in co-constructing the meaning of disability, both for them and for the researcher.

### 1.6. 4. Unit of Analysis and Sample Composition

The parents, both mothers, and fathers, who have children with certain physiological and mental diversities, formed the unit of analysis for the study. Though the central thrust of the research has been to co-construct the understanding of disability by drawing from the perceptions and lived experiences of the parents and connecting them to existing theories, several other variables have been observed to play an active role in framing the understanding of disability for the researcher rather than just the subjective experiences of the parents. The variables which had been observed to have highly influenced the parents' understanding of disability included the following: the age of the parents; the age of the children (at the time of interview); sex of the children; the age of the children at which the disability was diagnosed (by birth or developed later); kind and severity of the disability; educational background of the parents; types of profession or occupational engagement of the parents; the income of the parents; the structure of the family (nuclear, joint, or single); and marital status of the parents (married, divorced, or separated). Each of these variables is highly interconnected and interdependent amongst themselves. This has encouraged the researcher to adopt an intersectional approach in understanding how these variables intersect and mutually nurture each other, to develop a holistic and comprehensive understanding of disability.

I interviewed sixty respondents, out of which twenty-eight were fathers and thirty-two were mothers. The age of the parents (mothers and fathers) ranged from thirty-one years to sixty, with the average age of fathers being forty-one to forty-five years and that of mothers being thirty-six to forty years. This has been presented well in table no. 1.5.

**Table No. 1.5: The age distribution of the parents of the children with disabilities**

| Range of Age (In years) | No. of parents | Percentage (%) | Mothers | Percentage (%) | Fathers | Percentage (%) |
|---|---|---|---|---|---|---|
| 31-35 | 8 | 13.32 | 5 | 15.62 | 3 | 10.71 |
| 36-40 | 12 | 19.99 | 10 | 31.25 | 2 | 7.14 |
| 41-45 | 17 | 28.32 | 8 | 25 | 9 | 89.27 |
| 46-50 | 12 | 19.99 | 5 | 15.62 | 7 | 24.99 |
| 51-55 | 8 | 13.32 | 3 | 9.37 | 5 | 17.85 |
| 56-60 | 3 | 4.99 | 1 | 3.12 | 2 | 7.14 |
| **Total** | **N = 60** | **100** | **32** | **100** | **28** | **100** |

The kinds of disabilities involved in the research were: Down syndrome (nine children), Autism Spectrum Disorder (seven children), Attention Deficit Hyperactivity Disorder (four children), Rubella Syndrome (two children), Learning Disability (four children), Cerebral Palsy (four children) and multiple disabilities (two children). The educational qualifications of the parents varied, comprising three parents who completed their higher secondary school education; twenty-nine parents who completed their graduation degree programs, twenty-six parents had a post-graduation degree; one parent who had a doctorate; and one parent who completed his post-doctorate. The household income of the parents ranged from Rs. 11,000 to Rs. 1,50,000 per month, with an average income of Rs. 31,000 to Rs. 50,000. The information on the kinds of households involved in the research has been presented below in figure no. 1.1.

**Figure No. 1.1: The type of household of the parents in which the children have been raised**

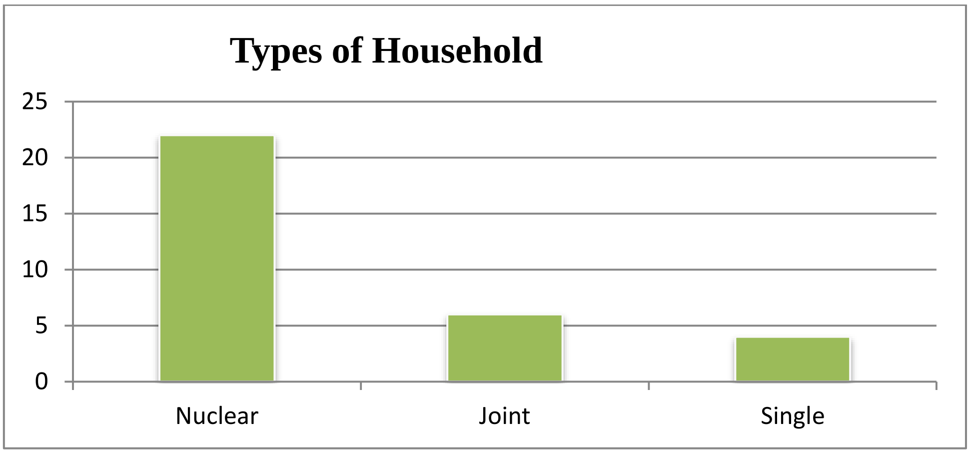


Figure No. 1.1 shows that most of the households included in the research were nuclear, with parents living with their disabled children. Out of thirty-two respondents, twenty-two parents lived within a nuclear family structure, six parents had a joint familial setup, and four parents (single mothers) had a single familial unit. In three of these four single households, the grandmother on the mother's (parent respondent) side used to stay with them, forming a collateral nuclear household.

Besides interviewing the parents, I also interviewed three doctors, three special educators, and three teachers to get a holistic understanding of the parents' experiences. Talking to the doctors has helped in shedding light on the contradictory positions of the doctors and the parents regarding their perception and understanding of disability. Insights from the perspectives and opinions expressed during the interview by three of the special educators included in the research facilitated a detailed discussion about the availability of facilities, the presence of infrastructure, and the parents' socioeconomic and cultural capacities in managing and addressing the challenges they had been facing with regard to the disabilities in their children. Conversation with the teachers (from three different regular schools) has helped in explaining the gap that exists between framing a policy and building the infrastructure for its implementation. This was especially discussed in connection to the implementation of inclusive education policies[18] in schools. Interviews with doctors, special educators, and teachers were used as a secondary supplementary source of information. The social, economic, and cultural capacities of parents have been conceptualized and employed in the research following Pierre Bourdieu’s theory of “capital”[19].

### 1.6. 5. Sampling Technique

I have adopted a non-probability[20] purposive sampling[21] and snow ball[22] technique to select 60 samples (parents) for the study. I have taken accounts of both fathers and mothers to avoid any presumed gender bias on the part of the researcher. From my social networks and acquaintances, I received contact from four parents who were relevant to my research. Of these four contacts, one parent was running an organization (“Jagori”) herself, which dealt with children with diverse needs. I asked her to provide me with details of some of the parents who had given their consent to be a part of my research. From there, I received some relevant contacts through the snowball technique. However, all the contacts were centered in the northern part of Kolkata. To avoid locational bias, I needed some contacts from the South and other areas of the city for a better generalization of my research findings. Through snowball, I received contacts of some parents who represented South Kolkata, and in doing so, I came to know about another organization named “Disha”, which had been working on children with diversity. The founding member of Disha was one of my respondents who had a daughter with ADHD. From Disha, I received recommendations and contacts from parents throughout Kolkata who became a part of my study.

### 1.6. 6. Data Collection

Once I had a ready database of the contacts of the parents, with whom I had already had an initial conversation regarding their consent to participate in the interview for the research, I went on to fix appointments with my respondents in accordance with their preference over time and place. All of the interviews were carried out at the residences of the respondents at a time when they found it suitable, with prior knowledge that the interviews might take two to three hours at a time. Since my research included detailed and in-depth queries and understanding regarding the diversities with which their children were born or developed later, there were many moments marked with emotional outbursts, and as a researcher, I had to maintain a good deal of sensitivity, flexibility, empathy, and friendliness towards the respondents during the interviews. Before initiating the interview, I tried to ease the interaction situation to make it comfortable and friendly for the parents so that they could participate unhesitantly. Before the actual appointment date for the interview, I tried to build a rapport with the parents over the phone to create a comfortable environment for initiating our discussion. Each of the parents was interviewed twice, primarily because it had appeared to me as a monumental task to combine all the components required for collecting qualitative data with quantitative aids within a short span of two or three hours. I felt that this would hamper the quality of the responses. So, I split the whole interview process into two separate days. On the first day, I invested some time in building rapport with the respondents, asking a few close-ended questions about the demographic profile of the samples. On the second day, I put more stress on listening to their lived experiences which were conducted by allowing them to narrate their stories in an uninterrupted manner. Their responses to lived experiences, and narratives were recorded on a voice recorder. In the end, I had asked a few open-ended questions which I felt were not addressed in the responses and narrations, and they were recorded in a notebook. I prepared the field notes soon after coming back from the interview to take account of the message or meanings conveyed between the lines of the narrations and responses.

A semi-structured interview[23] schedule was used as a data collection tool. The semi-structured interview tool had been selected because I found it suitable to explore the manner in which parents had perceived disability and to comprehend how they had constructed the social reality around them based on their perception of disability. Moreover, a semi-structured interview technique left enough space to receive clarification on probing questions. The flexibility of the semi-structured interview schedule to include both closed-ended and open-ended questions has remained its strength, providing space for respondents to narrate their lived experiences.

The interview was separately conducted with mothers and fathers, even when they lived in the same residence. Interestingly, it was observed that the participation on the part of mothers was more spontaneous and lucid than that of fathers. Initially, eleven fathers were unwilling to give interviews and participate in the study. It was only with constant probing on the part of the researcher that they agreed to participate. While mothers were free to narrate their lived experiences, in the case of fathers, as a researcher I had to constantly probe questions to get the relevant data required for my research.

### 1.6. 7. Addressing the Questions of Validity and Reliability

The questions of validity and reliability remain central to any research endeavor. Due to limited avenues for measurement, the issues of validity and reliability become difficult to address in qualitative research. LeCompte and Goetz (1982) have recognized the unattainable condition of social reality and context to freeze along socio-cultural and time dimensions. Social realities are subjective, multidimensional, and dynamic across time and context. Hence, any attempt to replicate the same context and reality for the purpose of attaining validity and reliability ends in an impossible venture. Many researchers and writers (Lincoln and Guba, 1985; Leininger, 1994; Bryman, 2012; Hammarberg, Kirkman, & Lacey, 2016) have proposed alternative criteria to assess the quality of qualitative research.

Researchers, thus, defend the integrity of research based on four pillars: trustworthiness, credibility, applicability, and consistency (Leininger, 1994). Trustworthiness of the study is gained through an in-depth, robust, transparent, and explicit description of events, interviews, and the process through which they have been collected and analyzed. The second criterion for evaluating qualitative approach-based research is credibility. Credibility in research is attained when the analysis, findings, and interpretation based on the research results are presented with robust descriptions of context and are recognizable to people who share the experiences and who are inclined to understand the shared knowledge (Hammarberg, Kirkman, & Lacey, 2016). This technique is often called respondent validation or member validation (Bryman, 2012, p. 389). The criterion of credibility acquaints us with what is known as internal validity. Applicability is the criterion that helps in assessing the external validity of the research. Applicability (Bryman called it transferability, 2012, p. 49) is achieved when the research findings match with other contexts external to the study situation. Geertz (1973) has argued that qualitative researchers adopt a thick description of the context which refers to the rich accounts of the contexts within which the respondents are situated. A thick description of the context and events provides a ready database that can be evaluated in a different research situation, making transferability of findings possible (Bryman, 2012). Finally, consistency, or dependability, is the criterion that assesses the reliability of qualitative research. Lincoln and Guba (1985) proposed the idea of dependability and argued for the researcher to audit the whole research procedure. This entails conservation of the records by the researcher at different levels of data gathering, transcriptions, analysis, and findings and making them accessible to other researchers for evaluation of the correct procedures (Bryman, 2012, p. 49). All the criteria of trustworthiness, credibility, applicability, and consistency were taken care of with great precision in this research. In this research, I have tried to apply the evaluation criteria by conserving all the detailed and in-depth information starting from data gathering to transcription and data analysis, and by connecting the research findings with existing theories and research works related to the theme of the research but carried out at different research settings.

### 1.6. 8. Analysis and Interpretation of Data

A large volume of data mounts up following a qualitative interview and narratives. Qualitative data is characterized by its richness, but it is difficult to put the data into interpretation based on different themes and descriptions. Data analysis and interpretation "involves making sense out of text and image data" (Creswell, 2009, p. 141), which includes preparing the raw data for analysis, understanding and going through the data deeply, unearthing different codes and themes, and interpreting the research findings, connecting them to different existing theories that might conform to the findings or even refute them. While conducting this research, I carried out the tasks of data gathering, transcription, and interpreting the data simultaneously. I have transcribed the data collected from interviews conducted earlier and, accordingly, began to analyze the data while interviewing the rest of the respondents. Transcription of the data was done by typing the field notes and the voice recordings with detailed intricacies. This step was the most time-consuming one. I spent almost one and a half years gathering data and transcribing it into field notes. Once all the interviews were completed along with their transcription, I started arranging the data and forming codes. Coding is the process by which the large pile of data gathered is organized into different segments by the researcher and then connects the different segments to make meaningful information relevant to the research (Rossman & Rallis, 1998, p. 171). This was the most difficult part of the analysis, which took a lot of time after transcription. Once the codes were ready, I developed certain themes out of them and attempted to provide an in-depth description based on the themes. Creswell (2009) defines description as the detailed representation and interpretation of people, places, events, or even research settings' experiences. In this research, I have analyzed the data into different themes and have been relating themes to understand the inter-dependability or interconnections between the themes. After interpreting the themes from different interconnections, I have linked them with diverse theoretical lenses that were found relevant to the research.

### 1.6. 9. Ethical Consideration of the Research

Keeping the ethical consideration of the research intact, consent was taken from the respondents, agreeing to which the interviews were administered. The names of the parents and their children with disabilities have not been disclosed anywhere in the research. However, in some instances where the names of the parents, their children, some parent activists, and a few institutions were mentioned in the research, it was done with their due consent.

The information extracted during the interviews has not been used for any immoral purpose beyond the scope of this research.

## 1.7. Structure of the Thesis

This research has attempted to unearth the diverse realities experienced and encountered by parents about their children with intellectual and cognitive diversities. The research has been divided into six chapters. Each of these chapters was further divided into different sub-sections based upon specific themes of discussion.

In the first chapter, the significance and relevance of the study within wider sociological discourse have been conferred. The chapter has attempted to address the need for in-depth research about parenting and caregiving for children with intellectual, developmental, and cognitive disabilities. The chapter has talked about the main objectives that have driven the research: to see how disability has been socially constructed and culturally operated in shaping parents' perceptions of disability; and to see whether and how such perceptions have changed over time and shaped parents' responses to their children's disability. The chapter was carried out further to discuss the methodological aspects of the research. The methodological understanding of the research has highlighted the way the research has been designed. Starting from the choice of theoretical lens in generalizing the research to collecting information from the parents, every detail has been provided minutely in this section. Data gathered from the parents was analyzed and interpreted by engaging a social constructionist lens, which helped to understand their paradoxical encounters with disability and care.

In the second chapter, existing literature on disability and parenting has been extensively reviewed, tracing perspectives and empirical stances both from the global north and southern realities to debunk the invisible cord that connects parenting, disability, and care. The chapter has attempted to provide an overall understanding of the disability discourse as it has been operating across the globe. The chapter has elaborately discussed the meaning and shape of disability discourse in India, which has been viewed as a combined impact of the development of different disability models, the amendments and modifications in the international laws relating to disability, and the structural changes that were incurred, to correspond with such modifications. The chapter attempts to connect the wider disability discourse in India with the care and parenting realities that parents have encountered in dealing with their children's disabilities.

In the third chapter, the reactions and responses of the parents have been accounted for when they first encountered the disabilities and diversities in their children for the first time. The chapter has provided accounts of how parents' knowledge and perceptions about disability, which they had been cultivating before their children with disabilities were born, have shaped their understanding of the same after they have encountered the reality of their children's disabilities. The diverse emotional reactions expressed by the parents have been evaluated under the theoretical lens of the sociology of emotions. Many relevant sociological works were referred to, which aided the research in understanding the social construction of such emotional expressions by parents about their children's disabilities and diversities.

The fourth chapter has an elaborate discussion about the everyday experiences and challenges of the parents in dealing with disabilities and managing the diversity of their children. The chapter elaborated on parents' experiences with both micro and macro-level social interaction. The practices and services related to care were analysed to see how far such actions were socially constructed and how such social constructions had an intense impact on the social and mental health of the parents. The gendered nature of care and parenting has been highlighted in this chapter. For theoretical grounding, the chapter has employed theories of gender ideology, theories from sociology of care, and feminist theories to understand the everyday realities of these parents in managing and dealing with the disabilities of their children. The chapter attempts to provide an explanation of the challenges that the parents have been experiencing in providing care to their children with disabilities.

The fifth chapter attempted to provide an account of the diverse coping strategies that were adopted by the parents to adapt to their challenging realities concerning disability. The chapter has provided a clearer understanding of the relationship between parents' acquisition of capital (economic, cultural, social, and emotional) and their formation of negative and positive perceptions of disability. To make the empirical findings more theoretically rich and grounded, the chapter has employed Pierre Bourdieu's concept of "field", "habitus", and "capital". The chapter has also provided accounts and stories of change and agency that were exhibited by the parents in managing the diversities of their children.

The sixth and final chapter summarizes the whole research. The chapter has discussed the general findings that were extracted from the narratives and lived experiences shared by the parents during the interviews. The chapter has provided certain research recommendations that could extend the scope of further research in the field relating to disability and care.

## 1.8. Conclusion

The research has contextualized the need for in-depth research about parenting and caregiving, especially for children having intellectual, developmental, and cognitive diversities in India. The aim of the research, thus, was to see how disability has been socially constructed and culturally operated in shaping parents' perceptions; to look into the challenges that the parents had been encountering both at micro and macro societal levels of interaction, and to see whether and how their perceptions towards disability have changed over time and shaped their responses and resistance. To address these questions, a qualitative research paradigm was understood to produce a good research outcome, and to this end, a thorough research methodology was drafted and devised for this research.

Qualitative research is an organized presentation that "describes the experiences and internal feelings" of the people under study (Naderifar, Goli, and Ghaljaie, 2017, p.

01). The study used a qualitatively driven mixed-method research design (QUAL+ quan) to gain a better understanding of the realities of parenting and care for parents who had children with intellectual, developmental, and cognitive diversities. Being driven on qualitative lines, the research had the scope to be flexible in choosing and mixing different methods of sampling and data collection techniques. The research has tried to generate and present rich descriptions from the heaps of non-numerical data to generalize the findings among the given set of samples. The study has employed a partially mixed concurrent dominant status design (Leech and Onwuegbuzie, 2000, p. 268) using the QUAL+ quan model where the qualitative dimensions and methods dominate the entire research process, with quantitative methods being used only as a supplementary backup to ease the presentation of the findings. Employing a mixed-methods design (QUAL+ quan) was found relevant for conducting this research because it could address a range of confirmatory and exploratory questions, engaging stances from the qualitative (QUAL) and quantitative (quan) approaches. 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. The broader theoretical perspectives that have been used to contextualize and ground the research included perspectives from symbolic interactionism, sociology of emotions, sociology of care, feminist perspectives on gender and care, general disability, and critical disability perspectives.

# Chapter - 02

# The Literary Journey of Parenting and Disability

> **“Neither the life of an individual nor the history of a society can be understood without understanding both.”**
>
> **- C. Wright Mills (1959, p. 3 )**

## 2.1. Introduction

There is no single definition of "disability." Disability is a heterogeneous concept drawn from multiple sources of historical trajectories, conceptual conjectures, and theoretical insights. 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. Within academic scholarship, discourse on disability intends to look into disability from multiple disciplinary angles that range from its philosophical and historical roots to medical understanding, psychological explanations, political actions and welfare approaches, and cultural and sociological explanations. I have attempted to explore the understanding and experience of parents in raising children who have developed (at the time of birth or in their formative years of development) intellectual, developmental, and cognitive diversities. To comprehend how parents conceptualized and comprehended disability in general and differences in their children in particular, I have attempted to investigate the mutual reciprocating relationship between existing knowledge on disability and the manner in which this knowledge has been constantly constructed and reconstructed at macro and micro-societal levels of interaction.

## 2.2. Conceptual and Conjectural Journey of Disability

### 2.2. 1. Foucault and the Medical Hegemony

Traditionally, disability has been understood as a “problem” (Titchkosky & Michalko, 2017, p. 127-128) residing within the individual with a disability. The thesis of understanding disability as a “problem” has revolved around the concept of the normal functioning of the body, which refers to the idea that there lies 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. The yardstick which has measured the degree of “normal”[1] and the criteria which have been portraying some people to be “normal” as compared to others based on such yardsticks have mostly been derived from the knowledge of biological sciences. Hence, any kind of disability present within an individual (be it physical or mental, or a result of some kind of failure of the sensory-neuron-motor coordination of the body) which makes the person unable to perform significant functions for survival, should be seen as a given reality for that person, which cannot be altered and for which no one should be held responsible. Conceived in this way, disability has been understood as a "lack of ability" within an individual. To be disabled means a deficit in physical ability compared to most people in society who are considered abled (Barnes, 2016, p. 16); "the lack of which has a substantial impact on daily life" (Barnes, 2016, p. 16). The individual model of disability has encompassed diverse issues, which are reinforced by what Oliver called the personal tragedy theory of disability. Michael Oliver (1990) has talked about the "personal tragedy theory of disability" as the "grand theory" that underpins most of the existing literature and studies on disability. 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”[2] by Illich (1975) (Ghosh, 2016, p. 3).

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[3] and panopticon[4]. 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"[5] (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'[6] in their children. Using existing classifications and categorization scales[7] the medical panopticon separated people/children with disabilities. The medical panopticon and the corresponding dominant discourse that arose from it placed medical professionals in the position of power by virtue of their possession of expert knowledge. Power, according to Foucault (1971, p. 11), has constructed "dominant discourses" in society (Goodley, Hughes & Davis, 2012, p. 198), and it was through the dominant medical model discourse that knowledge in the field was produced and power was bestowed on the structures, institutions, and people associated with the dominant discourse of disability.

### 2.2. 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. Until the 1950s, the medical model of health and disease was not considered a suitable topic to be brought under the umbrella of sociological inquiry. It was in 1951 that the publication of the work 'The Social System' by Talcott Parsons brought health and illness under the critical lens of the sociological inquest (Barnes, Mercer & Shakespeare, 1999, p. 40). Parsons maintained that, for the proper sustenance of society and for the maintenance of social order and stability within that society, all its members must perform the appropriate social roles assigned to and expected from them. Social equilibrium will be maintained within the society if each member of the society plays their own role in accordance with the expected social norms. Maintaining a good health state was described as something that was an appropriate social role for individuals, unlike illness and disease. For Parsons, 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 indicates deviance from those expected sets of norms. Parsons maintained that sickness should be seen as a deviation from the norm of being healthy. Thus, illness is a deviation. And to maintain social stability and equilibrium, the deviations are to be minimized (if not abolished). The need to resolve this deviance made the prescriptions of medical expertise the dominant means of social control. The medical profession has been entitled to maintain social control by managing sickness, which has been considered a form of social deviance (Barnes, Mercer & Shakespeare, 1999).

Though the sick role has provided valuable sociological insight into approaching disability and illness in general, it has come under fire from various quarters, who have questioned the concept's validity when applied to life-long disability, which has less scope for resolution through medical treatments and interventions to return to the "normative" health state. According to C. Wright Mills (1975), the way Parson depicted illness in general and disability in particular as deviance gives medical professionals and experts the ability to exercise social control (Barnes, Mercer and Shakespeare, 1999). By doing this, Parson legitimized institutions that control illness and disability rather than questioning their perceptions and actions. Scholars argue that returning to normalcy through medical interventions is impossible for chronic illnesses and impairments (Safilios-Rothschild, 1970). Parson’s depiction of disability and illness as deviance has been criticized by Ivan Illich (1975), who observed the institutionalization of power in the form of expertise and knowledge in the medical domain. Criticism came from the theorists of the interactionist tradition on the ground that Parson gave more emphasis to the medical professionals in negotiating illness, inclining the power differential more towards the doctors than the patients.

Parents who have disabled children frequently use the medical health care system to treat their children's disabilities. Parents, as active social actors, internalize the expected social norms and, likewise, their attitudes, beliefs, and actions are designed through socialization. Parents who have been socialized to see and observe children in specific ways perceive their disabled children to be out of the norm (as measured against bio-medical normativity standards). Consequently, parents feel that it is their obligation to treat their children and to resolve the disabilities they are born with (or have developed later). According to research, parents favour the medical and health care systems in order to correct their children's disabilities to the greatest extent possible (Bricout, Porterfield, Tracey & Howard, 2004, p.47). Most of these parents, having no experience or knowledge of disability, had very little understanding of how disability interacts with the larger health care structure. Any attempt to understand disability using the medical model requires situating the disability through a series of pathological diagnostic procedures. But this does not hold true in the case of all developmental or intellectual diversities. For instance, developmental disabilities which are caused by certain genetic anomalies (e.g., Down’s syndrome) have the standard medical diagnostic procedure for evaluation and measurement of the extent of the disability, whereas any attempt to diagnose Autism Spectrum Disorder within a clinical set-up may lead to an inappropriate diagnosis because they are noticeable only via observation of the behavioural attributes of the child (Bricout, Porterfield, Tracey & Howard, 2004, p. 49). This is also true for learning disabilities. Many studies have shown that clinical diagnosis does not always predict the functioning of children with developmental diversities (Pelkonen, Marttunen, Pulkkinen, Laipppala, Loennigvist, & Aro, 1998).

### 2.2. 3. The Social Model and the Construction of Disability

Following Berger and Luckmann (1966, p. 149), individuals are "not born as members of society," but it is through the internalization of expected norms and values of sociality that he/she becomes a member of that society. The process of internalization that takes place, rather than is ensured, through socialization, is reflected in the ways an individual comprehends and interprets the reality of which he/she is a part. This reality is presented to an individual with its objective and subjective dimensions. The objective is in the sense that the world is presented to the individual as something that is given, and the individual is required to comprehend this given reality based on the meanings that the world has for them. In doing so, the given objective reality is subjectively understood and apprehended by the individuals depending on the experiences that shape the meaning of their reality. According to Berger and Luckmann (1966), the understanding and perception of reality do not emanate from individuals independently; rather it happens when individuals take over the reality of others and try to comprehend reality from others’ positions in the social world that created the same reality. Parents perceive and comprehend the diversity in their children through the interaction with different stakeholders associated with managing the diversity (state, legal institutions, medical professionals, rehabilitation and intervention centres, researchers, academicians, and children with disability). This produces and constructs meanings related to disability and shapes their objective reality. Parents' constant interaction with this objective reality of disability re-produces and re-constructs the reality, giving it subjective meanings (Connors & Stalker, 2007; Reeve, 2004).

The approach of social construction sees and comprehends reality based upon the socially produced and culturally mediated knowledge available for a given set of realities. Thus, the social constructionist approach sharply does away with the person-centric understanding of disability. The social constructionist perspective looks for the problems within institutionalized practices in shaping and creating disability as a social category. This directs disability literature to look for the possible institutional discrimination that is faced by disabled people. The policies and legislation, which were framed to create an equal opportunity context to bring disabled people into mainstream social networks, were mostly planned and idealized, putting more focus on the individual and social attitudes relating to disabled people. Focusing on the issues from an individual point of view (micro approach) had consciously or unconsciously ignored the way powerful organizations and institutions relating to disability had been operating. As a result, even though the fight for formal equality has been notable and successful to some extent, structures of inherent inequality and stories of disadvantage have persisted (Gregory, 1991, p. 05). The social constructionist perspective views disability as an outcome of the institutionalized practices of contemporary society (Oliver, 1990). The thrust of the social constructionist approach is to show how the "presumed personal inadequacies are socially produced" (Barnes, Mercer and Shakespeare, 1999, p. 94).

The social constructionist approach defends disability as a social construction, produced and reproduced constantly by the cultural flux taking place within the society in question. This approach holds that disability is the result of the social limitations put on people who lack certain abilities (as qualified under existing medical diagnosis and monitoring); that disability is the result of the disadvantages that these people have been undergoing as they lack certain abilities; the result of discrimination they have been facing because they are different from the abled bodies, and the result of social exclusion from the generalized category of normal people.

Disability, understood under the umbrella of the social model, looks at disability as a social creation. It views disability as a construction that is socially produced and culturally reproduced. According to this model of understanding disability, society constructs and produces disability by imposing limitations and restrictions on people with disabilities. Thus, it is the social hindrances and limitations that cause people with not to function to their full potential as per their capacity to function (Hughes & Patterson, 1997; Harris, 2000; Swain & French, 2000). It aims more at exploring how disabling environments, social barriers, and cultural attitudes put limitations on the social functioning of the people with disabilities. The social model works on exploring the barriers produced by wider societal and cultural norms of what is understood as the able functioning of the body and mind, thereby aiming to remove the impediments to the disabled people's participation in their capacities in all segments of life and access to education, work, health services, and legal services, among others.

The social model places the accommodation needs of children with disabilities on the same footing as those of non-disabled children (Ravaud & Stiker, 2001). It placed the institutional, social, and political environments in charge of facilitating and making arrangements for such accommodation needs (Barton & Armstrong, 2001). The social model, therefore, requires parents' full participation and cooperation from service providers (institutional, social, and political) to form an integrated approach to serving the needs of each child and to intervene with their specific disability requirements.

The social model of disability faces criticism for its lack of including an intersectional understanding of the reality relating to the lives and experiences of disabled people. The social model approach has inadequately explained the life experiences of disabled people from diverse social positions like race, gender, sex, age, etc. While identifying social oppression as one of the major disabling traits that limit disabled people's full functioning and participation in diverse social roles, the model fails to recognize the source of multiple oppressions and the consequences that disabled people face. According to Bricout (2004), while the social model of disability explained the micro-level (individual) encounters of people with disabilities with their given social reality and the medical model had a more general focus on the more macro-level understanding of the limitations, none of them (social and medical models) have extended their reflections over meso-level encounters. Explaining disability reality from a meso-level perspective requires the inclusion of physiological (physical functional dimension), psychological (mind and emotional functional dimension), and sociological (social, cultural, and economic dimension) accounts in an all-inclusive manner in order to understand the reality of disability for these people and their families.

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

The emergence of disability studies from the 1980s onwards as an interdisciplinary field of inquiry has attracted different social, political, economic, and cultural perspectives to explore and explain disability in their own terms. The significance of culture as an explanatory tool to understand disability has gained a considerable amount of emphasis in recent years, particularly within American and Canadian disability studies (Goodley, 2016, p. 14). Sociologist Tom Shakespeare (1994) has claimed that "disabled people are objectified by cultural representations" (p. 283). Rosemary Garland Thomson (2002, p. 02) appealed for "understanding disabilities as a category of analysis and knowledge, as a cultural trope, and as a historical community." The cultural model of disability leaves room to understand disability as a "site of resistance and a source of cultural agency" that was put to suppression earlier (Snyder and Mitchell, 2006, p. 10).

Waldschmidt (2018, p. 75) has carved out four pillars over which the cultural model of disability was understood. In the first place, he argued that the cultural model understands disability, impairment, and normalcy as conceptual categories generated by academic, mass media, and everyday life interactions, resulting in shared understandings and beliefs about disability and impairment among the general public. We would later see that the understanding of disability that parents hold about their disabled children is mostly drawn from such discursive processes. Secondly, under the lens of this model, disability is to be understood as a category of human differentiation that represents itself in embodied and materialized forms. Thus, disability exists only when specific embodied and bodily differences can be differentiated within a given cultural and historical reality. Thirdly, this model holds that both disability and ability are connected with the existing symbolic orders, bodily practices, and social institutions, which together give birth to the binary frameworks between "normality and deviance, self and the other, and familiarity and alterity" (Waldschmidt, 2018, p. 75). Disability understanding weaved in such a manner gives scope to investigate the lived experiences of disabled individuals within the cultural context and to compare them to those who are non-disabled. The cultural model of disability questions the taken-for-granted ideology of understanding the normative. It recognizes how the practice of normalization yields the social-cultural category of disability.

The way the cultural model has contributed to the contemporary understanding of disability has been reflected well in the manner in which parents grasp diversity in their children. The binary between "normality and deviance, self and the other, and familiarity and alterity" shapes the perception of diversities their children have (Waldschmidt, 2018, p. 75). Empirical observations on the same have been documented well in the following chapters. However, the extent to which this has been implemented in reality and is practised to date calls for further research. However, the empirical observations as a part of this thesis will be discussed in the findings.

The transactional and relational model provides a framework to understand the interpersonal, familial, and organizational factors and their influence on the experience of disability for the child, his/her parents, and their extended familial relationships and, other support systems (Llewellyn & Hogan, 2000). Seeing disability from a transactional perspective enables us to examine how a non-supportive and non-cooperative environment creates and reproduces disability. The transactional and relational model take 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 disability (Ferguson, 2001). This model is capable enough to reflect upon the reciprocal responses resulting from the interactions between the child and his or her parents. This model also allows us to understand how such reciprocal responses shape children's and parents' experiences of disability when they enter school (Bricout, Porterfield, Tracey, and Howard, 2004, p. 52).

**Table No.2.1: Models of Disability**

| | **Minority model of disability<br>(USA and Canada)<br>1990-1975** | **Social barriers model of disability<br>(UK)<br>After world war II** | **Cultural constructionist model of disability<br>(Canada)<br>From 1980's** | **Relational model of disability<br>(Nordic Countries)<br>From 1980's** |
|---|---|---|---|---|
| **Meaning** | People with disabilities have minority status in society | Disability is a social construction; it is created. People with disabilities are disabled by society. | Disability is a cultural construction. It is reproduced by culture and the existing modes of production in a society. | Disability is created through – (i) the person-environment mis/match; (ii) situation and (iii) interaction |
| **Goals of intervention** | Increased accessibility of places and services; development of centres for Independent Living; Promote positive sense of disabled self. | Increased accessibility of places and services; broad systemic change; development of centres for Independent Living; disability arts. Promote positive sense of disabled self. | Destabilize cultural performances of dis/ability and ab/normality; promotion of disability arts and subculture | Increased accessibility of places and services; broad systemic normalisation and inclusive community living; an ordinary life. |
| **Benefits of model** | Promotes integration of disability into self. Focus on how world disadvantages PWD. Sense of belonging and involvement in a disability community. | Promotes integration of disability into self. Clear distinction between social barriers and impairment. | Sense of belonging and involvement in a disability community;; promotion of critical faculties in relation to the normate culture. | Sense of belonging and involvement in a disability community; Promotion of self-advocacy. |

**Source: Modified and adopted from "Disability Studies: An Interdisciplinary Introduction" by Goodley, 2016, pp.7-14**

The Nordic countries have clearly felt the interdisciplinary approach to disability studies (Thomas, 2007, p. 7). Disability researchers like "Bjarnason (2002, 2004), Tøssebro (2002, 2004), Gustavsson (2004), Kristiansen and Traustadóttir (2004), Traustadóttir (2004a, 2006a), Kristiansen, et al. (2008), and Björnsdóttir (2009) from Denmark, Finland, Iceland, Norway, and Sweden" are eminent scholars in the development of the Nordic relational model of disability (Goodley, 2016).

According to Thomas (2007) and Goodley (2011), North American, Canadian, Australian, and Nordic disability studies are more interdisciplinary in their theoretical and conceptual approaches to contextualizing disability in comparison to their British counterparts. Disability scholars from the U.S. are more in favour of a minority model of disability, whereas scholars from the UK tend to include the minority theory within the broad umbrella of the social model perspective. But there is no denying the fact that both these approaches have highlighted the position and role of society in contextualizing and explaining disability. Even in the following years, the appearance of the Nordic relational model and the cultural model of disability from Canada and the USA were all integrated towards situating disability in relation to society, culture, norms, values, and structures (Goodley, 2016, p. 20). With the passing years, disability discourse has witnessed shifts in the way disability is understood. Situating the experiences and understanding of disability within the social-cultural-relational model of disability paved the way for the formulation of different policies, legislation, and the consequent services by different national and international governments. This is well reflected in the shift in policies from welfare and rehabilitation towards a more rights-based perspective.

## 2.3. Parenting and Disability: Global Reflections

### 2.3. 1. Juxtaposition of the Medical and Social Model

Rapp (2000) has pointed out that while parents share and consider the prevalence of the medical approach, they additionally engage themselves in redefining the standards of normality in relation to their child’s capabilities and progress. Rapp calls this “doubled discourse of both diversity and normalization” (Skinner & Weisner, 2007), which begins from its conception as a taken for granted reality emanating from and residing within the individual (medical model) to its comprehension as a social-cultural creation (social model and cultural model) that has resulted from the limited social, cultural, economic, political, and environmental barriers upon the physical, developmental, or intellectual diversities of the individual. The way parents perceive and comprehend their children’s differences is heavily influenced by hegemonic medical knowledge on disability, which is defined as a deviation from what is considered the general standards of body and mind functioning. Thus, for parents, medical explanation and intervention (if not permanent cure) are believed to be the only ways that they can manage the diversity within their children. In a research conducted by Landsman (1998) on sixty mothers of children with cognitive and developmental delays, it was observed that in the initial periods of treatments and medical procedures of diagnosis, the medical model of disability was the dominant approach on which parents relied to perceive the diversity within their child. The social model of disability provides another perspective for parents to understand their children's diversity and become aware of the social, cultural, economic, and political limitations of this diversity. Parents, who acknowledged the prevalence of the social model, tended to counter the medical models of normality and did not choose to put their children into the assessment against those given standards of normality. These parents felt that the child’s personhood was diminished when they were compared with a regular child with their disorder or disability (Skinner & Weisner, 2007).

The change in the paradigm of the disability discourse towards a social-constructionist perspective began to comprehend disability from perspectives based on social oppression and deprivation, exclusion and stigma, marginalization, and so forth, situating disability in society, culture, norms, values, and structures. Increasing reinforcements on the objectives of welfare provisions through parents' (caregivers within the family) mobilization attracted academic scholars, health workers, social workers, and policymakers to highlight the importance of parents as the primary caregivers of people and children with intellectual disabilities (Twigg & Atkin, 1994). Recent policies regarding children with intellectual and developmental disabilities have begun to recognize parents both as providers and consumers of care services.

### 2.3. 2. Interface of Self, Emotion and Identity: Symbolic Interactionist Perspective

Emotion as a social category and as an important component of sociological inquiry, covering different social theories and understandings of justice, inequality, movements, power, and status, has received its due recognition since the 1980s. Emotions play a central role in everyday interaction—directing individual actions and behaviors, shaping agency, and contributing to the development and regulation of self, according to the norms of society. The theoretical foundations of the sociology of emotions owe much to the theoretical underpinnings of the interactionist point of view. It directs us to understand how individual emotional expressions are both embedded within and point to specific meanings. It also helps us to understand how these meanings are reflected and reproduced in others' responses in a given social context in which the interaction has been conducted (Stets & Trettevik, 2014). C.H. Cooley's (1902) concept of the "looking-glass self" helped us to conceptualize how individuals 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. According to Cooley (1902), each individual responds to what others think of them, and this response is definitely an emotional one (Stets & Trettevik, 2014). Thus, one's self is evaluated in relation to others' standards of a norm in particular, and to the larger socio-cultural construct of normativity in general. Self-evaluation at the micro and macro levels of interaction becomes an important tool for identity formation among people in a given society. From the angle of identity theory, emotion (at the macro-societal and micro-interactional level) operates the actions and behaviours of individuals. The socio-cultural mechanism by which individuals put themselves under the normative appraisal of others is heavily driven by emotion. Consequently, individuals in a specific socio-cultural setting, guided by specific moral codes, view themselves as either meeting the role expectations attached to a particular identity (considering that individuals possess multiple identities) in a specific setting or they find themselves as deviating from the constructed normative. Parents of children with disabilities in their daily interaction with the wider social reality develop meanings out of those interactions about disability, both for themselves as well as for their children. This not only leads them to perceive the interplay between disability (from a medical angle of deviance) and diversity (from a socio-cultural angle of acceptance of diversity), but also shapes their understanding of self.

Burke & Stets (2009) have observed that when individuals meet the expected social roles and identities, it generates an emotional response of prominence in contrast to the emotional response of salience when they assess themselves to have failed in meeting the socio-cultural standard related to their identity and role. Turner & Stets (2006) have defined moral codes as values that guide individuals in the dichotomy between good and bad; right and wrong; proper and improper; and so forth. At the micro-level, interactions among individuals are steered by these moral codes in the form of "norms" (Turner & Stets 2006, p. 556). Any deviation from the norm, which is also related to role expectations, causes emotional arousal. Hence, emotional arousal can be seen as a response to deviation from role expectations concerning the socio-cultural codes of normativity. It can thus be inferred that the emotional response of an individual is a reflection of the socio-cultural construct that remains embedded within the wider social, cultural, economic, and political structures, institutions, and organizations that the individual encounters.

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 are 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. However, it is through the interaction of the parents (having children with diversity) both at the macro (interaction with the larger societal structures and institutions) and micro-level (other family members, friends, relatives, and other acquaintances and associates), that they gradually develop an identity which repeatedly reminds them of the difference between what is normative and what is not. Depending on the severity of the disability and other socio-cultural factors, parents may gradually develop negative feelings about their identity as parents of disabled children (Barnett, Clements, Kaplan-Estrin & Fialka, 2003; Benderix, Nordström & Sivberg, 2006). However, this feeling of negativity within parents stems from negative attitudes and perceptions generated during interactions with generalized others, which are frequently accompanied by feelings of sympathy (Alaee et al., 2015; Broomhead, 2019). In such instances, parents withdraw themselves from entering into interactions that generate negative emotions within them, directing them towards the chronic stress of isolation. Parents tend to withdraw from social networks, which arouse negative emotions in them. This further marginalizes both parents and their children, to the point of being socially excluded from the mainstream social structures and institutions. This has been found to contribute to the engendering of feelings of stigma within parents (Benderix, Nordström & Sivberg, 2006; Alaee et al., 2015).

Turner (2006) has discussed two prerequisites that initiate emotional arousal within individuals—expectations and sanctions. Individuals relate their actions, attitudes, and behaviours to certain expectations of how those actions and attitudes are evaluated by others. When these expectations converge with reality, individuals experience positive sanctions. Contrary encounters of expectations with reality, on the other hand, result in negative sanctions (Clay-Warner & Robinsons, 2011). However, the positive or negative sanctions do not always hit the individuals overtly. Sometimes the challenge emanates from the norms and moral codes with which the individual identifies his or her identity. Stryker (1987, p. 60) has viewed identity as an “internalized positional designation” that individuals hold within society. Individuals internalize the expected roles against the different identities they possess. Shared expectations and meanings common to a particular socio-cultural context are connected to the social roles of individuals. These role expectations are internalized by the individuals as role identities. Every individual holds multiple identities, and each of these identities is related to certain role expectations. Thus, an individual performs multiple roles in society and, as such, carries multiple identities. In any instance where negative emotions are generated by a specific identity of an individual, multiple identities act as a resource to adapt to the feelings of negativity. In such cases, individuals “can switch to another identity” (Stets & Trettevik, 2014, p. 37) for emotional reward. The research has tried to generate such an understanding for parents who have children with disabilities. The goal of the study was to discover if and how parents may swap identities while associating their status as parents of disabled children with positive or negative feelings.

### 2.3. 3. Management of Emotions in Parenting

As Arlie Hochschild (1979) believes, feelings and emotions are "deeply social" (p. 555). Thus, the appropriateness of any emotional expression is appraised by certain accepted socio-cultural standards of how a person should feel in a given situation or context, which have been termed as “feeling rules”[8]. The person who is experiencing the emotion engages himself/herself in managing the emotions he/she should show, keeping in tune with the “feeling rules” of the context given. The feeling rules are guided by a certain ideological framework called “framing rules”[9], which guides how a person should feel in a context. Thus, in a given situation, the emotional expression of a person is guided by feeling rules, which are backed by framing rules, based on which the person manages his/her actual feelings and displays emotions. This kind of emotional management has been termed as “emotion work”[10]. The effort that a person puts into managing his or her emotions is called emotion work. The concepts of “feeling rule”, “framing rule”, and “emotion work” have been used in this research to understand the emotional responses of parents to the reality of their children being detected with disabilities. These concepts have been employed to see whether and to what extent such emotional responses and activities, driven by emotions, are gendered. Thus, an emotional culture[11], backed up by framing rules, produces a gendered culture within which men and women are expected to display different kinds of emotional work in providing care-work for their children. 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. Management of emotions has also been found to be an important factor in understanding the work-family interface for parents (MacDermid, 2005). Hochschild's (1989) work on gender and emotions has highlighted the areas where the framing 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. Affiliation to gender ideology has been considered an important factor that might have influenced the feeling rules the parents see fit for a given situation. The concept of feeling rules has been used to see whether mothers appreciate or discourage fathers' share both in caregiving and household work. The concept has aided the research in determining whether fathers' contributions to care and chores are regarded as primary need or secondary assistance for mothers. Studies have shown that, while mothers support and advocate for the idea of "involved fatherhood", in reality, fathers turn out to become the "junior partner", the "everlasting trainee" or the "guilty student" (Behnke & Meuser 2012, p. 131) for mothers who prefer to take charge of care.

Aside from the gendered nature of emotional display and responses to situations and context, Hochschild's concepts on emotion have been used to comprehend the encounter between medical professionals and parents of disabled children. Many studies have shown that medical encounters often involve emotion management by medical professionals displaying "affective neutrality" to avoid unwanted emotions (Smith & Kleinman, 1989; Francis, 2006).

## 2.4. Parenting and Care Giving: Global Approaches

### 2.4. 1. Care and Context of Parenting

Caregiving can broadly be understood as a disposition toward activities that are directed toward the fulfilment of others' needs (Tronto, 1994). Care, caregiving, and care-work for children have been understood as a domain that is specific to women/mothers. 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). From a feminist angle, caring does not just mean performing the mundane tasks related to care but signifies something which is characterized by emotion, intimacy, and affectivity for the people or things toward whom the care has been extended. 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. According to Hochschild (1989), women who are employed in the paid job sector may affiliate with the traditional gender ideology and may prioritize child-care and housework more as compared to their role as employees. On the other hand, a homemaker mother who subscribes to egalitarian ideology believes that being employed would add to her multiple roles and would want her husband to equally take part in managing care and household chores. Similarly, fathers, who are affiliated with traditional gender ideology, may find their job commitment to be their sole responsibility as the "man of the house" and may find their wives' employment status to be secondary to their primary role as caregivers and domestic chore managers. Fathers, who subscribe to the egalitarian ideology, however, may look at caregiving and household chores as being equally contributed to by all members of the family, including him. Parents, who adopt transitional ideology, lie somewhere in between traditional and egalitarian gender ideology. According to Hochschild's (1989) study, men remain more inclined to follow the traditional gender ideology, while for women it is the egalitarian ideology on which they hold their gender ideological affiliation (p. 196–197). Several studies on parenting children with disabilities have shown that fathers adopt traditional gender roles in terms of caregiving and housework (Lewis & Kagan, 2000; Gray, 2003).

There is no denying the fact that several research reports, papers, and academic literature that focus on fatherhood and masculinity are available. However, very few studies have attempted to present a link between the two concerning caregiving. The study on masculinities has hardly reflected on care, caregiving, and care-work activities by fathers. In fact, 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). Thus, masculinity and fatherhood remained discrete areas of research until the last decade. Some of the most recent sociological works 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). According to Ruby and Scholz (2018), while fatherhood has received secondary significance (if at all) in understanding masculinity constructions, motherhood has gained a central and significant position in femininity constructions (p. 78). "Caring for children is thus coded as feminine" (Ruby & Scholz, 2018, P. 78). To this end, Karla Elliott (2016) has urged us to provide a more intense and insightful theorization of caring masculinities. By "caring masculinities", Elliot (2016) refers to those masculine identities in her works 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. The "Generative fathering"[12] framework (Erikson, 1950; Dollahite & Hawkins, 1997) has been employed in the research to understand fathers' contributions to care. While earlier studies (the 1940s–1970s) have focused on 'inadequate' or 'absent' fathering, lists of current research are not rare that have conceptualized generative fathering perspective as a father’s strength and capacities in caring for and raising their children with disabilities (Mitchell & Lashewicz, 2018).

Parents’ contribution to care comes under the general purview of unpaid care-work performed towards their children. Research has shown that “norms, rules, and internalized cognitive frameworks”, which are exercised within the familial institution, have a huge impact on the patterns of unpaid care along gendered lines “despite social forces that could un-gender care” (Oliker, 2011, p. 971). Moreover, individual ideological beliefs and resources (to be understood using Bourdieu's concept of capital and emotional capital) have been found to be closely related to the way parents articulate with a "deeply institutionalized cultural schema" of the reality in which they are a part of (Oliker, 2011, p. 972-974). Thus, to understand parents' context and responses to care and agency, Pierre Bourdieu’s concepts “field”, “habitus” and “capital” have been engaged in this research.

### 2.4. 2. Reality, Resource and Response in Parenting

Pierre Bourdieu’s concept of "habitus" 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. Bourdieu defined habitus as a “structured and structuring structure” (1994, p. 170). It is “structured” through the past and present circumstances of individuals by means of the different forms of socialization one receives through interaction with diverse social institutions like family, education, health, polity, etc. At the same time, it is “structuring” because it shapes one’s present and future dispositions and practices. The habitus, in conjunction with the capital, which an individual possesses within a specific field, gives rise to practice. Following Bourdieu (1986, p. 101), this can be summarized as:

$$\mathbf{[(Habitus)\ (Capital)] + Field = Practice}$$

Thus, “practice results from relations between one’s dispositions (habitus) and one’s position in a field (capital), within the current state of play of that social arena (field)” (Grenfell, 2008, p. 51). 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 to expression of their agency. The concepts of "field", "capital", and "habitus" have also been employed to explain the positions and actions of medical professionals, which are often contradicted by the positions and actions undertaken by the parents of children with disabilities. Studies have reflected that the attitudes, evaluations of the situation, and interaction patterns adopted by the medical professionals related to managing disability in children often counteract those of the parents (Case, 2000; Carona et al., 2013; Ryan & Quinlan, 2018). The engagement of Bourdieu's concept of "field", "capital", and "habitus" has made the explanation of such relations between medical professionals and parents of children with disability more lucid.

### 2.4. 3. Parental Response to Disability

Sociological studies on emotion can be extended to understand the relationship between parents' experience of raising their children with diversity and the socioeconomic profile they are located within. Simon (2014, p. 437) has argued that the emotional well-being of individuals is related to the different social-economic statuses they are located within, and he proposed the idea of "exposure hypotheses" and "vulnerability hypotheses". Both of these hypotheses suggest 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, at least demographically. The experience of intense emotional distress reinforces negative emotions within them, which further exposes them to developing chronic stress. The more an individual is placed low in the social hierarchy, the greater the intensity of stress they are exposed to. The possible causes of this stress emanate from the nature of employment of the individual; patterns of family structures and roles performed within the family, accessibility to social network resources; and the quality of social relationships available. Several studies have shown that individuals with lower educational qualifications and income have less accessibility to or capacity to avail of psycho-social resources, exposing them to higher levels of emotional rigor (Simon, 2014, p. 437). However, it is not uncommon for studies to show that receiving assistance and maintaining quality relationships with different coping resources and social support networks help parents reduce the extent of emotional distress experienced by them (Simon, 2014). Freedman and Boyer (2000) have claimed that, in addition to the direct impact on the physical and mental health of the parents, they also encounter challenges associated with inadequate financial support, insufficient social support from family and friends, or unsatisfactory assistance from various social support agencies and organizations, in dealing with their children's diversity.

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. Literature on parenting children with disabilities has confirmed greater stress among parents with a number of challenges, driving them towards greater health complications, feelings of restriction, and a higher level of depression (Quine & Paul, 1985; Roach et al., 1999; Valentine et al., 1998).

While it is necessary to understand and analyze the hardships and difficulties parents do undergo, at the same time, it is important to look into the positive familial resources that assist in maintaining family functioning, mutual bonding, and support among the members with a positive emotional atmosphere (Kandel & Merrick, 2007). Parents tend to experience higher emotional burdens and fatigue due to the everyday challenges they have to encounter in raising their children with disabilities and sometimes difficult needs. While talking about the coping strategies, the “role strain”[13] experienced by the parents remained to be a significant finding. Role strain is defined by Kandel and Merrick (2007, p. 1805) as “a condition that reflects how parents evaluate their level of stress regarding their role as parents”. It is argued that these challenges or strains are often accompanied by the social expectations of the "normative consensual commitment" of the parents, and also by the "integration among the norms" held by those parents (Goode, 1960, p. 483-496).

Stryker (2004) theorizes that individuals who are capable of sharing affective meanings are more likely to form and maintain social networks and relationships with others. Emotions impact the extent to which social networks are created by individuals. When individuals receive sanctions, or when their roles, actions, and behaviours are recognized by the members of the network, positive feelings are generated within the individual, resulting in a positive emotional identity. The generation of positive identity motivates individuals to further cultivate the social relationships based on that identity and create or develop more social networks. But, in instances where individuals develop a negative emotional identity due to the non-recognition of their roles and actions by the members of a social network or group, it is more likely that these individuals with negative emotions will be discouraged from developing social networks. In these instances, where the individual identity encounters a negative emotion, different coping strategies are adopted to adapt to the feeling of negativity. Individual strategies differ depending on their demographic location within society. Individuals who can alter their way of thinking about the situation prefer cognitive coping strategies. Others, on the other hand, use behavioural coping strategies to change their behaviour in those situations (Stets & Trettevik, 2014).

The presence of social support was found to be an important component for parents of children with intellectual disabilities in adapting to the stressful periods and phases of the crisis. Studies on disability indicate that parents seek the assistance of diverse social support mechanisms as a buffer against stress and to improve their self-competence in catering to the special needs of their children in a more skillful manner (Cuzzocrea, Larcan, Costa, & Gazzano, 2014; Cuzzocrea, Larcan & Oliva, 2008). Much of the research supported the use of social support as an influencing element for families having children with developmental disabilities. For them, receiving support from spouses and friends has helped in enhancing their perception of satisfaction with family functioning (Jones & Passey, 2004; White & Hastings, 2004). However, a few studies in the field have confirmed the insufficiency (if not inability) of the professional support services to cater to the specific needs of the families, thereby multiplying the source of stress for the parents (Jones & Passey, 2004; White & Hastings, 2004).

## 2.5. Parenting and Stigma

### 2.5. 1. Conceptualizing Stigma

For Erving Goffman (1963a, p. 04), stigma should be understood as "societal reactions to abominations of the body". He argued that stigma bears and generates a sign of diversity between individuals, which he preferred to call an attribute. Goffman defines stigma as the result of social construction. The mark of diversity generates a perception of stigma within the individuals who bear the mark of diversity, and it also diffuses among those who are associated with the individuals who feel stigmatized. The perception of stigma by the stigmatized individuals and their associates is expressed and exercised by the individuals who do not bear any mark of diversity (whom Goffman called "normal"). The experience of stigma and stigmatization mainly occurs in any kind of interaction situation that takes place both at the level of structure and institutions and at the micro-level of individual face-to-face encounters. Following Goffman’s theory of stigma and diversity, Titchkosky (2000) made a distinction between desired and undesired differentness. She claimed that the different attributes possessed by people and their different natures of behaviour and appearance, which pass through the yardstick of what is considered "normal" or "normative" by the wider socio-cultural context (within which the interactions are happening), are accepted as desired diversities. In contrast, the attitudes, behaviors, appearances, and actions that do not qualify under the standards of already defined rules of being "normal" are evaluated as non-desired diversities. People possess multiple attributes. The social context in which the interactions take place heavily influences which attributes are considered desirable and which are stigmatized.

### 2.5. 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, p. 204). Normalcy thus understood is an unmarked site of diversity, which enables individuals with desired diversities to view disability as an undesired diversity. People with disabilities (diversities) are perceived to possess diversities that bear stigmatizing attributes based on their undesired diversities. Goffman sought to extend the concept of a primal scene[14] in understanding human interactions between the “normals” and the “stigmatized”. He has prescribed to reflect such understanding on how individuals form their conception of social identity and diversity and perceives themselves accordingly. 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).

Barbarin (1986) has observed that getting rejected or ignored in social interaction situations does not only stigmatize the individuals who are being ignored (because they possess socio-culturally accepted unexpected and undesired diversities in behaviors, actions, and attributes) but also excludes the people (from social participation in those interactions) who are associated with these individuals. As a consequence, stigmatized individuals are compelled to limit their social participation and choose to seclude themselves from social relationships that have recognized them to possess undesired attributes. In doing so, the feeling of stigmatization gets extended and diffused within people who are closely associated with the stigmatized individuals, like family. Likewise, the stigma attached to the diversity among the parents of the children gets extended and diffused among the parents and other care providers (other family members or friends) of the children. 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. Hence, social rejection acts as a form of social control (Edgerton, 1967; Goffman, 1963a; Schur & Deviant, 1983; Barbarin, 1986). This kind of rejection or exclusion is most dangerous and difficult for children who are perceived by their peers to possess attributes of undesirability, and therefore, is restricted from participating in social activities (Barbarin, 1986). This is well articulated for parents of children with disabilities. 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 (Sayce, 1998; Clarke, 2014). The parents have the least amount of interaction with their immediate extended family members and friends who are comfortable with their identity and activity as parents of a disabled child, and with whom interaction has fewer chances of generating negative attribution to their identity associated with disability. Birenbaum's (1970, p. 197) has found that parents of children with disabilities restrict socializing with those individuals and relationships where feelings of consideration or sympathy are expressed.

### 2.5. 3. Encounter and Experience of Stigma

Many researchers have found that families with disabled children experience “courtesy stigma”[15] whereby the family members are stigmatized, or that they have perceived 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; Voysey 1972; Scambler & Hopkins, 1986). Birenbaum (1970, p. 196) has regarded these family members as “normal yet different”. The family members related to the disabled people are identified as the “wise” (Goffman 1963a; Birenbaum 1970; Voysey 1972). Thus, the “wise” are those people who do not possess any stigmatizing attributes, but due to close association and affiliation with the stigmatized individuals, develop insights into their challenges and experiences offering them assistance, service, and care they need. Goffman (1963a) constructed a distinction between “the discredited”- when the stigmatized attributes are apparent - and “the discreditable”[16]- when attributes containing stigmatizing features are not so apparent or invisible. The parents of children with disabilities fall in the latter category in which though they themselves do not possess any characteristics that can be negatively attributed, but still they are stigmatized because they are associated with their disabled children. In these instances, it is the parent-identity of the individuals that are related to negative attribution and stigmatization. Thus, parents who have children with disabilities are identified as “discreditable”.

Parents often experience stigma in most public encounters. Scambler and Hopkins (1986) presented a distinction between “perceived stigma” and “enacted stigma”. When individuals perceive themselves to be stigmatized and evaluate themselves by the standards by which others might assess them, then the individuals will have a perceived stigma about them. Whereas, enacted stigma persists when the undesired attributes, behaviors, actions, and attitudes of the individual are witnessed by others in a group or interaction situation (Gray, 2002, p. 737). During diverse forms of interactions - that parents indulge in different points of time, in different situations within different groups or institutions - the parents perceive stigma that emanates from these interactions via different means, like not getting invited to social gatherings or not getting any or excessive sympathy from people in social and public spaces. The felt stigma often causes parents to isolate and restrict themselves from maintaining different social networks and relationships, creating further conditions that bar the parents from full participation in social networks and interactions. Non-participation in larger social networks and institutions makes parents feel excluded and discriminated against, resulting in parental enactment of stigma. However, it is significant to note that the felt stigma among parents itself was a product of wider socio-cultural constrictions that underpin the distinction between desired and undesired attributes, which are constantly reproduced through interactions that parents might have entered into. Thus, felt stigma should not be comprehended as a result of a personal construction of reality but as a product of social and cultural constructions produced and reinforced by wider cultural norms of the normative and reproduced through social interactions.

Link and Phelan (2001) mentioned that stigma possesses five inherent components: labelling, stereotyping, separation, status loss, and discrimination, each of which exhibits power differentials to a certain extent. Labelling refers to the identification of diversities and maintaining social salience over those diversities. Stereotyping occurs with the delegation of negative attributes to the socially salient diversities that are socially accepted to be undesirable. Separation results from the felt stigma of the stigmatized individuals, instilling a sense of differentiation from others. Status loss and discrimination happen when the individual's felt stigma limits him or her from full participation in their socio-economic life and community. It is important to note that when individuals lose their status and experience consequent discrimination, they also undergo a sense of enacted stigma around them (Green, Davis, Karshmer, Marsh & Straight, 2005). In the disability context, the parents of children with disabilities possess all the five components of stigma: whereby their children are labelled based on the social recognition of diversity from the biological norm; followed by stereotyping the diversity, which associates negative attributes with their children's diversity, extending the feelings of negativity towards the parents of these children; which is again followed by a feeling of separation from the wider social networks and relationships that generate negative feelings towards the children with disability and a feeling of stigmatization for the parents. The feelings of labelling, stereotyping, and separation drive the parents towards further experiencing feelings of status loss and discrimination, which result in their exclusion and marginalization.

### 2.5. 4. Response to Stigma and Development of Agency

Sociological and social theories on disability discourse have seen a shift from a 'deficit within the child' approach to an understanding of the disability within children in relation to the familial and social support system. In the early 1980s, "parents as partners" (O'Toole, 1987) became a popular slogan both in the disability research discourse on childhood disability and within the welfare services meant for these children. In both of these sectors working on childhood disability, parents' participation and active involvement in the education and care of children gained prominence. However, it failed on many grounds, and the voices of parents questioning it on diverse issues were prominent. Amongst other issues, parents have pointed to the existence of a power differential that was inclined towards states' control of services and professional hegemony of medical knowledge and expertise, thus leaving limited space for parents' advocacy (Panitch, 2012).

Interactionist theorists extended their sociological inquiry to look into the ways individuals utilize their capacity for agency to make their belief systems, actions, and hence feelings in tune with socially and culturally expected individual actions and behaviors. Hochschild (1979) maintained that individuals work on their feelings in their full capacity to respond to a situation. This response, to a large extent, is determined by what she called "feeling rules" (explained above). She defined feeling rules as cultural norms that guide how an individual should feel in a specific situation. She tried to convey that cultural norms and the human capacity to react in situations together arouse emotions within individuals (Stets & Turner, 2006). Understanding disability discourse and studying parents' lived experiences in raising children with disability through an interactionist perspective places individuals (parents, for this research) at the center of such discourse. Every individual as a parent is seen as an actor, having a self and possessing the ability to respond reflexively.

Rosalyn Benjamin Darling (1988), in her study on parental activism, argues that parents of children with disabilities, who view professional services and knowledge to be non-functional and non-productive for their children, and for whom the existing social networks are non-effective in coping with their daily life challenges, often resort to entrepreneurial paths as a way of empowerment both for themselves and for their children. Darling (1988) argued that instead of relying on the existing social networks and relationships, parents chose to form or join activist networks to voice their children's needs. Most of these activist campaigns comprise programmes that include: acting as pressure groups to develop policies and services for the different needs of these children; organizing awareness and sensitization programmes to popularize and mainstream the disabilities within children as diversities; building strong networks between parents who have children with such diversities, and arranging for a social network support system for the parents who would need that at times of crisis.

Sociologist Dennis Hogan (2012) observed that most of the policies are framed in favour of the deinstitutionalization of care for children with intellectual and developmental disabilities. This shifts the responsibility (if not the burden) of care work from concerned institutions to families without making adequate (if any) arrangements for support that these families might need to encounter the challenge of the special care work needed for their children. He argued that these parents are expected to perform multiple roles as doctors, nurses, therapists, educators, and advocates, along with the central role of being parents of their children. This requires parents to possess a good number of resources at their disposal, which Hogan prefers to call social capital. Parents with less social capital will lag behind parents with more resources when it comes to bargaining for services and rights for their children (Ferri & Connor, 2006; Ong-Dean, 2009). To understand this clearly for parents with disabled children, the research has engaged Pierre Bourdieu’s theory of “capital”, “field”, and “habitus”.

Research has shown parents claiming that plans and programmes designed for children with intellectual and developmental disabilities are not adequate to meet the diverse needs of their children; they are not sufficient to ensure that the support will still be there to combat the life-long challenge, both for them and their children (Webster et al., 2017, p. 185). Tincani et al. (2014) have suggested that parents' advocacy has played a critical role in ensuring proper interventions for their children having ASD, particularly in school settings. For parents, such advocacies are important to create compulsion upon the school authorities and other concerned stakeholders involved in policymaking to provide the required provisions and interventions to which they are entitled to. In their study of 36 mothers who have children with Autism Spectrum Disorder, Ryan and Cole (2009, p. 42) discovered that advocacy and activism are experienced differently and individually by the mothers, with many of them taking on the role of activist. Consequently, parents become agencies to mobilize policies and programmes not just for their children but for all the children who are experiencing diversity (Webster et al., 2017, p. 185).

Webster, Cumming, and Rowland (2017) mentioned that to become the voice for their children's special and diverse needs both in schools and outside, parents need to possess a good part of the knowledge of how the education system functions and how policies are made and implemented. Such advocacy requires parents to develop a clear path for thorough interaction with the teachers, administrators, and other concerned authorities above to make provisions for special education accessible to their child. Acting as agents also requires the parents to have adequate financial resources and social contacts at their disposal (social support systems like family, friends, neighbors, or community, and professional services). The level and intensity of parents' advocacy depends not just on time and resources but also upon the emotional resources and resilience they show they can express in dealing with their challenges. Parents' agency and their capacity to advocate have helped them to ensure their children's access to different support services and also to access equal and similar opportunities as their peers (Webster, Cumming & Rowland, 2017, p. 191).

Chang Heng Hao (2009) conducted a study with members of the Parents Association for Persons with Intellectual Disabilities (PAPID)[17], to determine the meanings of activism that those parents associated with the disability rights movement. The study shows that the disability stigma has a good impact on the family, especially mothers who carry the stigma associated with the disability of their children. Secondly, it was observed that the participants of the disability rights movement were mostly mothers of intellectually disabled children who not only advocated for their child’s welfare but also confronted the social stigma attached to disability and renegotiated their gender roles. It was noticed that this "association has become an important public space for these mothers, to escape home confinement and enjoy civic life" (Heng-Hao, 2009, p. 34). It was noticed that this association had turned out to be an important space for these mothers who could take part in the public civic life outside of their home confinement without being limited only to their role of caregiving (Hao, 2009, p. 34).

## 2.6. Recognition of Intersectionality in the Global South: Critical Disability Perspective

Critical disability studies have emerged as a response to diverse social and political practices that have dominated the terrain of disability discourse in the western world. Critical disability studies have attempted a critical assessment in understanding disabled people's lived experiences, with an emphasis on reforming the social, economic, and political conditions that contribute to their disablement. Critical disability studies have made a conceptual and pragmatic departure from the theoretical and conceptual binary debates (social/medical model of disability; British/American Studies on disability; and impairment/disability) that shaped disability discourse in the west (Meekosha & Shuttleworth, 2009, p. 50). Meekosha and Shuttleworth (2009) have mentioned that the critical disability perspective has questioned the exclusion and marginalization explanations of disabled people, especially in the context when there are already a good number of state legislative policies on the rights of disabled people. It has directly pointed toward the inherent discriminatory attitudes present within the structures of society (government, medical professionals, rehabilitation and intervention centers, educational institutions, etc.) which have been held accountable to reduce (rather than remove or abolish) discriminatory practices against disabled people. They have argued that these social structures, which have been made accountable to maintain non-discriminatory practices against disabled people, carry an inherent characteristic and language of regulation and control.

According to Hoskin (2008), policies related to the rights and lives of disabled people should be complemented by the inclusion of both bio-medical and social perspectives because certain issues related to the physiology of the disabled people require their management through medical interventions (like any other person in society who sees a doctor when they fall ill)**,** but that should not be granted as a frame of reference to judge the social-cultural-political-economic ability of the disabled people and to limit their participation in wider social activities to their full potential. 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). Critical disability studies have been directed to accept diversity as a form of human and social variability and have been urged to frame concepts of equality based on the framework of diversity (Hoskin, 2008, p. 11).

Meekosha (2008), in her article “Contextualizing Disability: Developing Southern/Global Theory”, has articulated the need for understanding disability with reference to the southern context of society, history, and culture. It is critical to recognize that northern disability theories have attempted to universalize their theoretical biases in conceptualizing and theorizing disabilities for the global south. However, this has resulted in an incompetent and inadequate enterprise, producing an incomplete and partial understanding of disability reality in the global south. Nguyen (2018) has preferred to engage a critical disability perspective to conceptualize disability, by contextualizing it within the transnational, national, and local contexts, offering disability discourse of the global south with reference to its own history, culture, language, and diversity. Connell (2011) has claimed that the theorizing and conceptualization of disability through the lens of a critical disability perspective has ensured the production of indigenous knowledge and understanding of disability for southern contexts and has challenged the intellectual hegemony of the global North (Nguyen, 2018). Anita Ghai (2002a, p. 96) commented that the western discourse “ignores the harsh realities of disabled people’s lives in countries such as India, which are caught in social and economic marginalization”.

## 2.7. Reproduction of Disability Discourse in India

### 2.7. 1. Parenting and Disability Literature in India

Indian scholars and activists have attempted to conceptualise disability discourse while considering the Indian reality of disabled people in terms of history, culture, economy, politics, and the country's wide social diversity. Research and studies in India have adopted a critical approach to conceptualize the diverse intersections existing within the disability category (form and extent of severity), class, caste, age, and gender of the disabled people in India.

According to Anita Ghai (2002a), most of the disability discourses in India and its policies have been structured by drawing nourishment from the western philosophies of the medical gaze, which has recognized the over-dominance of clinical understanding of disability and its consequent stress on impairment, prevention, and rehabilitation. This has made medical interventions look like the only available tool or instrument that could address the issue of disability, capable of providing a solution to the problem of disability (Ghai, 2002a, p. 50). As a result, the social model of disability has been limited in scope in terms of the country's social, cultural, and structural diversities, with a focus on macro-level policy formation rather than understanding from the perspectives of disabled people and their family members.

Nilika Mehrotra (2013) has mentioned that Indian legislative policies gave immense importance to prevention and rehabilitation perspectives as means of the welfare of disabled people and children, which in turn, has paved the way for discrimination against people and children with disabilities by excluding them from the right to participate in the mainstream social activities which they are capable of performing (Mehrotra, 2011). Furthermore, she recognized the significance of the care roles performed by the family and community, as well as their importance within the diverse social-cultural negotiations in public arenas. She provided an intersectional explanation of caste, gender, and kinship with state policies in India (Mehrotra, 2020).

Shuhangi Vaidya (2016c) presented a thorough discussion on how mental and intellectual disabilities have been constructed through historical and cross-cultural underpinnings in her work "Mapping the Terrain: Examining Discourses on Disability and the Family" (2016c). (2006a) has placed a significant emphasis on the family members and parents. In her works, a critical analysis of the states' role in formulating policies for people with disabilities that give due importance to their families has been reflected. In her book "*Autism and the Family in Urban India"* (2016a), Vaidya has provided a picture of the lived realities of parents who have children with autism. She has explored the experiences of challenges for parents, siblings, grandparents, and other family members in extending care work for their children with autism (Vaidya, 2016a).

Renu Addlakha (2020) has pointed out that the practice of disability care, in the Global South in general and India in particular, is a "familial experience". Through her work, Addlakha has explained the intra-house dynamics in caring for people with disabilities within families and has shown how such dynamics are influenced by micro and macro societal structures and institutions and vice-versa. Her works have also highlighted the gender dimension as a "critical structuring principle" involved in managing care and domestic chores (2020, p. 47). This work by Renu Addlakha was found to be very significant for this research, which uncovered diverse aspects of parenting disabled children within urban familial setups.

Upali Chakravarti's (2008) work has revealed how conventional beliefs and understanding of the care and disability context have given rise to a negative environment for parents in managing a disability, both within and outside familial contexts. A study by Chakravarti (2008) has shown how, in the absence of external network support for families, the management of disability becomes burdensome.

Nandini Ghosh (2016) has pointed toward "medical determinism" that has been present within disability discourse in India. She has explained how such determinism prioritizes an individual's biological limitations at the expense of the socially obstructive environments that create disability (2016, p. 3). For her, the prevalence of the "religion-moral-medical model of disability" (P. 7) in India has been found to be reflected in the welfare policies and programmes of the state. Nandini Ghosh's major works have included the lived experiences of disabled women in rural Bengal. In her work, Ghosh (2017) has portrayed the "feminization of care". She has explained how the care of children with disabilities, in the presence of disabling socio-cultural environments, constrains the lives of both caregiver and care receiver.

### 2.7. 2. The Medical Gaze and Parental Perception of Disability

Most of the existing discourse on disability in India has been found to revolve around medical recognition and certification of disability as eligibility to access diverse welfare schemes and support systems, in the form of medical and allied aids, concessions in education, employment, and public transport costs, and so on. The sole emphasis on medical expertise, beginning from certification to concessions, 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 of understanding disability among the common masses, within which the parents (respondents/unit of analysis for this research) of children with disability or diversity are also included. In the following chapters, we will see how the parents' understanding of disability is initially drawn from the way it is explained and diagnosed by the medical panel and the way it has been understood and defined in the legislation. The understanding of disability, which is centered on the medical approach, has discounted the role of wider social-cultural environments that actively contribute to the full functioning of an individual. It has been observed that "personal, social, and environmental factors actively take part in creating disability" (Ghosh, 2016, p. 78).

A closer examination of various strands of work and literature on disability has revealed a strong preference by the Indian state for the charity and welfare model in defining and approaching disability (Ghosh, 2016, p. 7). The contradictory journey of the disability bills and their implementation has shown reluctance on the part of the government to formulate a coherent disability policy that would have empirically responded to the all-encompassing needs of people with disabilities. In India, the use of the medical model perspective towards approaching disability has dominated the manner in which disability has been comprehended at all levels of the political, economic, social, and cultural landscape of the country. According to the human development report, physical disabilities have been recognized as genetic and biological defects that are present at birth, and it came up with recommendations that future research in the area must focus on finding the causes of such disabilities (Shariff, 1999, 148). According to Anita Ghai (2001, p. 28), such a statement does not only recognize the indispensability of medical interventions but also disregards the "contemplations of the social perspective".

The framing of the *United Nations' Rules on the Equalization of Opportunities for Disabled Persons* (1993)[18], which has created a strong base of activism from Indian disability activists, resulted in the formulation of the Disabilities (*Equal Opportunities, Protection of Rights, and Full Participation*) Act in 1995 by the Indian Government, with immediate effect from February 1996 (Mohit, 2000). The Act of 1995, though it was established as the first policy statement related to the recognition of rights and participation of disabled people in India, was found to have defined disability majorly in terms of the medical model, at the expense of evaluating its social conditioning. By law, disabled people are required to have a disability certificate, sanctioned by a panel of medical experts, to get their diversities recognized based on the medical classifications and categorizations of disability. The domination of medical rehabilitation, for extending treatment and welfare to the disabled people, was replaced by the social rehabilitation approach after the National Policy for Persons with Disabilities in India, 2006[19] was framed. However, this Act too, while acknowledging the creation of a social environment that would have encouraged full participation of the disabled in all realms of their social and cultural life, left the responsibility of recognizing and certifying the categories and levels of disability in the hands of the medical panels. As a result, access to policies and entitlements continues to require certification from an expert medical panel, reflecting the larger fact that the medical model of approaching disability has always existed and continues to exist (Ghosh, 2016, p. 9). The Act has, thus, overlooked the importance of reducing (if not removing) social barriers that limit the full participation of the disabled at all levels to survive in dignified living conditions; the Act has discounted the need to make structural modifications to provide such living standards to the disabled people of India. Nandini Ghosh (2016, p. 10) in her edited book "Interrogating Disability in India: Theory and Practice" has maintained that the categorization of disability or the extent of disability, which is required to pass through the medical panel to get recognized as a disabled person (to get included within the banner and benefits of the said Act), has eased the entry of some categories of disability at the expense of the others. Moreover, as the state provisions for the disabled people under the Act have been decided based on the disability card issued by the State Medical Board, instances of discrepancies related to the issue of the disability certificates for the disabled people have not been rare.

### 2.7. 3. Shift in Approach: From Welfare to Rights

The Disabilities (Equal Opportunities, Protection of Rights, and Full Participation) Act, 1995 (PWD Act, 1995) has brought a revolutionary change in policy framing. The Act focused on the protection of rights for disabled people, reservations, protection and security in jobs, employment, and other measures. But a series of questions were raised against the statement of this Act—do all the categories of disability come under the provisions of this Act? Who will receive these entitlements and who will not? On what grounds will they receive such entitlements, and so forth? The answer to all these queries was the issuance of a medical certificate for disabled people, which has the category and extent of disability (mentioned in numeric percentage form) needs to be mentioned. It was decided that people with more than 40% disability would receive medical certificates to become eligible to receive the entitlements mentioned in the Act (Chavan & Rozatkar, 2014). In this context, it was necessary for the medical boards to devise yardsticks to measure the disability of a person. This brings us back to the predominance of the medical model in entitling a person against discriminatory practices. The law, on one hand, has talked about guaranteeing equal rights and opportunities for disabled people by securing protection, through the reservation, in education and employment to reduce the discrimination that people with disabilities have been facing. This, as a whole, has helped in extending the national discourse on disability towards a social model approach. At the same time, the need to measure disability using medical standards of normativity was felt to be important and indispensable. Thus, both the medical and social perspectives on disability have been recognized exclusively in the law.

The National Trust Act (National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999) was also framed, in addition to the PWD Act of 1995, for persons with mental retardation, autism, cerebral palsy, and multiple disabilities. The Act of 1999 clarified the definitions given for understanding autism, cerebral palsy, mental retardation, and multiple disabilities. The clarification of the severity of disabilities within these four categories of disability mentioned in the act, has driven the parents (of children with disabilities) to make a choice between schools and home-based education. It was recognized that children with extreme conditions of disability were more vulnerable and required intensive individualized attention to which a regular school system could not cater. The Act is aimed at empowering these people to live an independent life with their families and supporting registered organizations to offer services to these families in times of crisis. The Act talked about providing care and protection for instances of the death of parents or guardians and made provisions to appoint guardians through a Local Level Committee (LLC) (Chavan & Rozatkar, 2014).

Following the footsteps and guidelines mentioned in the UNCRPD, The Rights of Persons with Disabilities Bill, 2011 was drafted, where the legal capacity, equality and dignity of people with disabilities were recognized. The ideas of inherent dignity, individual autonomy, equal opportunity, accessibility, respecting diversity, acceptance for all, and the evolving capacities of children with disabilities 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). The Disability Bill of 2011 required the government to make provisions for free and appropriate education that could be accessed by every child with a disability up to the age of eighteen years. The act is aimed at promoting the integration of children with disabilities into a regular school set up with specific provisions for special schools for those children who need such facilities. Under the banner of this Act, provisions for accessible transportation and infrastructure were also considered in order to facilitate these children's access to regular schools.

The Rights of Persons with Disabilities Bill, 2014 and the Mental Health Care Bill, 2016 were enacted to add, replace, and repeal the limitations in the existing bills of the Mental Health Act, 1987 and the Persons with Disabilities (Equal Opportunities, Protection of Rights, and Full Participation) Act, 1995. This was the first time that the legislative discourse on disability was instituted upon an approach that was based upon the rights of people with disabilities instead of following a welfare approach that reflected sympathy over obligation. However, thorough scrutiny of the Bill of 2014 has revealed that the contribution of family members and the caregiving challenges, which are often associated with isolation, stigmatization, violence, and frustration, have been outrightly ignored. Rao, Ramya & Bada (2016, p. 121), have observed that, unlike families in the West, Indian families happen to be the key resource in providing the care-work required for people with mental illness. They pointed out two probable reasons for this. First, the persistence of Indian traditional family principles based on interdependence and care for one another; second, insufficient professional aid and services necessitated attending to these people with mental diversity.

### 2.7. 4. Marginalization of the Marginalized

In India, disability rights movements have been receiving their impetus since the 1980s. Though the fight is still continuing, one cannot deny that, compared to other mainstream social categories and vulnerable groups, people with disabilities form a marginalized group in India, who has been sidelined from diverse mainstream services and benefits. To my immense surprise, revisiting 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 diversities were observed to be further marginalized within the disability group/s. This kind of marginalization of people with mental and developmental disabilities prepared a positively knit platform that staged the emergence of NGOs headed and run by families and parents for people/children with intellectual disabilities, which later played a vital role in making the Act of 1999 (The National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation, and Multiple Disabilities Act, 1999) work. The role that the parents had taken in making the bill pass was noteworthy in creating an organized mobilization towards extending rights and inclusive policies for their children. Action for Autism, AADI, and the names of a number of other organizations can be mentioned as pioneers in guiding diverse, inclusive policies for children with intellectual and developmental disabilities.

Nilika Mehrotra (2011) has observed that till the 1990s, the disability rights groups in India comprised only those people who were physically impaired; those with intellectual and developmental disabilities were largely left out from representing the disability rights groups. The main reason for this marginalized status of people with mental and developmental disorders was the belief that these people have special issues that require intensive and constant medical intervention, unlike the physically impaired groups of people.

Subhangi Vaidya (2016d) 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). The marginalized status of these disability categories within the broader disability group has been found to have been reflected in the laws until 2014. Before 2014, the laws did not recognize the importance of family members or caregivers as the chief interlocutors of people with intellectual and developmental disorders. However, it was through parental activism and advocacy that the Act of 2014 was properly implemented and disseminated among the people/children with intellectual and cognitive diversities.

### 2.7. 5. Place of Family within Disability Discourse: Recognition of Care

While talking about the lives and struggles of people with disabilities in general and of children with intellectual disabilities in particular, one area of discussion that has remained under the shade for a long time, yet is important to bring to the fore, is associated with the role and position of family members of these people or children. In her research, Upali Chakravarti (2008, p. 354) has observed the burden of care-work to fall upon the families of children with disability. She has argued that, in the absence of a non-institutionalized setup of formal support networks, the constant juggling of the parents with responsibilities of care-work and support has many negative consequences for the caregivers, primarily parents (more specifically mothers, as pointed out by Chakravarti, 2008). With parents (or family members) standing at the center of the care work services catering to the different needs of their children, coupled with the absence of an institutionalized care network, hiring paid external help remains the only resort. However, because of the high cost of hiring trained caregivers, this option appears to be limited to many parents with low incomes. According to Chadda and Deb (2013), the burden of caregiving falls on the family in Indian society due to its collectivistic nature, as opposed to families in Western societies. For him, most of the time (if not always), these services go unacknowledged and are classified as informal labor.

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. Chakravarti (2008, p. 355) has highlighted the paradoxical position of mothers, who are assumed to be the sole caregivers in Indian socio-cultural contexts. Some mothers have been found to make a difficult choice between caring and working, with a predisposition to choose care-work at the expense of their employment and career, while in some instances, mothers load themselves with the dual burden of earning a livelihood and caring for their disabled children. Talking about care-work for disabled children in India reflects a gendered distribution of the responsibilities. The main reasons for such gendered care division have been a lack of family resources (the absence of other family members in the nuclear family set up or the inability to hire external care agencies due to insufficient financial resources) and an inadequate (if not non-existent) institutionalized support system in India. Subhangi Vaidya (2016d, p. 104) agreed with the fact that in India, the significant role of the family (parents and/or other family members) in caring for, supporting, and sustaining the various needs of children with disabilities cannot be underestimated. She has maintained that family remains the central location within which disabilities are managed. For children with intellectual and developmental disorders, parents connect the child with the wider social, cultural, economic, and political institutions and organizations, becoming the voice for their children. In such a context of inadequate social security networks with poor support systems and services from the state, parents need to combat tremendous pressure and stress from all areas of existence (social, economic, legal, educational, and so on), making their life and living more challenging.

A thorough appraisal of the Persons with Disabilities Act 1995 indicates that, while identifying the significance of equal opportunities, protection of rights, and full participation, on the one hand, the act has inclined the whole discourse on disabilities towards extending welfare provisions for them, on the other. “It was as if the family had been rendered invisible, or that all disabled people had a dignified existence within the family had always been assumed” (Sen, 2016, p. 66). It was in 2014 that family and care agencies were given their due importance in the legal discourse after the implementation of the Rights of Persons with Disabilities Bill, 2014. Thus, the 2014 bill marked a significant departure from the 1995 Act, in which “home, family, and care make a space with the legal” (Sen, 2016, p. 65).

### 2.7. 6. Parenting Children with Disability and Education System in India

In India, the struggle of the families and parents of children with a disability has turned more difficult when it comes to the question of providing them with education and putting them in schools. 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”. She further stated that “integration and inclusion are difficult concepts in a culture embedded in discrimination” (Ghai, 2001, p. 32). Indian policymakers' provisions for special schools were not intended to be parallel to the real-life conditions of children with disabilities. This gap is visible when teachers of the regular schools find themselves unsuited and unable to meet the special needs of the children with disabilities within the schools, which are designed with mainstream architectural and infrastructural facilities that do not suit the requirements of the children with disabilities. This has pointed to the fact that the training the teachers might have taken did not include any modules on managing children with disabilities; and even if there were provisions for special education modules, they were mostly designed categorically without specializations based on the type and intensity of disabilities. Most regular schools do not appoint any special educators or recruit any trained and professional counselors to accommodate the training of the teachers and staff. Consequently, the curricula followed in regular schools do not accommodate the teaching-learning space needed for children with intellectual disabilities. Myreddi and Narayan (2000) have pointed out that most (if not all) teacher training institutions do not have modules that are specially designed for teaching and learning about children with disabilities.

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.

The integrated school system has been theoretically designed to include children with any category of disability, but in reality, they are unable to include people with intellectual disabilities (Meena, 2015). Zachariah (2001) has observed in his research that regular schools have not been able to remove or modify their architectural barriers to accommodate students with intellectual disabilities. And more often, they refuse the admission of these children with disabilities to such schools. Most of the schools in India do not have the necessary resources that are required to admit and maintain the academic fervour for children with disabilities.

In the UNESCO World conference held in 1994, it was clearly stated that a school should:

> *"……accommodate all children regardless of their physical, intellectual, social, linguistic or other conditions. This should include disabled and gifted children, street and working children, children from remote or nomadic populations, children from linguistic, ethnic, or cultural minorities and children from other disadvantaged or marginalized area and groups". (UNESCO, 1994, Framework for Action on Special Needs Education, p.6)*
>
> *And that "these inclusive schools, must recognize and respond to the diverse needs of their students, accommodating both different styles of learning and ensuring quality education to all through appropriate curricula, organizational arrangements, teaching strategies, resource use and partnerships with their communities." (UNESCO, 1994, Framework for Action on Special Needs Education, p.11-12)*

To achieve the target of inclusive education, it remains important to make significant changes in the curricular and structural patterns of schools. The aim of inclusive education will be satisfactorily achieved once all children, irrespective of their physical and intellectual diversities, can participate in learning activities in their full capacity.

### 2.7. 7. Children with Disability and External Structural Barriers

As M. M. Jha (2002) puts it, children with disabilities encounter a "dual barrier". The external barriers come from the hurdles they face before and while getting enrolled in schools; the physical locations of the schools far from their homes; the social stigmatization; and the economic position of the parents. Internal sources prevent them from fully participating in school. Internal sources of barriers include insufficient architectural support to facilitate the movement of disabled children; the mainstream curriculum; and teaching methodologies that limit the learning and participation of children with intellectual disabilities. These children are frequently (if not always) assessed, identified, and isolated within schools and classrooms, resulting in a discriminatory curriculum within mainstream arrangements (Jha, 2002, p. 15-16).

In an attempt to fulfill the said three objectives (of providing equal opportunities, protection of rights, and full participation in society), the Act of 1995 had made provisions for equal access to education and employment for the people/children with disabilities. Various affirmative actions were adopted to make certain kinds of jobs accessible to these people. An attempt was also made under the Act towards making access to regular schools via inclusive education policies, which made provisions for special schools for disabled children. However, these were all in pen and paper. In reality, the challenge which was never thought about was how these children would reach these schools? Although, the Act of 1995 has mentioned the need for building accessible roads and transport facilities, but that has been largely left to the financial capacity of the state governments. Rukmini Sen (2016, p. 66) has pointed out another lacuna that was present between the policy and its implementation, as to how the legislation would ensure that the families of the disabled children would bring out their disabled kids to the special schools overcoming the stigma, which they might have to face while managing children with diversities in public.

## 2.8. Conclusion

Multiple barriers have hindered Indian children with disabilities from their full participation in society. Parents, as primary caregivers, act as a bridge between children’s needs (educational, health, social, and public participation) and fulfilments of their diverse requirements. This is where the primary challenge for parents emanates from. Lack of or limited access to information, coupled with the discriminatory attitudes at all levels of society towards these children or people with disabilities, has added to their experience of marginalization. For parents, the structural barriers to accessing regular and special schools have compelled them to choose between accompanying their children to school and opting for home-based education. The key factors which have driven parents towards making such choices range from the physical location and distance of the schools to the difficulty of accessing public conveyance with their children with disabilities to reach the schools.

The following chapters have highlighted some of these empirical issues as narrated by the parents themselves.

Lack of awareness about the diverse programmes and schemes related to childhood disability, by the parents catering to the needs of both the child and family, has been another reason that children do not realize the benefits and provisions of such schemes. Accessing the legislative entitlements through the issuance of the disability certificate does not reach all the children with disabilities who are eligible to possess one. Lack of knowledge and confusion regarding the place from where to generate the certificate, non-transparency about the whole procedure, and lack of understanding of the utility and importance of generating the disability certificate have actively contributed to the limited scope of inclusion for these children.

# Chapter- 3

# Confronting Disability

> ***"Emotions pervade all social life…The most prosaic daily routines, seemingly neutral, can provoke violent emotional responses when interrupted. ... Not only are emotions part of our responses to events, but they also – in the form of deep affective attachments - shape the goals of our actions"***
>
> ***-Jasper (1998, p. 398)***

## 3.1. Introduction

The reactions and responses of the parents towards their children's disabilities were conceptualized through a constructionist lens of understanding reality. A constructionist understanding of parents' lived experiences revealed that parents' responses and reactions did not arise from the diversities or conditions that caused disability, but rather from the social and medical negotiations that parents encountered during the process of detecting and diagnosing disability in their children. A constructionist conceptualization of the parents' experiences reflected that "disability had been created" through the diverse forms of encounters the parents had with macro and micro-social interactions both at individual and systemic levels. Viewed in such a way, disability was understood not as something which was "given" as it is believed in general, following the naturalistic accounts of disability[1], but as something which was created through medical, social, and cultural negotiations. The knowledge and confrontation of the detection of diversities were observed to be a "complex and powerfully emotive experience for parents" (Avdi, Griffin & Brough, 2000, p. 243). In-depth interviews and long hours of conversation with the parents had acknowledged intense phases of emotional turmoil and stress among them, which were primarily drawn from the social context and the cultural meanings that were associated with disability. The available cultural meanings about Autism, ADHD, Multiple Disabilities, Learning Disability, Down syndrome, Cerebral Palsy, and Rubella syndrome, which they had derived in the past from the social context they lived within and through their encounters with people they interacted with, were found to nurture parents' perceptions of their children’s diversity. Many of these perceptions about disability and diversity were fostered by parents before their children were diagnosed with certain disabilities.

A naturalistic account of the disability perspective has been presented by Elizabeth Barnes in her work “The Minority Body” (2016) on the basis of three beliefs (or misbeliefs). First, that disability is a deviance from the idea of the normal functioning of the human body. Second, that disability indicates a lack of ability that most human beings should possess (which is evaluated against the standards of the normative). Third, disability is caused by impairment's maladaptation and maladjustment to the social environment (when impairment is defined as a deviation from the accepted standards of body and mental functioning) (2016, p. 13-21).

The perception and expectation of a ‘perfect child’ received a robust setback when they confronted a different reality after the diagnosis of the disability. The process and manner of disclosure made by the medical professionals about the child’s disability have been observed as a “framing event”[2] (Advi, Griffin & Brough, 2000, p. 243). It is through such “framing event” that the different behaviors and expressions of thought and actions, observed in these children, were considered as symptoms; and on the basis of which certain body and mind conditions were labelled as disabilities. The process of labelling specific health conditions as disabilities were found to have been based upon the accepted medical classification of diseases[3] related to intellectual, developmental, psycho-motor, and neuro-motor functionality of the body and mind. Detection of disability, diagnosis process, and planning of the prognosis altogether were observed to have created a medical gaze over the children and their parents. The medical gaze presented an objective reality of understanding disease and disability before the parents. At the same time, through their continuous exposure and everyday experiences in managing and dealing with the diversities and through constant negotiations with the systems-level interaction with different institutions and organizations, the parents were observed to have comprehended a subjective reality surrounding disability and diversities out of the given objective reality they had encountered for the same. Thus, parenting children with diversities provided room for them to reconstruct and redefine what so long had been understood as disease and disability.

The chapter has been divided into five themes that have attempted to explore how disability and diversity are constructed through medical and professional encounters. The first theme begins the chapter with an introductory note on how parents have experienced the disability of their children. The second theme discusses how disability has been created through interaction at micro and macro-structural levels. The third theme has highlighted parents' immediate response to the event of childbirth, knowing that the child was detected with disability. The fourth theme of the chapter gives a detailed account of the emotional responses and reactions expressed by parents after confronting the fact that their child was detected with a disability. And the final theme of the chapter ends with a concluding remark.

## 3.2. Social Construction of Disability

### 3.2. 1. The Art of Disclosure and Creation of Disability

Within the scope of this research, the children with disabilities included both children who were born with certain disability conditions and children who developed the conditions leading to disability in their early stages of development. When parents learned that their child had been diagnosed with certain disabilities, they were confronted with a counter reality in both the cases discussed above. Empirical observations have shown the existence of a reinforcing connection between the manner in which the medical experts and professionals disclosed the information about the diversities that were present in the children and the immediate response and life-long impact such disclosure had upon the parents. This was well reflected when a mother of a three-year-old boy narrated that:

*"We (mother and father of the child) were waiting for the doctors to come. They asked us to wait. After around one and a half hours, a doctor and a nurse came with a bundle of papers (reports) in their hands, and we entered his chamber. Among many other conversations, what I still remember was the first sentence the doctor uttered:*

*“I am sorry to say that your child has been diagnosed with autism with borderline OCD”.*

The mother who was narrating her story about the disclosure of her child's disability condition stressed more on her emotional reactions and responses she felt at that time. However, as a researcher, I was stuck in the words stated by the doctor “I am sorry to say”. The word “sorry” associated the diagnosis with negative attribution which contributed to shape the manner in which the mother perceived disability and diversity in her child as something which was not expected and hence was non-desirable. Middleton (2000) has termed this as “abnormalisation”[4] or “creation of special need” (Warner, 2006, p. 25). This kind of attitude had clearly reflected the prevalence of the medical model perspective of disability among the medical professionals and clinical staff in their understanding of disability. This was further observed to have extended and diffused among parents and shaped their perception and comprehension of disability.

Perceiving, conceptualizing, and comprehending disability in this manner did not aid parents in adapting or adjusting to their child's diversities, but rather made it more difficult for them to cope with the living experience. As a result, the parents began to feel isolated and the diversity in their children made them feel ‘different as parents'. The parents were thus observed to have developed what Goffman called “courtesy stigma” (Goffman, 1963, p. 129), which was generated due to their close association and encounter with their children and their diversities, respectively.

MacKenzie & Scully (2007, p. 338) pointed out the existence of different views of reality and perspectives that were possessed by disabled and non-disabled people. The medical professionals’ expert knowledge provided them with an objective and normative understanding of the diversities in the children that were often discounted by the subjective experiences of the parents. Parents perceived and understood disability through their daily interactions with their children's diversities. The different realities encountered by professionals and parents have contributed to different constructions of reality surrounding disability and diversity. Interviews revealed a contradictory understanding, concerning how parents conceived and comprehended disability and diversity in their children. The contradictory understanding among the parents was observed to have emanated out of their interaction with two different and opposing realities concerning disability. On one hand, it was the medical/biological model of understanding disability, with its intrinsic focus on diagnosis, treatment, rehabilitation, and prevention of disability; while on the other hand, it was the social model of disability, which emphasized more on the acceptance of disabilities as diversity. The social model of disability highlights how the existing social structures have put limitations on the diversity that causes and creates disability based upon such diversities. Parents were observed to have experienced and encountered both of these realities with two different worlds of reality in their everyday lives and living, in dealing with the diversity in their children.

Disclosure about the child's health to the parents requires good communication skills on the part of the professionals, clinical staff, and doctors. Responses from the parents indicated that when the diverse health conditions of the children were communicated to them in an understandable and comprehensive manner, it became easier for parents to accept and adjust to the reality of their child's diversities. In such instances, the parents could accommodate themselves to the needs of their children, which, in the long run, was helpful for them in understanding the course of future prognosis. A mother of a fourteen-year-old with multiple disabilities expressed her embarrassment and confusion when she visited a government hospital to show her son when he was five months old:

*"I was called inside a room (within the hospital) where around fifteen to twenty people were already present. The nurses called me to come near the doctor's table. He said to me, "Look, your son cannot be cured to normal; he has some issues with his brain that will not allow him to act like us". I have forwarded the prescription. Go to room No. 16. They will tell you the details of the treatments. "While saying all this, he did not even look at me and was busy writing the prescription. I felt shy and cold when he said this to me, shouting in front of all the other people sitting inside the room, and they started staring at me as if I had committed something I should not have. I didn't even understand what the problem with my son was".*

The manner of disclosure had a positive impact on the parents and has been found to have influenced the management of their mental health status. Understanding diversity from the angle of deviance added to their feelings of distress, anxiety, and stress. Parents found that comprehending or accepting their child's health state as a diversity had helped them in adjusting and coping with the challenges of raising children with disabilities.

Conversations with the medical practitioners revealed that it was an unpleasant and stressful task for the doctors to “break bad news” (Shakespeare, 2018, p. 50). The doctors expressed the quandary position that placed them in tautness between being an individual who lives within society and being a doctor for whom maintaining affective neutrality was important. On one hand, their long-term training as medical practitioners prepared them to remain value-free as much as possible to maintain their objectivity towards the disease or pathology they needed to treat, while on the other hand, they were expected to express humanity while encountering the subjective beings of patients and their families. In disclosing the detection of disabilities in the children, the doctors were required to regulate their emotions and remain objective and value-free towards the diversities they had detected. 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. Thus, the contrasting “fields” and “habitus” of the doctors and parents, made it harder for the parents to accept the confronting reality of the diversities in their children.

### 3.2. 2. Comprehending the Cause of Disability

What parents knew about their children's various health conditions and how they perceived the entire disability discourse was essentially rooted in the parents’ larger socio-cultural dialogue. Much of this dialogue, however, drew its nourishment from the medical model understanding of disability. Though the social model has surpassed the medical model in terms of understanding disability since the 1980s, it has only reached a small percentage of the general population. The social model understanding of disability remained more of an element of intellectual discussion within and across disciplines without gaining the required amount of pragmatic implementation. It became even more compelling in the Indian cultural context as the medical interpretation and definition of disability interacted with local beliefs, knowledge, and understanding about what was considered normative (Vaidya, 2016a, p. 3). Interaction between the medical backdrop of understanding and defining disability with the indigenous interpretation of the same constructed an image of children with disabilities. Underlying such images, the personalities and personhoods of the disabled children were also constructed and negotiated (Vaidyaa, 2016).

Most parents believed that medical and clinical treatments and interventions were the only ways to manage or treat their children's disabilities. The way disability is defined and interpreted in medical parlance has contributed to shape parents' perceptions of disability. This becomes evident from the following extract from a parent's response:

*"I had no idea of what the doctors were talking about. I have never heard of such an illness (Asperger's syndrome). I was told that my son was not a normal child. He may not be able to live a normal human life and will require ongoing treatments, supervision, and therapies to survive".*

Many (seventeen) respondents believed in fate or destiny to be the cause of their child's exceptional condition. These parents had lower expectations from treatments and fewer hopes for the scope of improvement. To them, it was God's will that their child was not like other children who had no such diversities in their body and mind functioning. Table No. 3.1 describes how parents have perceived the causes of disability in their children.

**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 |
| **Total** | **60 (N)** | **100** |

Four parents had accepted that their child’s disability was a consequence of the wrong deeds from their past life. Some (seven) parents among the respondents had even tried their luck in spiritual practices and rituals (by keeping fast, praying, visiting certain holy places, and taking services of “Ojha” or shamans) with the faith that this could improve their child’s health. Nine parents perceived the cause of disability to lie in some kind of biological imperfections that the parents might have, mainly mothers. Eleven parents believed that genetic disorders in their children might have caused the disability. And twelve parents pointed towards the presence of biological factors in the children that might have caused the disability in them. The table thus reflects that twenty-eight parents (i.e., 46.64%) have comprehended the cause of disability to reside in their past life or wrong deeds of the past in their present life.

Trotter and Chavira (1997, p. 35) reported that Mexican Americans believed in both biological and spiritual causes for illness. However, a family who believed that their child’s condition was due to certain biological variables was found to have sought medical treatment as a cure for disability. For them, 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. Similar findings were observed in research conducted by Ravindran and Myers where parents believed that disability was caused by some external agents in the environment (2011, p. 313-316). Hence, the socio-cultural background, coupled with the spiritual beliefs and the cultural context of the parents to which they belonged, played a significant role in shaping their perception and understanding of disability, in general, and the diversity of their children, in particular.

The reactions of the parents to the diagnosis of their children with one or more diverse health traits reflected anxieties among them. These anxieties were prompted by the social-demographic location of the parents. The monthly income of the household units, educational qualifications, occupations, and professions of the parents were found to shape their perceptions of reality with regard to disability and diversity. Their reactions were observed to have been reinforced by “middle-class aspirational structure, the highly competitive education system, the need to earn a living through one’s intellectual capacities and attainments, the dwindling of traditional avenues of support, and the absence of alternative structures to replace them" (Vaidya, 2016a, p23).

### 3.2. 3. Parents' Reaction to Disability

The birth of a child into a family has a significant impact on the dynamics of the family. It changed many reckonings that existed before he/she was born. Parents, as well as other children (if the parents previously had more than one child) and other members of the household, had to go through a number of changes to adjust to the pressure of a new member in their family set-up. Becoming a parent called for a new role that disciplined them into new situational changes and sometimes into crisis. This acclimatization or disciplining pattern became more profound and challenging for the parents when the newborn arrived with a certain disability condition that was mostly unknown and unexpected to the parents. This was observed in instances where the children were born with certain birth developmental anomalies or any neuro-motor asymmetry. In some instances, the disability conditions could be diagnosed right after the birth of the child, while in some other cases, the disability conditions reveal themselves gradually during the early years of the child's development.

The initial process of knowing made the parents confront a reality that they had never expected to encounter. Parents of children with disabilities flashed 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. Their reactions ranged from despair, hopelessness, denial, confusion, trauma, and anxiety to logical exposure to the problem gradually over a certain period of time. While agony and worries about the future did eventually take hold of the parents, their immediate reactions upon being told about the child's condition subscribed to denial, shock, anger, despair, and disbelief. In most of the accounts, the feelings of self-blame, projection of fault, grief, withdrawal, guilt, rejection, uncertainty, insecurity, anger, anxiety, depression, and frustration have been retrieved.

**Figure No. 3.1: Information on the distribution of the types of disabilities that the children were detected with**

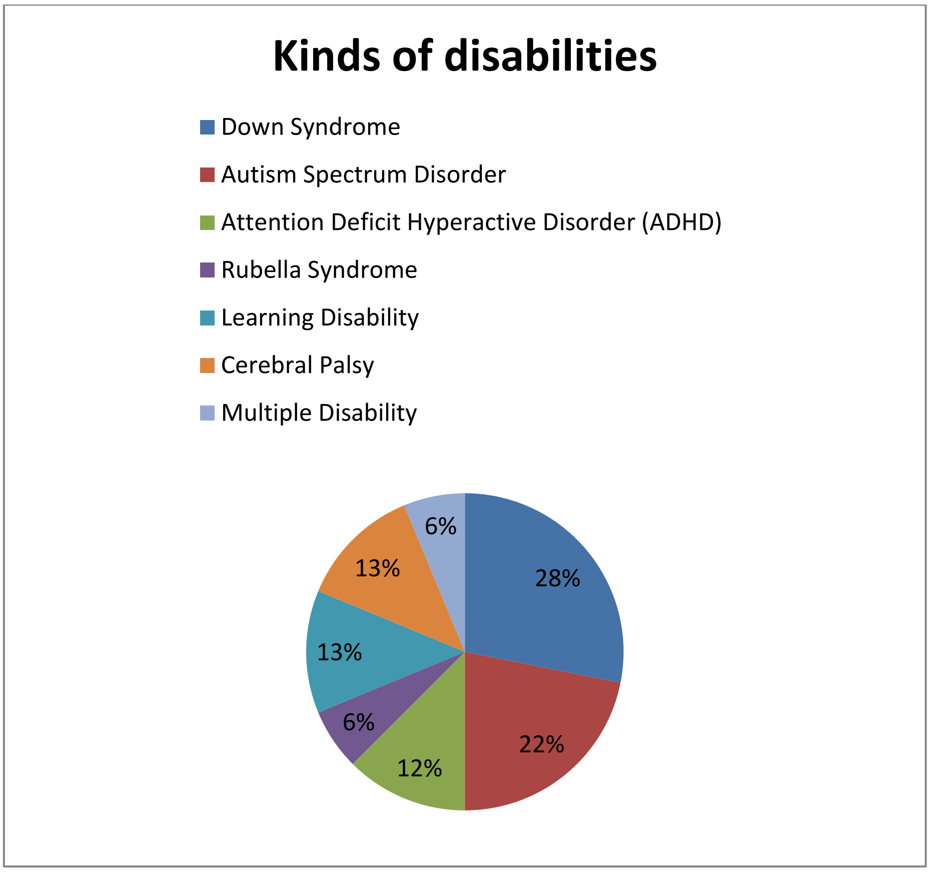


Figure 3.1 shows the information on the kinds of disability categories that the research has included. The disability conditions that have been accounted for in this research included the neural tube defects giving rise to some special health conditions like cerebral palsy; developmental and intellectual disorders causing conditions like Down syndrome (nine), Autism Spectrum Disorder (seven), specific learning disability (four), neurodevelopmental disorders like ADHD (four), Rubella syndrome (two), cerebral palsy (four), and multiple disabilities (two). In some cases, the diverse expression of disability in children appeared as a concoction of more than one health condition (if not a complication).

The responses of the parents varied and depended upon different social and economic factors taken into account. The reactions expressed by parents are shown in a numeric representation (Table No. 3.3) for visual clarity, but in reality, the responses were not very discrete to be accounted for as a single category of expression.

The parents were observed to hold complex emotional states, showing diverse reactions at different points of time during their articulation. 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. Hence, in some cases, parents' preliminary reaction was expressed as denial, while in some other instances, the initial expression of shock led to a sense of emotional crisis, steering to long-term problems of trauma and anxiety among the parents, which in some cases generated feelings of confusion and hopelessness among them.

**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-flame** | 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 |

One respondent explained that:

*"The knowledge of my daughter's health shook me from inside. I heard about them only in tales and watched them in films. I was completely broken…could not believe it was real. I was in utter shock from which I have still not recovered. I often drench into periods of depression. Any thought about our future scares me a lot."*

## 3.3. Parents' Response to Childbirth

The life passages of the parents rolled along with different socio-cultural obligations that society put upon them. Getting married and having a child was considered to be a socio-religious responsibility and obligation for them, as most couples in India feel the same (Vaidya, 2016a, p. 23). Having children and becoming parents were taken to be symbols of the ultimate accomplishment of their life goals (Vaidyaa, 2016, p23). All the respondents highlighted the cultural significance of having children. Thirty fathers agreed straightly that becoming a father was a moment of pride for them. Mothers mostly (twenty-three) expressed their feeling of completeness after knowing that they were carrying a life within them. The admiration of sensing completeness among mothers was found to have mostly been fashioned by the 'construction of motherhood', which had been celebrated as a spontaneous urge among women. And adhering to such a motherhood construction had provided them with a way to feel accomplished in order to complete their cycle of womanhood. Rich (1995) claimed that, "motherhood is earned"[5] firstly, through the passage of conceiving, maintaining the pregnancy, and giving birth to a child, which involved intense emotional, psychological, and physical involvement of the mothers with their child; and secondly, by nurturing and providing care and support to raise the child, which was constructed and gazed[6] by the norm of "intensive mothering" and becoming "good mothers" for their children. Both fathers and mothers, engaged in this research, agreed that by being able to give birth to a child, they had fulfilled their social and cultural commitment to their family and society. Parents have shown a sense of gratification, contentment, and fulfilment in being able to bear a child, which they believed would continue the familial or parental legacy across the next generations.

## 3.4. Gendered Expression of Emotions

Encountering the knowledge of the birth of a child with certain intellectual, cognitive, psycho-motor, neuro-motor, or developmental diversities, parents were observed to have expressed diverse forms of emotional responses and feelings. A deeper understanding of the narratives revealed a difference in the emotional responses between the mothers and the fathers. Though both mothers and fathers were found to feel stressed, the reason for the stress was observed to vary across the gender of the parents. The health and well-being of the children, care-work demand, and capability to fulfil the exclusive care requirements had generated stress among the mothers. For the fathers, stressors emanated from their capability to financially respond to the child-care and rehabilitative needs and their perception of their future bonding, both with the child and the wife. However, issues related to the future of the child stress both the parents. While talking to the mothers during the interview, it was noticed that mothers were more concerned about the responsibility, care, and dedication they would have needed to develop to fulfil the constant care work demands of their children. Research (Sloper & Turner, 1993; Timko et al., 1992) has affirmed that mothers question their own abilities to become good mothers, and in doing so, levels and intensity of stress were found to have been higher among them as compared to fathers. “They set high standards for themselves, particularly in lavishing care on the child, thereby generating more stress for themselves” (Hochschild, 2003, p. 237).

But in the case of fathers, the conversations reflected their worries and stress related to the outer social world and talked about the impact the social world would have on their children with disabilities. Their narratives had hardly expressed the emotional responses they had within them after encountering the reality of their child’s functional diversity of body and mind. At this point, it would be relevant to bring Hochschild’s (1983) concept of “surface acting”[7] into the discussion. Narratives and in-depth conversations with the parents had pointed out that fathers resorted to surface acting while displaying their responses to the reality of knowing about their child’s diversity. When fathers learned that their children had certain diversities, they were found to be more prone to feigning their true emotions. Talking with the fathers revealed that though from the inside they were very stressed and anxious, they tried to be more practical in their approach while interacting with others. 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. A father of a 14-year-old child with cerebral palsy expressed that:

*"When doctors told me about the disability of my son, I was broken from the inside. But as a man of the house and as a responsible father, I felt it was necessary for me to control my emotions to support my wife, who would be shocked after knowing this. I told my wife the truth and asked her to accept the reality and focus more on our future".*

It is important to note that fathers did not express many of their true feelings after learning about their children's disabilities. Their expressions of words and emotions conveyed what they wanted to display before others, both at the time when the interview was taken and at the time when they learned about the disability of their children. According to Hochschild, in a given situation or context, individuals in a given society feel according to certain "feeling rules", where the latter is guided by a certain ideological framework fabricated within the wider socio-cultural context in which the situation or event is taking place. 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". The framework provided by framing rules allowed parents to develop feelings rules in situations where they encountered disability. Fathers' adherence to the traditional gender ideologies was observed to have framed their feelings, which further shaped their emotional display and which seemed appropriate to them, with regard to the given context (knowing about the reality of their child's disability). Thus, adopting the strategy of surface-acting, fathers tried to be more practical in their approach and attempted to manage or control their true emotions, which they actually felt inside.

## 3.5. Parents’ Reaction to the Disability: Emotions that speak

### 3.5. 1. Denying the Diagnosis- “This cannot happen to me/us”

The parents' initial reaction has been observed to be the most common initial reaction that was communicated by the parents to the news of their children’s detection of disabilities. Learning about the disability condition in the children, which had no permanent cure other than specific interventions and therapies that worked to ease the level of difficulties, had a life-changing impact on parents. Most (forty-three) of the participants reported the response of denial when they first heard about their child’s diversified health condition. Of them, twenty-nine mothers were seen to have recounted the reaction of denial, whereas there were only twelve fathers who communicated similar responses. The constructed image of a child that the parents had been weaving among them since the time of conception put them into a different reality after they had learned that their child with disabilities did not fulfil their expected image of a child which they had been constructing for a long time. The reaction of denial was expressed in defence of this new and unexpected reality. One parent (mother) of a child identified with cerebral palsy narrated:

*“I could not believe that this could happen to me. I came to know about my child’s abnormality the next day after my delivery. My husband gave me the news. I shouted at him. I told him to check whether the baby had been exchanged by mistake with any other baby in the hospital. I exclaimed that I had a healthy pregnancy throughout... All my reports were normal.This cannot possibly be my child”.*

Parents’ reaction of denial to their child’s disability condition was observed to have been different for different disability conditions the children had. The extent, level, and source of such a reaction (denial) were different for every parent. Parents of children with cerebral palsy experienced feelings of denial as a result of their children's differences from other children who did not have any disability condition. These parents believed that their children who were different would remain socio-culturally unacceptable and would not be able to fulfil the expected socio-cultural commitments as responsible individuals in a society. Hence, denial for them directly stemmed from this understanding of difference and from a sense of “other”[8]. Baraitser

(2008a, p. 20), in “Maternal Encounters”, has commented that while talking about their immediate reaction after birth (in cases where disabilities were present at birth), it was common for the mothers to surprisingly encounter otherness. A mother exclaimed,

*“My child is not like other children. He is different. He will be different.”*

In the cases of certain conditions such as Autism, Down syndrome, and ADHD, denial and its cradle were completely different. In these instances, everything seemed normal right after the child was born. The health state of the child remained unexplored until he/she reached his/her early years. Over time, the conditions creating disability were unmasked when the children could not match the expected developmental yardsticks. Parents who had previously assumed that their children were like any other child without disabilities were confronted with an unexpected reality. For parents, it became an arduous task to accept that their children, who had learned to walk and speak the initial words, and even reacted or responded to events happening around them, were actually developing certain disability conditions within them. In these instances, the reaction of denial was stimulated by confrontation with an ‘unmatched reality’ through which they were living. They suddenly found themselves in a maze. One respondent with a child who has Down syndrome recounted (with a tear in her eyes) that:

*“I could not believe that my child could have any kind of abnormality. My husband and I went to another doctor... We thought the diagnosis was wrong. We repeated all the tests from different centers. I witnessed my child walking, smiling, saying her first words, and playing with his toys like any other child. How can he suddenly develop this abnormality?”*

The emotional state from which the feeling of denial emanates was reported to be different for fathers and mothers. For mothers, the reaction of denial primarily came from a disbelief in the reality they had encountered with regard to 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.

A father said:

*"We exactly followed what the doctor had suggested doing during pregnancy. We did all the tests that the doctor asked us to. We did all the scans on time. My wife maintained a healthy diet... then what led to the abnormality of my child? I still don't get it."*

The response to denial differed based on the diverse socio-cultural background of the respondents. Denial was observed to be more aggressive in parents with higher education degrees (Master's Level or above), good professional exposure, and higher pay[9]. For these parents, accepting the health condition of their child was difficult. This was due to their high expectations of their children in the future, which the parents had expected to match their social profile. Acknowledging the fact that their children had a disability condition was difficult for the parents, and denial was expressed as a coping response to such a difficult encounter with reality. This kind of denial reaction was reported by two fathers—one of them was a lawyer and the other one was a businessman. The feeling of one parent at the time of knowing was:

*"…….doctor called me separately in his room and disclosed that my son is suffering from Cerebral Palsy. I asked him…..what was that? I had never heard of it before. When the doctors made me understand the disease I could not believe that we can have a son like that…I am a lawyer…very well known in my locality…..everyone in my family is well educated and healthy? Definitely, there might be some mistake somewhere."*

However, these fathers agreed that though their reaction of denial was expressed at the time when they had learned that their child had a certain disability condition, later on, they gently coped and accepted the diversity in a subtle manner. It followed from the fact that before their encounter with disability in general and diversity in their children in particular, parents had a limited understanding of what is known as the social model of disability. Their understanding of disability revolved around the concept of 'biological normativity' of health, illness, and functionality of the body and mind. Such an understanding of disability through an exclusive medical model perspective shaped their perception before their children were born. Narratives have shown that it was through the everyday interaction and challenges that parents encountered with the wider social structures (health, education, public infrastructure, and facilities) and in managing disabilities in their children that the parents got affiliated with a social model of understanding disability. They realized that their children's disabilities stemmed from the way society perceived them.

### 3.5. 2. Trauma: Contesting the Given

The birth of a child or the detection of a child with a diverse physiognomy and health state has been observed as a traumatic event for the parents. The moment of learning about the detection of their child with one or more disability conditions left the parents to suffer a devastating emotional breakdown.

The shock stemmed primarily from the parents' disbelief over the diagnosis, which had engulfed them when they learned about their children's disabilities. Most of the parents (forty-nine) conveyed their initial reaction of trauma or shock once they got to know that their child had been diagnosed with one or more health complications, which made them labelled as disabled. A mother of an ADHD child explained her incredulity at the diagnosis, which made her go for medical counselling from different experts at different centres throughout India.

*"I could not believe that this could happen to my child. He was born healthy, he had the right weight, he was even responding to me, and he was feeding well, so what made it happen? And how did it happen? I was shocked. I did not believe the diagnosis and went to many other doctors for his diagnosis. I was sure something was wrong there. Finally, at NIMHANS, Bangalore, his diagnosis of ADHD was confirmed. The world outside stopped there for me. I stopped living from that point (with a heavy voice)."*

The disruption to their expectation of a child and the vision of a future family that the parents had been weaving within them since learning about their pregnancy caused the initial trauma or strain. The parents kept on nourishing and adorning such images throughout their complete gestation period and had constructed a visionary reality for their future family. However, the child's unusual symptoms, followed by a clinical diagnosis with certain diverse physical or intellectual traits within the child, plunged the parents into a different reality; a reality that was unexpected and unanticipated. This kind of abrupt and unexpected estrangement of the mundane reality from the one that was imagined left the parents to fall into absolute strain and trauma.

A systematic assessment of the conversation with parents revealed a preliminary reaction of trauma over a certain period of time after they knew that their child was detected with a disability. Though almost all parents in the study reported a shock reaction followed by a traumatic phase, the duration of the traumatic phase was found to vary across the 'dual-stimuli' within which the parents were able to reflect back on their trauma. The first stimulus is arouse out of the type and intensity of the disability, which can be entitled as 'internal inducements' of trauma. The second one was generated by the 'external inducements' that added to their experience of such 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. Hence, the 'external inducements' of trauma have been observed to remain embedded within the overall social-economic and cultural profile of the parent.

"*Yes, it is true that, initially, the thought that my child would never be 'someone' in society haunted me. I am a lawyer. My friends, cousins, and relatives are all in established positions. Some of their children are also doing very well, and the ones who are young will surely do well as they are healthy and normal, unlike my child. I began to compare the future of my child with theirs. This made me more shocked and frustrated."*

The traumatic phase among parents was seen to have persisted from a period of six months to one year. However, in rare instances, the duration of such emotional trauma was stretched to even two to three years. Fourteen parents have reported that they had experienced trauma for a longer period of time, which persisted for years. The 'internal inducements' of trauma caused variations in the duration of the traumatic phase, which evolved out of the type and intensity of the diverse health states of the children. 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 'perception of rejection' was an acuity with which parents tended to perceive the diversities in their children under the lens of socio-cultural standards of (bio)-normativity and evaluated them against the expectation of their children to become socially productive and responsible beings. Such a perception of disability made the parents more susceptible to trauma. This reaction to trauma became acute for parents whose children had multiple complexities. For example, a child who was detected with birth defects due to Rubella syndrome had multiple health intricacies that included paralysis of lower limbs coupled with an inability of vision and hearing, and malfunctions of the heart, and which had led to the development of different intellectual and cognitive disability conditions. The experience was observed to be somewhat similar among parents with children having cerebral palsy and in cases where the child had been detected with other neural-tube defects during birth. This was affirmed in the words of a mother who was reported to have been suffering from trauma for two and a half years after giving birth to her son with cerebral palsy:

> *"My son was born with cerebral palsy coupled with allied health complications. The knowledge of his health shook me. I was told he can't move, he can't walk, he can't talk, he can't see... I went silent for some days... I understood that my child was not normal... Not like the other children I have seen so far...he will never go to school, he will never earn a degree, he will never earn by himself, and he will always have to live on the mercy of others."*

Constant clinical interventions, therapeutic sessions, and the promise of gradual improvements made by the medical paradigmatic procedures have been noticed to have raised hope among the parents. Parents had started to believe that their children would be able to satisfy the bio-normative standards of being 'normal' to some (or greater) extent and hence would be accepted by the larger society. It is here to note that social acceptance- driven by recognition and recommendations from bio-normative standards to be called 'normal'- continued to shape parents' perception of the disability of their child. This is particularly true for parents whose children have been detected with developmental or intellectual disabilities at the time of birth or sometime later during their early years of development. This was found to have been true for conditions like autism, Down syndrome, and ADHD, where there were chances of improvement to a lesser or higher degree (depending on the level of complexity) with the aid of medical interventions. A parent of an autistic child explained:

*"Doctors suggested that continuous therapeutic sessions and clinical procedures would make my son able to live a 'normal' life. He will go to a 'normal' school, he will be able to mix with people, and he will even able to can earn his living as other people in society do."*

In this narration, the inclination to get approval from the medical practitioners for their child to be labelled as normal was clearly evident. Most of the parents could not accept the diversity in their children and believed that medical interventions would cure the conditions causing disability conditions to a certain extent. They experienced trauma as a result of their refusal to accept diversity. Only a few parents could accept their children's disability as part of their biological and intellectual diversity, and that diversity was not always negative. They had accepted the fact that their children were diverse and were diversely able to conduct and survive themselves within the larger societal systems and structures.

Whatsoever, even if the parents managed to surmount the trauma emanating from the 'internal inducements' there were certain times when the 'external inducements' took a front seat that prolonged the phase of trauma among the parents. The 'external inducements' of trauma were located in the demographic profile of the parents, including the socio-economic class (to which the parents belonged), the academic levels they had accomplished, and their professional background.

Interviews with the parents revealed a positive correlation between the intensity of trauma (at the time when they had learned about their children's disability) and the level of the educational accomplishments, economic class, and professional position of the parents. Various research has confirmed the observation that –the higher the location of the parents in the demographic ladder, the greater the intensity and duration of the trauma (Harper, 2013, p. 2604-2616; Dardas, 2004, p. 265; Emerson & Hatton, 2009, p .107-110). Parents located in the higher social hierarchy got into trauma fearing the social stigma that was attached to their perception of disability, which was further embedded in the construction of such a perception within a specific socio-cultural reality. In this context, the trauma was rooted in a ‘perception of stigma’ coming from the social sphere within which the parents constantly operated and consequently constructed and reconstructed meanings attached to their life and living related to managing disabilities in their children.

The ‘external inducement’ was also rooted in a ‘perception of challenge’. This has occurred when parents feared to 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 cost involved in attending all the therapeutic sessions that were recommended for the child. In general, such sessions were required to have be accessed at regular intervals, ranging from two to five classes per week, with a very extensive fee structure demanded by the therapeutic experts and physiotherapists. Initially, when the parents had learned that their child had been detected with one or more health complications that might have affected their general intellectual and developmental progress, and when doctors and experts proposed specific intervention procedures and sessions to make things easier for their children in the near or later future, the first reaction that was expressed by many parents was fear and insecurity about the affordability of such clinical interventions. For many parents (nine), the overall expense has almost surpassed their total family income. This was evident in the narration given by the father of a child with autism:

*“Doctors advised us to provide special sessions in the center recommended by them. To improve his speech a special educator at home was also advised. A special physiotherapist had been prescribed to improve his locomotion. The total cost stood around at a figure of Rs.23000 a month leaving aside the cost of conveyance and medicines recommended for him. My monthly salary is Rs.48000 and the cost of treatment is huge. I had to skip some of the recommendations. It felt like I was compromising the health of my son. But I was helpless."*

This huge punch of expense did not only include the direct medical cost involved in the clinical interventions required for the child but also incorporated certain indirect expenses related to the medical procedures involved. For example, the costs that were hidden in accessing special conveyance, particularly when the intervention center was located far away from the place where the children resided and with due consideration of the materiality that adequate transportation facilities and infrastructure to support the journey of children with disability was absent. Indirect cost was also involved in cases where specialists or professional therapists were recommended by the experts as supplementary support in addition to the medical interventions which were carried out.

### 3.5. 3. Predominance of Guilt: “Am I the Cause?”

The most commonly observed emotion among the parents was ‘guilt’. Parents were observed to have been struggling with guilt. They felt that any of their misdeeds might have caused the child to have been born with a disability. Among sixty respondents, twenty-six parents reported the emotion of guilt for the disability condition of their children. Twenty-one of them were mothers. The prevalence of guilt is primarily derived from limited exposure to knowledge regarding the diverse conditions with which the child was identified. Mothers were observed to have put their pregnancy periods under thorough self-scrutiny down their memory lanes to understand the mistakes that they might have committed during their pregnancies. These mothers believed that their children's disabilities were caused by unidentified mistakes or misdeeds committed at any point during their gestation period. A mother of a rubella child narrated:

“*The day the doctor told us about our child’s health, I kept on thinking the whole day about my pregnancy time. The foods I ate. The places I visited. Any hurt or injury I faced. I thought all the time, “what did I do wrong in my pregnancy?”*

The level of guilt expressed by parents varied according to the type and severity of the children's disabilities. In the case of the above-mentioned story, the child was affected by rubella. A child with rubella or cerebral palsy is diagnosed with a health condition shortly after birth. Inadequate knowledge about the disease and its sources made the parents, particularly the mother, review the phase of pregnancy looking for the cause that created the disabilities.

However, in the case of some exceptional conditions such as Autism, ADHD, Down syndrome, and learning disabilities, the guilt was found to stem from the methods and techniques used by the parents to parent their children. In some cases, mothers blamed their mothering skills and practices for how they handled their children during the early phase of child development. This happened because, in the case of autism and ADHD, the child in his or her initial years from birth appeared to be healthy until he or she was diagnosed with some developmental and behavioral disorders. From the time of birth up to reaching the toddler stage (the diagnosis varies between 0-5 years), the parents had known that their children were like any other children who till then had shown no sign of disability. The parents’ gradual encounter with developmental difficulties that went unmatched to the regularly known developmental milestones a child should reach, and the sudden news of their child being detected with Autism or ADHD, made the parents’ encounter a terrible shock.

The collected data showed that mothers initially tried to link the developmental disorder of the child with the wrong parental practice that they might have been exercising in parenting their children. It was learned from conversations that the feeling of guilt was more intense when the parents (particularly mothers) had limited knowledge of what autism was, what ADHD meant, or how learning disabilities occurred. A father of an autistic boy recounted that:

*“I recollected the moments where I was wrong, for an endless number of times, which we did commit while raising our child. He was absolutely fine and healthy when he was born. Gradually, we observed that his behaviour was not normal. He became so restless... always running... always looking for something... screaming without a reason... and keeping on shouting. We thought we had failed to manage his behaviour, until we knew he had ADHD."*

Guilt among parents had led them to lose their confidence in parental practice, leaving them to reconsider the practices (which they exercised before learning about their children’s disability) that they thought might have improved the situation for them in dealing with the disability of their children. In many (eleven) instances, parents reported that they altered the previous parenting routine in order to discipline their children. This often took a toll on their regular survival practices. Some even went to the extent of feeling that it was the lack of proper attention and care that their child had developed a tendency to remain aloof from any guests who visited them. The father of an ADHD boy reported that they had stopped watching television or any other form of entertainment media after returning from work because he believed it was due to his lack of quality time with his son that had caused the boy to behave or express himself aggressively. Five mothers (two of them had children with Down syndrome and three with autism) had left their jobs in order to take proper care of their children. According to them, their children may have developed the disability as a result of their absence. The mother of an autistic boy said:

*"The day I knew that my child had autism, I almost left all that I previously loved to do, so that I could devote my full time to attending my son, which I should have done long before. The thought that it was because of my ignorance that my child had developed such developmental delays haunted me for a long time."*

This feeling of guilt was observed to have persisted more among parents when the expression of developmental delays in children surfaced at a later age, say from three to six years. In such cases, the child did not show any difference in developmental milestones during their early years. It was only with the passage of time that the diversities began to appear.

The persistence of the feeling of guilt has affected the emotional health of parents, particularly when they are left unattended. Conversation with the parents revealed that by receiving additional exposure to knowledge regarding disability conditions and exchange of words and counseling with experts, parents had learned different ways to understand and manage their feelings of guilt. Continuous counselling from special health experts and special educators assisted the parents to come out of this feeling of guilt. Parents (seventeen) reported that recurrent visits to counselors facilitated them with expert guidance on the disability and diverse physical-mental health conditions of their children, which consequently helped them to come out of their guilt.

### 3.5. 4. Grief: “Why Me (Us)”?

Grief had been defined as a manifestation of an emotional state when people were confronted with any kind of irretrievable loss (Turner & Sets, 2006, p. 518). From an understanding based on the sociology of emotions, grief was conceptualized as a mixed bag of emotions that was constructed from and shaped within a specific socio-cultural context[10] (Turner & Sets, 2006, p. 518-519). The nature and intensity of the felt emotions of the parents with regard to the detection of the diversities in the children and the consequent response towards such diversities were primarily shaped by how disability and diversity were conceptualized in the cultural context within the parents. Generally in India and Kolkata in particular, common sense understanding of disability among the people was observed to have been shaped by a tragedy model (individual and medical model) which induced an emotion of grief among the parents. The parents’ perception of ‘loss’ was constructed by the wider socio-cultural perception of the disabilities as tragedy, which the parents had internalized through the socialization of the long assumed traditional stereotypical socio-cultural beliefs regarding disability.

Dialogue with the respondents revealed an intense feeling of grief among them. Many (forty-one) parents had subscribed to the feeling of grief once they understood that their children’s needs were distinct; that their children would need special interventions to manage the diversities. 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). Turner (1998) claimed that “emotions drive individuals to act consistently with expectations" (Thamm, 2006, p. 27). The inconsistency stemmed from an unmatched reality and the parents' constructed reality of a child's body image. This was precisely the case with parents whose children had been identified with diversified conditions such as cerebral palsy, Down syndrome, or Rubella. A mother of a boy with cerebral palsy exclaimed:

*“Throughout pregnancy, I have been dreaming of a baby as we see on posters or calendars - with chubby cheeks, healthy... I fantasized about moments in the future*

*with my baby. But when I held my baby in the hospital, I noticed something was wrong: his legs, posture, eyes, everything was different from what we normally see in a baby; nothing was normal. I felt like heaven had fallen through".*

The feeling of grief, however, did not differ much with the level, extent, or type of health condition of the child. Whether it was cerebral palsy, where the diversities were identifiable right after birth, or autism, where the special behavioural features gradually revealed themselves with time, feelings of grief were reported to be the common response among the parents. In some parents, feelings of grief were found to be closely connected with anxiety or uncertainty surrounding the future of the child. Parents were concerned that the manner in which a child with no intellectual or cognitive differences was discovered to complete his or her developmental milestones by attending preschools and primary schools, by attending some other classes of entertainment, or by preparing himself or herself for a comprehensive personality that was culturally accepted by society, would not be a reality for their child who had certain diversities within them. These parents had expressed their grief that their children would never be capable of doing things independently, within the capacity of their individual autonomy. They had explicitly expressed their fear that their children would never be able to earn a living. The following is an extract from a conversation with a mother.

*"My son will always be at the mercy of others. He cannot even express his hunger or thirst. Tears rolled down her cheeks !"*

The expression of grief among parents had confirmed a gendered response and was found to have affected mothers and fathers differently. Though both mothers and fathers communicated about their intense emotions, it was found harder for the mothers to accept the diversities in their children. Greater proximity with the kids made it harder for mothers to deal with the plethora of emotions. The research had confirmed an expression of 'double mourning'[11] among the mothers which was generated from the confronted reality of their children's disability. This was found to have suppressed a mother's image and perception about her child who was yet to be born and the dream she weaved for her child from the time she had conceived. The second source of mourning emanated from the perception of her future image as a mother who would have nothing left in her life but to provide continuous and intense care work to her child. This was well narrated by a mother of a fourteen-year-old boy with cerebral palsy:

*"When I learned that my son was born with cerebral palsy, all my dreams, thoughts, and planning which I made throughout the journey of my pregnancy turned meaningless. I knew that my son and his health would be the only concern from now on. There will be no career, no job, no friends, and no social life left for me now. I will be living only for my son."*

It was observed during the research that this kind of double mourning among the mothers was common in the initial phases of detection and diagnosis of the disabilities and was found to have lasted for a few weeks or months. Constant exposure to interventions and counseling sessions for the child and themselves helped the parents cope and organize themselves towards a more adaptive role.

The reaction of the fathers, however, was no less intense in terms of grief and pain, but the manifestations of such emotions were not similar. As compared to mothers, fathers were found to be less expressive about their experiences and emotions about their children. Five fathers have accepted that they mourned and still mourn, sometimes, about the future of their children. Nine fathers had acknowledged that they chose to make themselves involved in work that was not related to their child, and this had helped to keep them away from negative emotions. Fathers' limited expression of grief during the interviews could be explained and analyzed in terms of the cultural standards of gender construction by which men are not expected to express their emotions. Hochschild (1983, p. 163) maintained that "emotional labour"[12] and the expression of grief had followed different emotional rules based on societal cultural standards. Masculine socialization had prevented fathers from expressing their grief and other intense emotions about their children's differences. Fathers have been found to have adopted the strategy of surface-acting while displaying their emotions. By adopting surface-acting, the fathers had attempted to display the expected feelings in situations that they sensed as appropriate, fulfilling the expected rules of the emotional culture of the society they belonged to. The emotions displayed by the fathers using surface acting were independent and different from how they actually felt at a given time, situation, and context.

### 3.5. 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 for the disability of their children. The account of blame, however, was not a universal generalized experience for all mothers. In instances where the children were detected with diversities during their early years of development-like in the case of Autism Spectrum Disorder, Down syndrome, specific learning disabilities, and attention deficit hyperactivity disorder-the mothers (thirteen) were blamed for causing the disabilities in the children. Parents’ accounts had revealed that blaming was mostly encountered before the diversities were detected and confirmed. Before the detection and diagnosis, the mothers were held responsible and accountable for the different behavioural and action patterns of the children that violated the wider socio-cultural norms of behaviour expected from children of similar age groups. Mothers’ accounts of blame, which they had faced before the diagnosis of disability in their children, reflected a societal gaze. It was through this social gaze that the mothers were evaluated against the standards of being good mothers[13].

**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<br>(husband, immediate family members from both in-laws and parental side, extended family members and neighbours) | 05 | 38.46% |

Table No. 3.3 presents information on mothers who received blame from others. The table clearly shows that though the mother received blame from almost everyone inside and outside of her family, it mostly came from mother-in law and the generalized others in society. This explains the “gaze of others” explained by Sara Ruddick (1995) that the mothers in my research had experienced. 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. This ‘everyone’ included family members (both from the mother’s and father’s side), extended relatives, or neighbours who used to convey that the mother was not dealing with their children properly or that she was not attentive enough to see and capable of handling the wrong behaviours that the child had learned. The mothers had pointed to the stress, anxiety, and tension that this “blame-game”[14] (Vaidya, 2016a, p. 87) had caused them. Many of these mothers were stereotyped as “cold mothers” or “refrigerator mothers”[15] unable to care for their children and failing to instill and teach the expected cultural norms in their children.

The diagnosis of any type of disability is not an easy task for parents to accept. “In Indian society, disability was viewed as a tragedy worse than death” (Vaidya, 2016a, p. 04). The birth of a child with disabilities evoked a sense of “otherness” (Clapton & Fitzgerald, 1997, p. 1-3) among the parents when they compared their children with children without disabilities. Existing literature has also suggested that parents often tend to blame themselves or each other as a reaction to the disability of their children (S’lungile, Ntinda & Hlanze, 2015, p. 206). Similar findings have been stated in a study by Riasat (2012) where both parents blamed themselves or blamed each other for causing disability in their children, which they believed to have been caused by “genetic disorders, alcoholic nature, worries or tensions, or other rational or irrational reasons” (p. 32).

Parents, particularly mothers (fifteen), were prone to blaming themselves for their children's disabilities. Six mothers expressed their distress in talking about the unmanageable mental and emotional state they had experienced during the phase of pregnancy due to some unbalanced toil in their relationship with their husbands and with other family members. Some of them (three) were under professional supervision and required regular counselling sessions. They regularly took antidepressant medicines before and sometimes even after conception to maintain a stable physical and mental state. The response of self-blame was intense among these mothers who blamed themselves and the situation they had experienced as the cause of the disability in their child. These mothers had pointed toward the people (mostly husbands and, in some cases, other members of the family) who made them fall into such a derogatory position, making them unwillingly compelled to undergo such treatment methods while being pregnant. A single mother of a fourteen-year-old son with multiple disabilities narrated:

*"My husband used to beat me like an animal, even after knowing that I was pregnant. My husband and mother-in-law abused me often. They wanted a property that my father gifted me. I left my in-laws' house at 5 months of pregnancy... and filed for divorce... I was broken. I had to consult a psychologist. I was on medication for a long time."*

The self-blaming for mothers (eleven) who had healthy relationships with their husbands and other family members (as reported in interviews) stemmed from a sense of grief and tragedy because something had happened to them that had not happened to anyone else they knew in general. Mothers' reactions were found to be been underpinned by a sense of "why me?" (Vaidya, 2016a). Mothers continued to blame their children's disabilities on any of their misdeeds or even karmas from a previous life (as retrieved from two mothers).

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 3.4 shows a tabular representation of the responses by parents to self-blame and their educational qualifications to explain how exposure to knowledge and education has helped them to perceive disability in a more practical manner than by giving in to the conventional socio-cultural understanding of disability.

A father of a 15-year-old daughter with Rubella explained that:

*"I never once regretted it or blamed myself... or my wife...or anyone else for it. I did not allow my wife to blame herself. Nor did I allow anyone to blame my wife for whatever had happened. I knew that it was a virus that affected my wife during pregnancy to cause such birth defects in my child... and medical treatment could only work for her".*

This was observed to have occurred because parents with a greater understanding of disability initiated early detection and intervention procedures rather than waiting and relying on supernatural or religious equipment to provide any cure for disability issues.

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

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

### 3.5. 6. Confusion- “What is it? How to deal? Shall I (We) be able to Manage it?”

Having been detected with certain disabilities, the parents were often left confused about what next should have been done that would help or improve their children’s disability condition. The initial response of confusion was reported by many parents (thirty-nine). Parents had expressed a feeling of discomfort and confusion about the exceptional physiognomies of their child; about the kind of interventions that the child would have required before the actual interventions had begun. Parents were often observed to remain bewildered after they encountered information about their children’s disabilities. 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. Parents’ understanding of the diagnosis was induced by the existing multiple discourses on disability, which mainly restricted the medical model's understanding of disability. To make sense of the diagnosis, parents adopted a disability understanding that remained woven into the larger social fabric (Avdi, Griffin and Brough, 2000, p. 251). A father narrated:

> *“I went to see my child the next day after delivery. The doctor called me separately and asked me to book an appointment for my child in the diagnostic centre for some immediate tests. He suspected some features that were not normal, handed me a piece of paper and left. The only thing that haunted my mind was if he was abnormal..? ”*

In their works, Kandel and Merrick (2007, p. 1801) have described how the doctors reveal the diagnosis and inundate the parents with intense confusion about the diagnosis and the treatment required. “Physicians do not always have the appropriate training to help the parents at this difficult moment of disclosure or the appropriate skills of communication and support” (p. 1801). Physicians resort to various communication techniques to disclose the diagnosis to the parents. The parents reported that doctors and medical professionals had disclosed the diagnosis of their children’s disability using explicit medical terms with excessive use of medical terminology that led the parents to comprehend nothing of it. This further mystified the parents' knowledge of what happened to their children. Hence, acts of disclosure by medical experts were noticed to have played a vital role in the way parents reacted to the initial knowledge of their children's intellectual and cognitive diversity.

Confusion was observed to be more intense and common in cases where children were diagnosed with conditions such as autism, ADHD, and learning disabilities. It was usually around the first or second year of child development that parents began to sense that the developmental progress and proceedings of their children's growth were irregular or unusual. Initial confrontation with certain unusual behaviours from children often leads parents to cast off the possibility of anything unusual or different. Parents often tended to think that even if some unusual behaviour was expressed by their children, it would be within the due course of time that the children would learn age-appropriate behaviours and actions. In these instances, parents knew from the time of the birth of the baby that he/she was healthy and had no signs of disability or diversity that could be detected. Parents experienced and enjoyed seeing their children reach developmental milestones such as crawling, starting to walk, and responding to what was going on around them up to the age of two or three years, and in some cases, up to the age of four years (in the case of a learning disability). However, the sighting of certain "moments of truth" (Vaidya, 2016a, p. 56) generated responses of confusion, and a 'fear of the unknown' or 'fear of imperceptibility' was witnessed while analyzing their responses. Every parent has their own moment of truth when they are unexpectedly confronted with their son or daughter's existence. This has happened to most parents when their children are diagnosed with autism and learning disabilities. These moments of truth had spawned an unknown fear among parents about the child's behavior, most of which seemed to be imperceptible to the parents. Some instances were narrated during the interview where the parents had encountered behaviours that generated a 'fear of the unknown' or 'fear of imperceptibility' among them. Parents have reported incidents where the child kept on repeating a particular word, when the child chose to avoid eye contact, or when a child preferred to play only in his room without talking to or responding to anyone else present there. Even in some cases, children remained unresponsive to their parents' presence or calls. A mother of a 4-year-old autistic child recalled:

*“I was reciting rhymes in front of him. He repeated the lines but did not look at me. This happened for many days. I did not care much... The same happened with his father. One day, I called him, but he did not answer. I kept on calling him by his name. I went near him. He still didn’t look at me as if I was not present there. But I know he can hear sounds”.*

These instances, which the parents encountered during the initial stages, kept them engaged in utter confusion. The stories narrated by the parents demonstrated an oscillation between confusion and hope. The uncertainty and the ‘fear of the unknown’ had immersed them in phases of awkwardness. Restricted erudition about the exceptionality of their child’s health and continuous tests and series of diagnostic procedures made it further uncomfortable for parents. Sometimes specialists and experts take a long time to make a proper diagnosis of the condition, specifically in cases where the child reveals symptoms of more than one kind of disability condition. The confusion was found to have been set in deep as the parents knew that their children had some disabilities and there was no permanent or proven cure for them. Later, parents understood that only interventions could assist the child to cope with his or her disability, which might work fully or partially depending upon the extent and type of disability the child had.

The reaction of confusion was found to be more intense among parents who had comparatively lower educational achievement. These parents were observed to have sustained the feeling of confusion for a longer duration of time than parents who had relatively more educational accomplishments. Greater exposure to knowledge and access to higher frequencies of interaction with people from all diverse social categories might have contributed to a better understanding of disability for parents with higher educational credentials.

### 3.5. 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. Learning about their child’s disability, their abrupt responses of shock, confusion, fear, and helplessness had driven them into intense episodes of stress and frustration. The stress stemmed from the new role that the parents had to adapt to in order to properly care for and meet the parenting needs of their disabled children. Parents had to adjust not just to the new role of parenting that came with a lot of challenges and experiments that suited children's exclusive needs, but the adjustment was also required on their part to cope with their thoughts, which they had so long sustained about their expectant child and his/her future. The parents' encounter with a different reality, which was a contrast to what they had understood and nourished for so long, made the parents creep into severe phases of stress and anxiety.

The period following the diagnosis and the phase before waiting for an intervention programme to begin was the most stressful period for parents. During this phase, parents struggled to adjust through the initial stages of grief and adaptation. Dialogue with the parents had conveyed a nerve-wracking ring of stress after they knew that their child had developed certain diverse health conditions that were distinct from what the parents had understood about illness or ailments in general. In the words of a mother:

*"I knew my child was not well and there was no cure. Physically, I could not see anything wrong with his health. But he has been diagnosed with ADHD. I had no idea what ADHD was. I could only grasp that his behaviour was not normal and we needed some long-term treatment that included more than just medicine".*

The level of stress among the parents was found to vary in different contexts. 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. On occasions where the children were detected with conditions that were diagnosed at birth and had higher levels of complications, which often led to several corresponding and consequential health complications (like what we saw in the case of cerebral palsy or Rubella syndrome), the level of stress among the parents was noticed to be higher. This was because the kind of aid that these children were offered and which assisted them in performing their own part in their daily survival struggle was predicted to result in a very limited scope of improvement. The stress among parents was generated out of the realization that their children would never act or behave in a way that was considered to be normal, along with the yardstick of socially accepted normative behavior. Parenting stress depends upon the severity, visibility, unpredictability, and number of invasive procedures such as surgeries and the overall type of disability—behavioural or developmental—rather than the medical diagnosis (Breslau et al, 1982, p. 682–686).

In instances where early detection and early interventions with the appropriate style of therapy and sessions promised to minimize or ease the developmental and intellectual intricacies to some extent, the levels of stress among the parents were observed to be comparatively lower. These kinds of responses were recorded from parents of children with Down syndrome, autism, and SLD. The lower levels of stress among these parents were due to an understanding of optimism, which was often buoyed by the interventions and therapeutic procedures that generated a level of confidence about improvement in their child's diverse abilities. 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. However, such an optimistic portrait was very rare and very infrequent. Understanding of disability in such a manner was reported only by eight parents. Most of the parents, however, continued with their sorrow and grief, leading them to remain immersed in a muddle of stress. A father of a thirteen-year-old daughter with Down syndrome stated:

*"Gradually, we (both parents) accepted the fact that our daughter has a special condition called Down syndrome. However, doctors assured her that with proper treatment and ongoing therapy, she would be able to do things on her own. She can respond to people in a normal way and can conduct things, but in her own manner. And we can see such improvements too. We were assured about her and her future to a certain extent."*

Research has shown that parents' income and financial resources significantly impacted how their stress was managed by them. Pandey and Dubey (2019, p. 165) showed that higher financial resources and stability helped reduce stress among parents about the disability of their children. Resources, here, meant adequate monetary backup to support the early detection of the specific difficulties that the child might have suffered from and for the much-needed early intervention to cope with the disability of the parents to carry on the therapeutic procedures as a part of the prognosis. The expense of therapeutic sessions, accessing the centres with a special arrangement of vehicles (as public transport is not viable in conditions like cerebral palsy, Rubella, and extreme degrees of ADHD), and arranging complementary drill sessions at home as follow-up exercises, has turned into an exorbitant business. A single mother of a fourteen-year-old boy with autism and multiple disabilities confirmed that it was an exorbitant task to take her son to special classes and sessions, particularly by public transport. She continued…

*"I stay in Kaikhali and my centre is in Ruby (approximately 19 km apart). I need to take my son to the centre every day at 10:00 am, which happens to be during peak office hours. Getting on and off public buses becomes difficult, sometimes almost impossible for us. He is fourteen now and has become too heavy for me to handle. Moreover, he gets irritated and violent with so many people and noise around him. My earnings do not permit me to book a cab. As a result, it became impossible for me to continue the classes in that center, which is a government one, and which I could afford. I had to discontinue."*

In this research, levels of stress have been found to be closely related to the educational achievement and profession of the parents. It was found that parents who were in professions (which have higher social status in our society) like managers, engineers, teachers, doctors, founders, or chairmen of small workshops or business centres felt more stressed out in comparison to parents who were in professions like foremen, clerks, or owned small businesses. Parents in higher-status professions were more stressed about their children's adult living standards because of a "fear of falling". This perceived sense of lack of competence in their children had driven the parents into an intense pool of stress and depression. However, higher levels of stress among the parents who were engaged in prestigious occupations were found to occur due to a thwarting feeling of their higher expectations from these children; a higher perception of shame; the frustration at not being able to restore the condition of their child; and more restrictions that they had to put on their social and professional activities to balance the requirement of care. The narration of a father of a son with autism, who had been working as an executive in a top Indian public-sector company, expressed his frustration when he compared his son with the children of his fellow colleagues. He said:

*"The news of my son's diagnosis turned my world upside down. Now I know that I am a father who will never be able to play with his son. The thought that first came to my mind was, what would he be like in the future? What would he do? What will he become?"*

The narration of a father who had been the owner of a small medicine shop was found to be relatively assertive when he was talking about his autistic son:

*"I knew he had some health condition, which is different from a general illness or disease. I knew there was no cure. But I also knew that surely there were treatments to make him able to respond to things. I knew that we needed to be strong and positive for the good of our son."*

**Table No. 3.5: Information on the distribution of the care work for the children with disabilities**

| Care work provided by | No. of respondents | Percentage (%) |
|---|---|---|
| Both Parents without external help | 9 | 28.12 |
| Mother only | 6 | 18.75 |
| Father only | 0 | 0 |
| Parents with other family members | 2 | 6.25 |
| Parents with Hired mid-wife or nurse | 13 | 40.62 |
| Hired mid-wife or nurse only | 2 | 6.25 |
| **Total** | **32** | **100** |

Table no. 3.5 provides a detailed picture of the distribution of care work within households. In some families (thirteen), the mothers fulfilled the role with the help of hired caregivers. But, for a few families (seventeen), seeking help from an external caregiver remained far-off due to financial limitations. The table explains why the burden of care is still borne by mothers. And in instances where the mothers were assisted by other family members, it was mostly the female members of the household. Mothers revealed a higher degree of stress as a response to the disability of their children as compared to fathers. This higher intensity of stress resulted from their perception of having more responsibility and caregiving responsibilities to meet the needs of their special children. It was found during the conversation with the parents that most of the caregiving and nurturing roles of the children were managed by the mothers.

The finding has been discussed by Dalal (2002). In most cases, the mothers were assisted by the maternal grandmothers of the children to provide care. Exclusive hired care services were an option only for two household units. For others who accessed hired services, it was only for a few hours or as assistance to mothers who were working. Thus, for mothers, the time they had at home before and after coming from the office was thoroughly involved in managing the care demands of their children with disabilities.

### 3.5. 8. Emotional crisis

The birth of a child with a disability has been found to have created an emotional vacuum or crisis among the parents. Long before the birth of the child, parents tended to weave a future image of what the family would be; they had constructed their vision of having a child who would turn out to be like any other child they saw and interacted with. Learning that their child did not meet the criterion of normative societal understanding of a healthy child threw the parents into an emotional quagmire.

Kandel and Merrick (2007) classified parental reactions to disability and the consequential emotional crisis encountered by them into three categories: The first one was called "the crisis of change" (p. 1802), which happened when certain unexpected events or changes occurred in an individual’s life and depended upon how the person perceived such unexpected events. The second one was related to the alteration of individual respective values as a result of a certain crisis. People were socialized based on certain ethical and moral systems, which provided them with the required feelings of accomplishment as rewards. The birth of a disabled child prevented the parents from feeling the sense of accomplishment that they would have felt if the child had been born without any disability conditions. The third one was called "the crisis of reality" (Kandel & Merrick, 2007, p. 1802), which was mainly associated with the material resources required to manage and deal with the child’s disability conditions, like financial resources and the parents’ investment in quality time and energy for providing care work both inside and outside of the household.

All three categories of the crisis were observed to have been exhibited among the respondents. 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. Kandel and Merrick (2007, p. 1802) pointed out that the crisis of change did not happen due to disability but because of the sudden and unexpected change in their rhythms of life. However, this has been found to be partially correct for this research because parents have been observed to have reacted to the disabilities and diversities themselves. Unexpected life circumstances were one of the viable factors that had generated a feeling of crisis among them, but that reaction was not exclusive to the diversity that their child had been identified with. A mother of a daughter with multiple disabilities expressed her feelings of crisis by saying:

*“My child was born with a defect in her nuchal cord. According to the doctor, she will be unable to move, speak, or respond to anything around her. I could not understand what he was saying as I could see a visibly healthy child in front of me. I had never heard of this disease. I did not know what it was about. I could only grasp that my child was not a normal, healthy child, unlike the other children lying by his side in the nursery."*

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. This was evident from the following statement made by the father of a Rubella child:

*"The birth of our daughter brought immense happiness and joy to our lives. We had so many ideas; we had so many plans for our child; for her future. We bought new dresses and we decorated her room. We bought a pram. But who knew that this joy would last for four months when we discovered she was a rubella child? Our dreams got shattered. All the plans came to a halt. We were not ready for this. Now we know, we have altogether entered a new life... with a different reality".*

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. This was also evident in the words of a mother of an ADHD child:

*"Doctors now say that her extreme behavioural ups and downs could have been managed well if the problem had been detected earlier. But who will detect the problem? I took her to so many paediatricians and every one of them said that with age she would be fine. It is just that she is extremely naughty and rude...Now she is a kid and too young to be controlled! But now she has been diagnosed with ADHD at 5 years of age*."

Throughout this journey, one finding that recurrently came to the surface was the absence of early detection and intervention facilities in Kolkata and its surroundings. Delay in early detection remained a major crisis for parents in almost all cases, particularly for autism, Down syndrome, and ADHD.

Figure No. 3.2 and Table No. 3.6 explain the emotional crisis experienced by the parents. The model of the emotional crisis was adopted from the one provided by Kandel and Merrick (2007). It is evident from the figure (3.2) and table (3.6) that although all of the three crises were found significant among the parents, the crisis of reality was experienced by the parents more frequently (90%) than the other two forms of crisis.

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

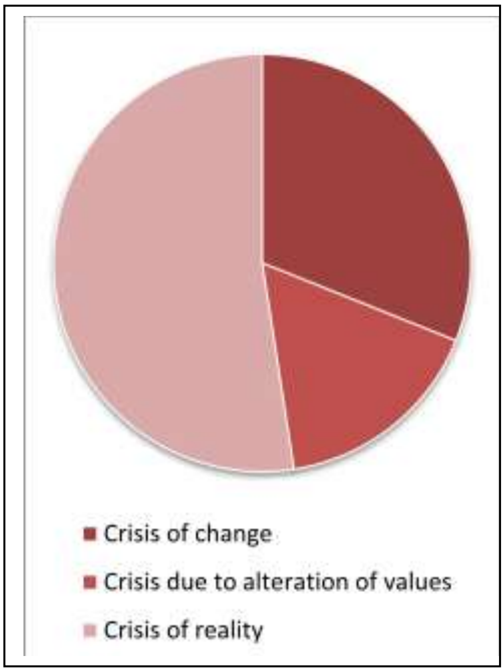


**Table No. 3.6: Information on the emotional crisis of the parents**

| 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 intensity of such an emotional crisis among parents, however, was found to vary depending on the kind of exceptional physiognomy with which the child was identified. Those parents who had children whose disability conditions held some hope of improvement; or, to be more precise, in cases where early interventions and therapeutic sessions offered hope for parents to see their children being moulded into mainstream socially accepted behavioural patterns and personality development, the degree of the emotional crisis was observed to be decreasing with time. In such instances, parents had managed to connect with the normative structure of childhood development patterns (much of which was expressed through behaviors, actions, and personality development of the child in his or her early years) as it was shaped by the socio-cultural environment within which the child was being raised. Such instances are common for conditions like Down syndrome, ADHD, specific learning disabilities, and autism.

Parents of children with health conditions like cerebral palsy or rubella syndrome expressed significant levels of emotional crisis in their interviews. High degrees of emotional crisis did not seem to cease over time, even when constant medical interventions and therapeutic sessions were taking control of managing the disability. Extensive conversation with the parents flashed periods of intensive emotional crisis among them, which primarily stemmed from feelings of ineptitude. The feeling of ineptitude was observed to have been derived from the existence of higher levels of diversity and challenges in the children, on one hand, and on the other hand, it was derived from a perceived sense of futility over the interventions that were adopted or recommended for their children. This perceived sense of futility among the parents was nurtured and sustained by a conceptual model of what they considered to be a healthy child and how they perceived the diversities. This parental conceptual model of disability was the result of a socio-culturally cultivated ideology of what was considered normal and healthy. When the parents placed their children with disabilities outside the socially and culturally accepted standards of being normal and healthy, they found themselves with emotions that could not be explained in words and expressions. Such reactions among the parents have been accounted for in this research as a crisis, or an emotional crisis. The following statement by a parent makes it more transparent:

*"My baby has been diagnosed with Autism Spectrum Disorder. Doctors say that there is no permanent remedy for this disease. Only continuous treatment and therapy can alleviate the difficulty and increase the child's ability to respond. I was very sad and down, which still persists to some extent. I didn't know what the disease was about or why it happened to my child. But I knew that my child was not a 'normal' child and he would never be normal. My child will never go to a 'normal' school, will have no friends, and will never have the 'normal' life that we live."*

The degree and intensity of emotional crisis have also been observed to vary based on the socio-economic profile of the parents. 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, make 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.

## 3.6. Conclusion

People confront the world of reality by perceiving it objectively as a given frame and subjectively reflecting back, which reshapes and helps in the re-conceptualization of their given reality. This is primarily executed based on the experience, context, and internalization of the wider cultural norms that an individual learns through socialization. Titchkosky and Michalko (2012, p. 129) have commented that the world was encountered and received by people as a "framed" reality. Disability in general and conceptualizations centering on intellectual and cognitive conditions in children, in particular, were presented before parents in frames that guided their perception and comprehension of disability and diversity. The narrations and lived experiences of the parents reflected that when the parents had confronted the reality of their children being detected with certain disabilities, they were presented with a ‘dual framework’ of understanding the disabilities. Firstly, when the parents had learned about the diagnosis, their immediate cognition was drawn heavily upon the common sense understanding of what and how they already knew about disabilities and diversities, much of which was shaped and ornamented by the wider socio-cultural framework within which disability and diversities had been defined. Thus, they were presented with a socio-cultural framework for understanding disability. Secondly, the parents were presented with a medical framework of understanding disability that looked at disability as a problem (Goodley, Hughes and Davis, 2012, p. 132) and hence needed a solution (treatment or rehabilitative measures). The parents had been observed to have accepted such a medical framework of disability and had begun to comprehend the diversity in their children as a problem and not just as a natural condition born out of biological diversity.

The initial reactions of despair, stress, fear, stigma, emotional crisis, and trauma among the parents were sensitively woven around the frame within which they understood disability as a problem. When they had internalized the fact that their children were born with some problem or defect, they encountered a reality that was completely different from the one they had already taken for granted. This sudden counter-interaction with a different reality made the parents sink into feelings of shock and trauma, followed by periods of emotional crisis. The following extract makes it more understandable:

*“Disability is framed as a phenomenon located and locatable only outside of the taken-for-granted life-world as well as outside of the natural attitude. As such, it is thus understood as marginal to the common-sense world and, as such, as outside the intuitively given reality. Disability is one source of what Schutz (1973, p. 228) calls the “fundamental anxiety” insofar as disability can, and often does, disrupt the taken-for-granted character of the world and our life in it."* (Titchkosky and Michalko, 2012, p. 132).

The understanding of disability among parents has been shaped and moulded by the social reality within which they live and acquired its meaning through the shared understanding of that reality with their social counterparts. Knowledge and understanding of disability have also been woven into the social reality as something which is not deserved, not expected. In instances where the children were detected with developmental delays or intellectual developmental disorders like Autism spectrum Disorder, Down syndrome, or specific learning disabilities, the optimism that was attached to existing interventions reduced stress among the parents. The reality, however, was very different for parents who had children with extreme forms of disabilities like cerebral palsy, Rubella, and multiple disorders. In these children, the scope of improvement through medical interventions was very limited. This has intensified the burden of trauma, stress, and anxiety among these parents. The hope that the counter-reality could not be re-produced and re-shaped into its previous equilibrium was distorted permanently, which left the parents to dig further into feelings of grief.

# Chapter- 4

# Challenges of Parenting: Care and Contests

> ***"A Child is as disabled as their environment and the beliefs of the people around them."***
>
> ***-Bala Pillai (DPTS, PCS)***

## 4.1. Introduction

Children with certain diversities in their intellectual, and cognitive functioning stood at the juxtaposition of a 'dual-identity'- of being a 'child' (like any other child we came across in the social world) and a 'child with disability'[1]. While raising children with disabilities, parents faced needs that emanated from both these identities. Children with disabilities had needs and requirements, that were similar to those of other children of similar age and stage of development, and at the same time, they had exclusive needs that were unique to them. 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. It was, however, important to understand that those identities were produced and reproduced among the parents in the interaction situations that took place, both at the micro and macro-societal levels.

In-depth interviews and conversations with the parents revealed several issues that parents had encountered in raising their children with disabilities. Their accounts did not only reflect their experience with other people, friends, relatives, professionals, and doctors as individual actors from different social systems in their society but also exhibited their encounters with the wider social structures and institutions while managing and dealing with their children's diversities. Parents' engagement with the wider contextual macro-level societal interactions was observed in many instances when they had applied for the disability card in the government hospitals and needed to pass the bureaucratic maze; when they had taken their child for admission to a school; or while choosing whether to put their children in regular or special schools; and even when they experienced hindrance about the mobility of their children with disabilities in the structural and architectural planning of public places and poor transportation facilities and arrangements that barred the parents from carrying their children. In all those encounters, both at the micro-individual and macro-societal level with which parents were engaged, the definitions, meanings, and understanding of disability were constantly constructed and re-constructed. Detailed analysis and interpretation of the parents' accounts indicated that the perception and understanding of disability among the parents were nurtured by the wider socio-cultural context within which they resided and had been shaped by the medical gaze in which they found themselves when they encountered the reality that their children were diverse. Parents' encounter with a different reality and their confrontation with everyday challenges in taking care of their children with diversities have contributed, to a great extent, to understanding how disability and diversities are constructed through their interaction with the mundane social reality. This provided the research with the scope to re-conceptualize the construction of disability within social realities.

In the following section, we have analyzed and interpreted parents' accounts of their experiences and challenges in raising their children with disabilities and diversities. Three broad themes, followed by concluding remarks, have been reflected in this chapter to express parents' accounts of their challenging experiences. The first theme has shown how the medical gaze on disability has impacted parents' perception of disability. The second theme has been covered through discussion about the nexus that exists between parenting and caregiving. The third and final theme of this chapter has highlighted the challenges that parents have encountered in the public domain, at the system level of interaction.

## 4.2. Confronting the Medical Gaze of Disability

### 4.2. 1. Knowledge Supremacy and Real Contradictions

The medical model of understanding and conceptualizing disability has been observed to have shaped the disability discourse in India. 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 the 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 has been 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). It also aided the research in understanding how they 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. Within the medical model of disability discourse, the panopticon has been observed to have developed and emerged out of the expert knowledge that shaped the medical paradigm in relation to disability and formed a medical gaze around the diversities in children. This kind of medical gaze has been found to have encircled parents' understanding 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 in their children. Thus, the power of expert knowledge was found embedded in the medical paradigm and was observed to have a profound impact on parents' understanding of disability and diversity. Power, according to Foucault (1971, p. 11), has constructed dominant discourses in society (Goodley, 2012, p. 198), and it was through the dominant medical model discourse that knowledge in the field was produced and power was bestowed on the structures, institutions, and people associated with the dominant discourse. The discourse, which was born out of the medical model of disability, had a wide impact on the manner in which the parents perceived diversity in their children. The initial reaction of the parents after encountering the reality of their children's diversities was also found to have been influenced by their knowledge about disability—the knowledge that was shaped by the dominant medical discourse on disability.

The creation of disability as such has been well reflected in the way diversity has been defined and adopted by the state legislation regarding disability. The Persons with Disabilities Act of 1995 and the National Policy for Persons with Disabilities in India (2006), talked about certain entitlements and reservations in the sectors of education and employment from the state which were meant for children with disabilities. However, this came with the condition that the disabled meet the required forty percent level of disability in order to obtain the disability card[2] and receive certain state benefits. In this context, it was necessary for the medical boards to devise scales or yardsticks for measuring the diversities in the children and to see whether they qualified for the required level of forty percent of disabilities in them. For children with intellectual, psychomotor, neuro-motor, and developmental diversities, evaluation, and measurement of disability levels were difficult and did not have any fixed criterion based on which such measurements could take place. A clinical practitioner in the field from the Institute of Psychiatry, Kolkata, maintained that:

"*In cases of Autism Spectrum Disorder, Down syndrome, ADHD, OCD, and specific learning disabilities, we do not have any fixed measuring device. We have certain activity-based scales with which we match the symptoms of the children and collect data from the parents' observations. We match all of them and reach certain conclusions about the disorder the child is facing. The level at which the child shows symptoms varies according to the social and familial context. Thus, we depend more on the symptoms the child has been expressing through his activities and behavior. At any point in time, we cannot say that our diagnosis is 100% correct, but based on observation and symptoms, we can reach a certain conclusion about the disabilities.*"

From the above narration, it became clear that there was no universal device or scale to measure the level of disability for a child and that it was more based on the symptoms the child had been expressing through different activities and behaviors. Parents complained that the results of such an evaluation were far from the everyday reality and challenges that these parents and children were exposed to. A mother of a four-year-old son with Autism Spectrum Disorder said that:

*"My son is shy. He is scared of too many crowds and unknown people. Every time I took him to the hospital, he became very quiet. During his sessions with the doctors, whatever activity they gave him or asked him to do, he responded by being very scared, and when he failed to do the given activities, he sat quietly moving his hands and legs rapidly. His autism levels, according to the doctor, are not at 40%. I repeatedly told them that his behaviour at home is completely different and that he can be very violent and difficult to deal with at times. But doctors said that since no such behaviours had been observed in any of the sessions, he was not eligible to receive the disability card."*

Once during the interview, this mother expressed her anger and anxiety, saying that:

*"Sometimes I wish that my son was a bit more disabled, a bit more autistic, to reach that 40%... at least we could get the "so-called' benefits from the state in education and employment."*

### 4.2. 2. Encountering a Bureaucratic Maze: "My Child but not My Decision"

A mother of a five-year-old boy with Down syndrome pointed out that from the moment his son was detected with Down syndrome, it was like all decisions regarding her child's life, actions, and activities were to be decided upon by the medical system at large. She narrated that:

*"Every time I visited a hospital with my child, I felt like I was moving from one department of child and infant care where his physical check-up was conducted to another where his hearing capacity was measured, then to another where his speech was observed, and so on. Even outside the hospital, visits to special intervention centres for speech therapy and physiotherapy and making decisions for him which were not mine but as per the recommendations of the medical professionals, sometimes made me feel that my son was not mine! !"*

The parents' accounts of their lived experiences reflected a completely different world of reality than that which was perceived by the medical professionals about raising children with disabilities. Ludlow, Skelly and Rohleder (2012) in their research observed that parents of disabled children found the medical gaze and professional interventions to be intrusive, which often involved inadequate understanding of the socio-demographic profile of the parents. This was often overshadowed by unquestioned adherence to the medical model of disability.

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

| **Responses on disability card** | **No. of cases*** | **Percentage (%)** |
|---|---|---|
| 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 |
| **Total** | **32** | **100** |

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

Table 4.1 shows details about parents' responses and attitudes towards accessing the disability cards. Eleven parents in my research had never applied for a disability card because they saw no usage or utilization of such cards unless the structural barriers of the public spaces were worked upon. For example, the provision of special schools was assessable only when the children could be carried on public transport or roads with accessible provisions for easy movements of the wheelchair or other aids used by the children. Similarly, reservations in education and employment only became meaningful when access to the relevant institutions and organizations was made possible through public transportation and changes in the architecture of public buildings, roads, institutions, and organizations. Nine parents had reported that after moving to the concerned offices several times for several months after applying for the disability card, they had discontinued their effort to receive the card. They had stopped visiting the offices and did not think the effort of getting the card would be worthwhile for them.

These parents had said that it was becoming impossible for them to visit the hospitals so many times, leaving aside the number of hours it took each day to get tickets and wait for their turn for evaluation. A father said that:

*"I just stopped at a time. I had been trolling around this hospital and that office for almost nine months with no positive feedback from any of the departments. My leaves were over. It was not possible for my wife alone to run here and there along with my daughter (who has ADHD). I don't want any cards or help from the state. I understood that she is my child, and I have to make a decision for her. My child was not mine anymore with these hospitals and doctors. They didn't listen to us. They treated her like any other object of experimentation. Enough of it! I would rather earn more and secure her future with some organization that would take care of her after us."*

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. Parents had agreed that receiving disability cards was a real challenge for them. The different 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. This had caused the parents to move to the government offices several times to get their papers certified and sanctioned by the concerned authorities. The whole process caused a lot of physical, mental, and emotional drain on the parents. All the parents who received disability cards had accepted that it took almost one to two years to get the diverse needs of their children certified.

### 4.2. 3. Non-Recognition of Parents’ Knowledge: “I know My Child the Best”

In the context of India, parents are considered and recognized as the primary caregivers of children with disabilities. The parents' constant interaction with their children's daily needs and requirements trained them to be experts in understanding their behavior and communication. With due course of time, understanding their children’s behaviour and needs, making decisions about their requirements, and discussing children’s responses to the treatments and interventions with the professionals had enhanced their knowledge and expertise in dealing with these diversities.

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”[3] (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”[4] (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. One of the clinical practitioners in the field from Kolkata agreed that parents’ constant exposure to the disabilities and diversities which they had encountered in their children developed expertise and understanding of the disability, which sometimes outstripped the understanding of the professionals, particularly while dealing with the diversities in the real familial circumstances. The parents in my research claimed that they knew their children better than anyone else did. A mother of a ten-year-old girl with autism Spectrum Disorder shared one such instance:

*"We have two professional therapists who visit us to provide speech therapy and physiotherapy. My daughter enjoys drawing and painting whenever and wherever she wishes to. I help her with drawing, sometimes holding her right hand. One day, during her physiotherapy session, the therapist was trying to move her right hand up and down when suddenly she took it away with a heavy jerk. He tried another time... She repeated the same thing. This was repeated several times. The therapist left. He reported the incident to the doctor, mentioning that she had developed problems moving her hand up and down. At the next visit, when the doctor asked me about her right-hand functioning and explained what the therapist had reported, I told him that she was having no issues with moving her hands, it was just that when you hold her hand she thinks she needs to draw, and when you are pulling the hand down she is taking the hand away as she wants to continue her drawing, though in the air. I was surprised that the therapist just concluded about her health without having a discussion or at least informing me. I am the mother, and I know my child best!"*

Children with disabilities are likely to experience several encounters with doctors, medical staff, and professional therapeutic services concerning their special and complex needs. Hence, the quality of the relationship that the parents developed with the medical staff had a greater impact on the quality of services these children received and experienced (Hewitt-Taylor, 2008, p. 132). Moreover, a healthy and positive relationship between parents, medical staff, and professionals was observed to have helped in the coordination, communication, and organization of the services the children had received. A mother of a child with autism shared her awful experience with the hospital's staff whenever she applied and queried about the disability card for her son:

*"It has almost been one and a half years since I visited the hospital and every concerned department to get the disability card for my son. My son is required to reach a 40% level of disability to get the benefits of the card from the government. And to prove that whether he had that level of disability or not, I had to take my son every time they asked for"*

The issue of disability cards for their children to receive state entitlements and benefits was another monumental challenge where the parents had encountered the bureaucratic structure of the medical and state facilities meant for disabled people.

**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<br>Collaborating with parents at different stages of decision making with regard to interventions.<br>Encouraging or motivating parents in encountering the diversity<br>Generating optimism about future* | **08** | **25** |
| **Negative** | Dis-belief and dis-trust by doctors to parents' observation<br>Talking to parents in strict medical terms<br>Recommending interventions without discussing the affordability or other related resources the parents required to have. | **18** | **56.25** |
| **Indifferent** | Very impersonal levels of interaction without much reciprocity.<br>Majorly one way interaction that followed from doctor to parents, and the latter accepted it as general interaction pattern between doctors and patient. | **06** | **18.75s** |
| **Total** | | **32** | **100** |

***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.**

Table No. 4.2 captures the relationship between parents and medical professionals based on the responses given by parents. Interviews with the parents also reflected a positive development of relationships with the medical professionals and experts. A father, who took his son to NIMHANS where the child was detected with ADHD with symptoms of OCD, asserted that they (the parents of the child) along with the doctors, medical staff, and members of the management were working together as a team. The doctors had listened to the parents and recognized their observations and even altered certain parenting practices while dealing with the child that might have proven beneficial for the child in the long run. Parents were involved throughout the medical process, starting from the diagnosis to the interventions required and in the overall decision making -at all levels of the treatment procedure.

In my research, parents reported that this was the most difficult journey that they had experienced. They had pointed toward the non-coordination among different departments in the government hospitals that were responsible for issuing the disability card after running a series of diagnostic procedures on the children to prove that the child had 40% disability and was eligible to receive the disability card.

### 4.2. 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 centers 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. In-depth conversations with the medical professionals and clinical therapists revealed that early detection of the disabilities and early intervention after the diagnosis had yielded significant results for these children. According to them, the early years were important for these children in learning, and with required interventions, they could have maximized their learning potential. Early intervention has been proven in many evidence-based types of research to leave immense scope for providing relevant information, recommendations, and support for parents that are specific to the diverse needs of their children. It was suggested that delayed detection and intervention might have led to the development of further behavioral, cognitive, and psychomotor complications which could have been resolved with early intervention. With early intervention, it was also important for the parents to have conducted and administered the instructions and suggestive procedures correctly, or else that might have led to further deterioration of their health.

In-depth interviews with the parents illustrated how the hegemonic medical knowledge and supremacy had disregarded and overlooked the parents' observation of their children. In instances where the diversities in the children began to show or develop during the early years of their developmental stage - like in 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. 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 stimulus around them. However, the observations and knowledge of the parents about their children were discounted against the existing medical diagnostic procedures.

The elaboration of one instance would make the context crystal clear. Mr. and Mrs. Goswami from Barasat (an area covered under the Kolkata Municipal Developmental Authority) had their second child (a son) which was twelve years after their first child (a daughter) was born. At around the age of two, the mother began to notice that her child was not responding to her calls every time she used to call him by his name. When the child was two and a half years old, Mrs. Goswami could notice that his response to her calls was getting gradually reduced and he was becoming shyer than before in the presence of other family members or friends. She began to suspect certain changes in her son's expressions and behaviors. During a regular medical check-up and vaccination she expressed her concern to the paediatrician, who outrightly rejected her claims, after running some regular physical check-ups on the ground that she was being overly attentive and conscious about her son. He also suggested she not put her son under close monitoring because that might create more behavioral complications for the child. However, Mrs. Goswami was not satisfied with the reply. When she discussed this with her husband, he suggested she keep an eye on the situation but not be too anxious about it. At around three, their son completely stopped answering calls and began to avoid eye contact. This made her more anxious, and they took him to see another renowned pediatrician from Kolkata. It was the same story again when the doctors had prescribed the child to be normal without any noticeable difference from a regular child. At around four, he was put into a school when complaints from the teachers began to increase. Most of these complaints included his extreme level of inattentiveness and disobedience. Mr. and Mrs. Goswami decided to take their son to Vellore and started contacting the doctors both over the phone and online. From there, they were recommended to contact the doctors from NIMHANS, Bangalore. After preliminary discussions, they took their child to Bangalore, and there he was diagnosed with an autism spectrum disorder with borderline OCD (Obsessive-compulsive Disorder). The doctors there even told them that, had this condition been detected earlier with the necessary interventions, it would have yielded good results as the interventions would have worked well at the early stages of development of the condition.

The story of Mr. and Mrs. Goswami was not an exclusive one. Many parents in my research had undergone similar experiences where the paediatricians had neglected parents' observations and opinions regarding their children. The story reflected the negligence of both the state and central governments with regard to the establishment of specialized institutions for early detection and intervention of certain diversities, which were not possible in a regular hospital set-up without any experts having specialized knowledge in the field. Conversations with a few doctors regarding my research pointed out that most practicing paediatricians had very limited exposure to issues that were associated with the intellectual, developmental, and psychomotor disabilities of children. There had been no provisions for any special training or workshops for general paediatricians who were not specialized in the field.

Delayed detection and diagnosis were also found to have resulted when the disabilities were not manifested as prominent symptoms but masked behind other health issues that were not directly associated with the disabilities. For example, the parents of a child with rubella syndrome described how their child was born premature and was kept in the intensive care unit with complaints of breathing difficulty, which happens to be true for most premature babies. They had brought her home after two months. She had begun to develop the symptoms of bronchitis within one month and was again hospitalized. At around the age of five months, she caught pneumonia. Until it was around six months later, when the child's uncle, who happened to be a doctor in the United States, noticed her crossed legs posture in almost all the pictures they used to send him. He suggested they carry the matter forward with serious attention, and finally, she was detected with symptoms of rubella syndrome. It was also detected that her continuous ailment related to breathing was due to the ill-formed lungs and the poorly positioned structure of the heart.

## 4.3. Care and Parenting Realities

### 4.3. 1. Parent as the Primary Care-giver

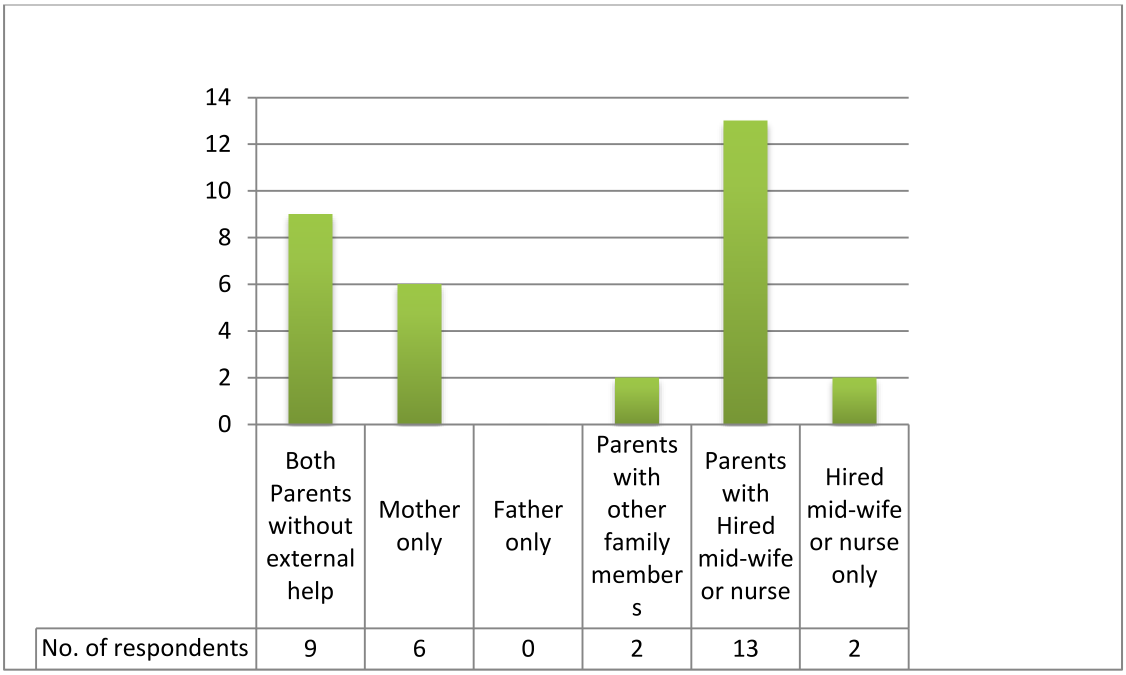
In social interaction situations, both at the micro-level (with friends and family members) and the macro-level (with medical and clinical experts, care providers, and other service-related facilitators) the parents' identity as mother or father of a child with diversity became dominant in the other identities and the role the parents were found to have possessed and executed respectively. A mother of a child with autism spectrum disorder expressed her disgust when other people looked at her primarily as a mother of a child with autism. Everybody who saw her used to ask and talk about her child and about the recent interventions in the market that might have worked well with her child's disability condition. She felt like she had no other identity than being the mother of an autistic child. She claimed that:

*"In addition to being the mother of my autistic child, I am a wife, a daughter, a sister, a citizen, and a former school teacher. I like to talk about other things and I do also have opinions regarding other things - about the state, politics, education, and so forth, but not just the autism of my child."*

Within the recent context of disability and care, the home was observed to have institutionalized into a rehabilitative space where people with disabilities were taken care of, where their daily interaction with other people in the family turned into "teaching moments" and where the therapists and special educators came and went throughout the day (Sarrett, 2015, p. 260).

Figure No. 4.1 shows the detailed picture of the care work burden shared by the parents of children with diverse needs in Kolkata.

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



| | Both Parents without external help | Mother only | Father only | Parents with other family member s | Parents with Hired mid-wife or nurse | Hired mid-wife or nurse only |
|---|---|---|---|---|---|---|
| No. of respondents | 9 | 6 | 0 | 2 | 13 | 2 |

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. The figure also conveys that in households where there were provisions for hired care services, it did not go without the intense involvement of the parents, particularly the mothers. Only in two households was the care work handled by a hired midwife or nurse solely.

In India, family and care agencies were given their due importance in the legal discourse for the first time after the implementation of the Rights of Persons with Disabilities Bill 2011 and the Rights of Persons with Disabilities Bill 2014, following the footsteps and guidelines as mentioned in the UNCRPD. However, still, no clear definition of "home" and "family" had been provided in the bill, as if it was taken for granted that it was the parents and family members who had the primary responsibility for the care of these children (Sen, 2016, p. 69). The central role of a family in extending care, support, and sustenance has also been pointed out by Dalal (2002, p. 21), particularly when disability is under discussion. Dalal (2002, p. 21) has further mentioned that the major burden of this care work is sustained by the female members of the family, like mothers, sisters, and daughters; and most of the time (if not always), these services remain unacknowledged and continue to be recognized as a form of informal labor.

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. A similar pattern of raising children with diverse abilities was noticed in my interview with some (parents of fifteen children) parents, who had expressed their doubts about the prevalent special education and learning systems that were meant for children with disabilities. These parents, instead, focused more on teaching and training their children to meet their daily needs by themselves.

This trend has been found popular among parents who were involved with organizations, like “Jagori”[5] and “Disha”[6] in my research, who had jointly devised ways to teach their children activities like folding clothes, washing their own plates, wearing clothes and shoes, combing hair, and maintaining their personal hygiene. In some instances, they were assisted by trained special educators whom they had hired at their own cost. These parents made it clear that they had developed the least hope from the state for the development and maintenance of their children, and as a result, they set out to train their children in doing and managing things in their own unique ways. A father narrated:

*"In these four years, running several times to hospitals, visiting doctors hundreds of times, and a series of check-ups and therapies have made me learn one thing: if I cannot help my child, no doctor, specialist, state or even doctor can save my son. So, I decided to work on him. I read many books and journals and kept in constant touch with one doctor I met at NIMHANS, to discuss the improvement I noticed in my son."*

## Table No. 4.3: Parents' response on type of schooling they preferred for their children with disabilities

| **Responses** | | **For No. of cases*** | **Percentage (%)** |
|---|---|---|---|
| **In support of special schools** | Admitted the children to special school and still continuing **(10)** | 17 | 53.12 |
| | Admitted the children to special school but had to leave it later for issues related to accessibility and expense **(03)** | | |
| | Supported special schools but could admit their children due to issues related to affordability, expense and physical accessibility. **(04)** | | |
| **Not supporting special schools** | Did not support special schools but could not admit to regular schools either **(04)** | 13 | 40.62 |
| | Admitted the children to regular schools **(5)** | | |
| | Admitted the children to regular schools but has to withdraw later due to stigmatization and non-cooperation from teachers, management and other children. **(4)** | | |
| **Preferred home teaching** | Did not support special schools and did not admit their children to regular schools | 02 | 6.25 |
| **Total** | | **32** | **100** |

***The number of cases refers to the number of children.**

Table No. 4.3 enumerates how parents expressed their views on putting their children with disabilities in regular or special schools.

Both fathers and mothers, engaged in this research, agreed that being able to give birth to a child had fulfilled the social and cultural commitment they felt they had towards their family and society. Parents had expressed gratification, contentment, and fulfillment in being able to bear a child, believing that it would carry on the familial or parental legacy for future generations. In my research, I included the accounts, experiences, opinions, narrations, and perspectives of twenty-eight fathers who had children with disabilities, along with the thirty-two mothers, to reflect gender-neutral parental perception and understanding of disability in general, and the disability condition of their children in particular. Taking into account both fathers and mothers also aided in highlighting the existing gendered division of labor in relation to the care-work and chore-load that the parents had to bear.

### 4.3. 2. Father's Involvement in Care

With regard to child care, fathers were considered secondary, with mothers bearing the primary burden of caregiving (Gupta, Rowe & 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 of their children, at least up to the initial years (Ghosh & Banerjee, 2017; Ghai, 2018; Chakravarti, 2020). Five fathers in my study were found to have subscribed to the conventional ideology of fatherhood, in which household obligations and care responsibilities began and ended with providing financial and material support for child care, making family decisions, and being the breadwinner. There were also many fathers who were observed to have supported their wives both materially and emotionally and were found to have been actively involved in child care. Fathers' perceptions, roles, and emotional involvement with the child could not be universally generalized as there was "no single type of father" (Parke, 1996, p. 2).

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

| Father's involvement towards household and care-work | Fathers | Percentage (%) |
|---|---|---|
| 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% |
| **Total** | **28** | **100** |

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. These fathers maintained a clear conventional gender division of labor as far as the care and chore activities were concerned. They considered that their responsibility was to provide all kinds of material comfort to the family and to provide them with the required material financial security. On asking about sharing the care and chore activities in the household, the father of a child with multiple disabilities replied that:

*"My task is to earn money, bring food, and provide all the things necessary to survive in good condition for my wife and child. It is my wife's duty to handle the home and my son, and she does it very well. I think women have this inherent quality within them. Since she takes care of our son, I support all her decisions and choose not to intervene in the way she likes to handle the care activities for our son."*

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. On asking about the involvement and engagement with chores and care, they narrated that they had assisted their wives by taking care of their children so that their wives could finish the household chores without any hurdles. A father of a child with Down syndrome said:

*"I try to keep Akash" (the child's name) engaged by playing with him or doing other activities with him so that his mother can complete her tasks at hand without the simultaneous caregiving hassle she takes during my absence."*

Nine fathers were found to have supported their wives both emotionally and materially by sharing the tasks of care and chores. These fathers were found to be actively involved both in caring for their children and also in sharing certain everyday household tasks, to assist their wives in managing the home and the children with disabilities.

The above findings were found to have ample resemblance to Hochschild's classification of three types of gender ideologies about the division of labour in the household: traditional, egalitarian, and transitional. In the traditional ideology, the conventional ideology of home-centric women and men's domination in the workplace and public spheres was idealized. Under egalitarian ideology, both men and women share the responsibility of both paid and unpaid labour in the household. In the transitional gender ideology, it was observed by those who believed in women's empowerment and celebrated their significant engagement in the public sphere, but at the same time, held that family and care-work should remain a women-centric domain. Fathers who were observed to remain uninvolved (five) seemed to have adopted the traditional gender ideological model in justifying their disengagement towards their share in household and care activities. Similarly, fathers who were involved in child care and household work believed in an egalitarian gender ideology. Thus, gender ideology was observed to have framed the feeling rules for the fathers, which they adopted to justify their emotional display and which they felt appropriate to employ within their social and familial context. Fathers' role and contribution towards sharing the care-work responsibility of the child or sharing the household chores were accounted for from fathers' narration of their lived experiences and opinions and from a mother's opinion on their husband's contribution in handling both care and chores. A mother who was a homemaker narrated that:

*“My husband made it clear from the beginning that he could not give much time to our child. He said that he can help me by watching him do things or monitoring him or stopping him from doing things that would harm or injure him while I complete my regular household chores, but cannot play with our child. He does not know how to play. He said he would bear the expenses, as much as possible, and whenever needed.”*

Paiva (2016) demonstrated in his work how fathers were evaluated using dual social standards (Gupta, 2020, p. 51-52). On one hand, fathers were reproved for not contributing to a child’s development or for not being present in the life of the child whenever he/she needed him the most. On the other hand, fathers were expected to bear the excessive burdens of expectations on them to fulfill all the material demands of the family and also to set an example on the professional front to become role models for their children. In my research, fathers stated that they 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 commitments and childcare tasks. A father of a ten-year-old child with Down syndrome commented that:

*“I liked taking my child to doctors, intervention centres, and special therapeutic sessions, but I had to stop. Initially, I carried both my child and wife to attend the intervention and therapeutic sessions, but the number of leaves from the office created job concerns for me, and I had to face work issues with my colleagues and the clients whom I dealt with. I had to stop. Now my wife has to take him to his therapy sessions. We often miss one or two sessions a week. It is not possible for my wife to manage all alone.”*

Many (nine) fathers in my research claimed that they shared the load of care work and helped in managing household chores. Their claims had been well supported by their wives when a mother narrated that her husband (a father) cooked dinner and organized the vegetables and other stuff that she might have required the next day to cook breakfast and lunch. Similarly, another mother said that:

“*We (mother, father, and daughter) play together in the evening. Play-related activities are guided and recommended by professionals. We practice it in the form of* *play every day. She (my daughter with autism spectrum disorder and borderline ADHD) enjoys this time of the day... She loves her father a lot."*

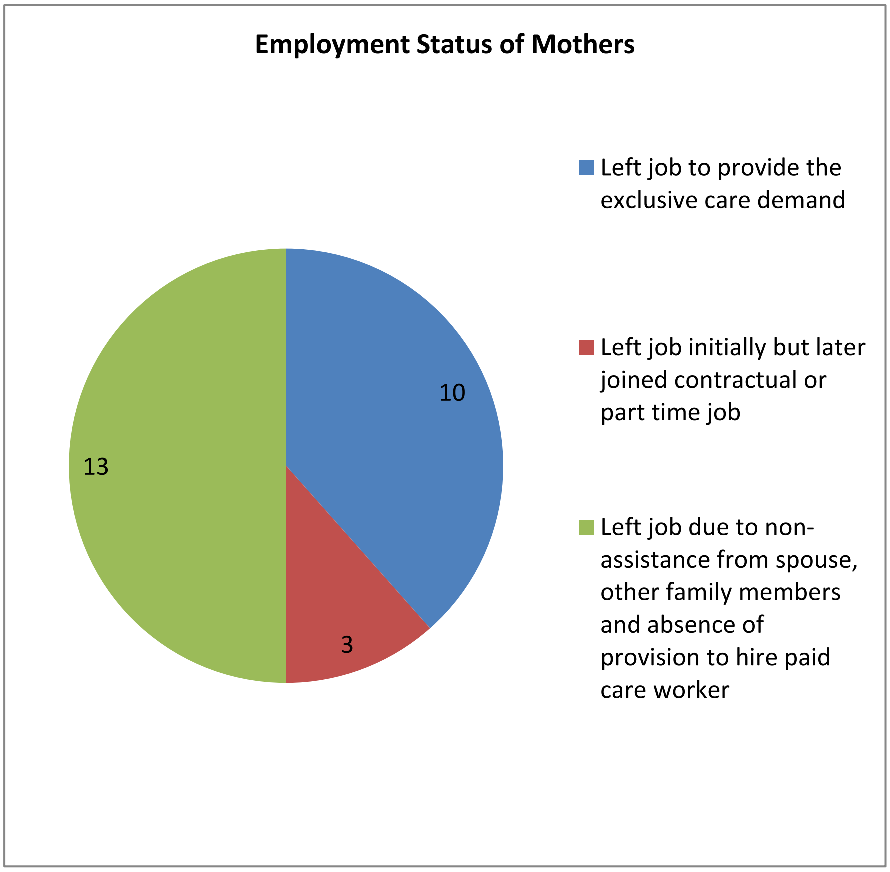
Of the twenty-eight fathers, fourteen directly took part in child care. The kind of care work performed by fathers included day-to-day activities of care like feeding or bathing, taking part in the development and improvement of the child's health state, and playing, which engaged the child with specialized activities that were recommended by the medical professionals. Some fathers agreed that due to their highly emotional attachment to the children, they often failed to play and interact with them, as any failure or inactivity by the children made them negative. They, instead, preferred to assist their wives in handling and managing the household chores. A father of a child with ADHD commented that:

*"I ignore playing recommended games and activities with my son. Seeing him doing things in a different manner makes me worried and adds to my already existing stress and anxiety. I ask his mother to continue with the activities while I finish off cooking, cleaning stuff in the house, putting clothes in the washing machine, and other things that my wife asks me to do. I would rather feel good when I am at work… be it office-work or household…does not matter."*

### 4.3. 3. Seeing Mothers as the Epitome of Care: Internalization of Motherhood

In India, mothers are considered to be the primary caregivers of their children (Edwardraj et al., 2010; Azeem et al., 2013). This consideration became more profound when the child was born with disabilities and turned out to be more stern and demanding when the disabilities began to develop during the early years of the developmental stage of their children. In my interview, mothers subscribed to the belief and perception that no one could take the best care of their children and could understand their needs better than they. Seven mothers among them, who were working previously, believed that the caregiving role and career prospects of a mother could go hand-in-hand, and they were found to have chosen to leave their jobs in order to provide care and attention to their children and manage the diversities well. Personal accounts of these mothers reflected that the perceptions and ideologies relating to motherhood were deeply embedded in them. By stressing their role as mothers, they placed their motherhood at the center of their lives and identities, which even made them compromise their professional lives and careers.

**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.**

Mothers' responses to the perception of care and career are represented in Figure No. 4.2 and Table No. 4.5.

Figure No. 4.2 shows that the majority of the mothers who were working before their children with disabilities were born left their jobs to provide care. Among all the reasons that compelled them to leave their jobs, the non-assistance from family members and spouses was the most significant. Getting back into paid job sectors was possible only for three mothers.

In my interview, mothers expressed that the medical professionals and doctors reflected more on the mothers when it came to suggesting and recommending care-work and management of child behaviors; but while discussing matters regarding monetary expenses or any kind of decision-making issues, they preferred talking to the fathers. Thus, a gendered loom was clearly evident among the medical professionals and doctors in the manner in which they approached the parents. While mothers considered that although they were the best caregivers and mentors for their children, it was never compensated for by the mothers' need for time and space for themselves. Some mothers (sixteen), however, believed that care work could and should have been shared by other family members or fathers or by any hired care worker whose service would fulfill the needs of their children and would also provide care and love, which might not match the mother's love but which by no means could be underrated. There were some mothers (thirteen) in my interview who, while believing in the idea of balancing care and work, had to leave their jobs against their choice due to the lack of adequate social support (assistance from family members, neighbors, friends, or hired professional services) and also as a result of the financial calculations they made from their context.

In-depth conversations with the mothers reflected a strong affiliation of the mothers towards "intensive mothering"[7] (Hays, 1996) and care. Mothers of children with disabilities were observed to have perceived their role of caregiving as an indispensable part that was inherently associated with their identity of motherhood, and this kind of perception of the indispensability of a mother as a care provider was learned through internalization of the socio-cultural gaze she lived within. Adrienne 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.

**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 |
| **Total** | **32** | **100** |

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. The following narration of a mother made it more comprehensive:

*"I left my job. Neither was it my spontaneous choice, nor was I forced by anyone but circumstances. I earn well, but my husband earns more. We calculated the expense that we would have if both of us continued to work. We found that the expense of hiring a full-time care worker, domestic help, and expenses related to managing the disability condition of our children have exceeded the budget taken together. Taking all the expenses together, it was more than the money I earned."*

Mothers reported that over-involvement and over-indulgence with the care-work burden made them lonely and isolated from the peer circles they had earlier. In her work, Upali Chakravarti, in her work "Burden of Caregiving in India" (2008, p. 358), pointed out how women often had to look for paid employment to ease the financial burdens along with organizing the household and managing their needs and caring for their children with disabilities. These contexts, along with the absence of strong social support systems and assistance from family and friends, have been found to have affected the physical, mental, and emotional health of the mothers. Mothers in my research talked about their phases of frustration and about their journey of depression in combating the challenges of dealing with the disabilities that their children had. Figure No. 4.2 and Table No. 4.5 above provides a comprehensive picture of mothers' employment status and their perception of care, respectively.

### 4.3. 4. Mother's Experience in Providing Care Work

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; practicing the speech recommendations; carrying the children to regular visits for medical follow-ups and attending different intervention 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. Mothers who were employed had presented instances where, at times, important job commitments made earlier were confronted with an urgent need of the child that required immediate medical attention. In all such instances, mothers prioritized their role as mothers over their career and commitment. This sometimes came with the cost of not receiving promotion and career benefits attached to it. A mother who worked as a school teacher narrated that she could not finish her in-service higher studies (Masters and B. Ed) due to the exclusive attention and care work demand she had outside of the working hours, which directly affected her promotion and pay scales later. She said:

"Despite *having a good academic record and good teaching performance, I get low pay because I could not complete my B.Ed."*

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. Thirteen mothers were reported to have left their full-time jobs to prioritize the care of their children, who, they believed, needed constant parental supervision and monitoring. Three mothers chose to work independently, taking projects from different agencies, which permitted them to work with flexible hours. A mother of a five-year-old with ADHD expressed her obligation to provide her daughter with much-needed care:

*"I had planned to return to my job after a short break following my delivery. Everything was going as planned. I even joined my job as per plan, and everything was going well until she was diagnosed with ADHD at the age of three. I had to quit my job. Though we have hired an 'aya', I feel that I can manage her needs better due to my exposure to the therapies and counselling sessions we attend."*

The children's unpredictable behavior and needs, as well as the lack of professional care work centers or services in Kolkata for special children, made it difficult for both parents to continue with their previous job commitments. In such a context, mothers had to quit their jobs to provide the required care for their children. In instances where both the parents continued with their respective jobs, support from other family members and hired care workers remained the primary support system. Hiring a full-time care worker had been observed as a luxury for many of the respondents, for whom the monthly monetary allocation was kept aside for treatments, special therapies, special school fees, medical expenses, and other expenses related to the maintenance of the child's health often exceeded the monthly family budget. Fathers frequently used job stress and job-related anxiety as a defense mechanism to shift their responsibilities to their mothers. On asking about how they had contributed to the care-work for his eleven-year-old boy with learning disabilities at the weekends, the father replied that:

*"His mother's task is to take care of Bubun (their son). I have my job commitments and pressures to handle throughout the week. My duty is to earn money to fulfill the needs of my family, and I feel I am doing it well! I prefer to take a rest on the weekends, so that I can work hard throughout the week. His mother takes him out for special classes on speech, which take place on Sundays. Well, in the evening, I play with my son and spend some quality time! His mother gets some time off then."*

Conversation with the mother revealed that while fathers gave some quality time to the son and kept him engaged, mothers utilized this time for completing their cooking and other pending household chores. Husbands described this care-free (non-care-work) time for their wives as "some time off" or "off-time."

Changes in the employment status had a significant impact on the identity development and self-perception of the mothers. Mothers who had left their jobs had their parental identity (being a mother of a child with a disability) as the dominant identity trait. This had limited their possibility of switching over to other identities when displeasure or dissatisfaction emanated from their parental identity of being parents of a disabled child. This was found to have caused long-term conditions of stress and depression among mothers. While mothers who had chosen to continue with their jobs were observed to have received positive inducements from their ‘other’ identities, they had as part of other roles they played outside of being a mother of their disabled child. Thus, parents reported that at times when they were surrounded by negative thoughts and emotions related to the health condition of their child and their future, they tried to deviate themselves and indulge in work related to their job. These mothers also reported that spending a good amount of time (office hours) at work provided them with the necessary space out of the monotonous, repetitive routines associated with the care of their children. Therefore, mothers, who were in the paid employment sector, received rewards and pleasures from their ‘other’ identities as individuals rather than just being mothers. The identity of only being a mother was observed to have compensated for their socially perceived non-rewarding identity as a mother of a child with a disability. Interviews with the mothers indicated that mothers who acted as full-time care-workers for their children, and who had (had to) leave their jobs to provide the care-work, suffered from intensive periods of anxiety, stress, and depression compared to mothers who were continuing their employment status.

The mother of a daughter with Autism Spectrum Disorder stated:

*“For me, it was very important to get back to work. Initially, I had decided to leave my job to provide for the care and needs of my children, which were very different and exclusive from other children we saw. My daughter cannot speak well and doesn't respond to me every time I express myself to her. This is really heartbreaking... I felt I was losing myself. I felt I needed to do something that would be rewarding. Finally,*

*after almost two years, I got back to work. At work, I am not just a mother, but a mother with other jobs who can contribute to her family and society in ways other than motherhood. My confidence level went higher. After coming back from work, I give time to my daughter... I take her to the special classes on the weekends, and in a certain context, I do take leaves. Though it is hard sometimes to balance both, I feel good and confident."*

### 4.3. 5. Gendered Nature of Care: Stories of Affirmation and Deflection

Caregiving was intricately associated with a role relationship that was found to have existed between the caregiver and the care recipient. Parents were expected to fulfill their roles as caregivers in providing care (within residential or home settings) to children with diverse needs. In caregiving, the "roles, role demands, and role expectations" were framed by the social and familial context within which the care activities were performed (Bruhn & Rebach, 2014, p. 5). The primary findings of the research identified how mothers and fathers, both being parents to a child with certain diversities, had adopted different roles in caregiving. 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. Fathers who were observed to be active and involved only in caregiving but did not share household chores (fourteen) believed that household chores should be managed by women. But at the same time, these fathers were observed to have believed in women's empowerment and considered that women should be given their space; that they should not be restricted from getting engaged in paid employment if they have chosen to; and that they should be given the liberty to decide for themselves, their children, and the well-being of the family as a whole. Thus, fathers in this category have adopted a dialectic-dual stance between traditional and egalitarian ideology. Following Hochschild’s classification of gender ideology, these fathers have been observed to have adopted a transitional gender ideological approach.

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. This was observed to have happened when individuals were able to perceive and comprehend the care demands of the person who needed care and recognized their articulated and implicit needs to be taken care of. However, recognition and identification of needs were not sufficient unless and until someone had assumed the responsibility of organizing and managing the needs and requirements to meet the demands of care. This phase of caring or being involved with care has been specified as “caring for”. Thus, "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. Thus, "caregiving" requires having knowledge about how to care for and the kind of caring tasks that need to be performed. While caring-about, caring-for, and caregiving have been theorized from the perspective of a caregiver or care provider, the fourth component of care, that is, "care-receiving", has been understood from the perspective of the care-recipient. It involved the responsiveness of the people (or groups of people) who received the care services. Empirical reflections of the current research have indicated that fathers, in relation to caring for children with disabilities, were more involved and engaged with the first two phases of care, that is, “caring about” and “caring for”. Five fathers reported that, although they had recognized and understood the care demands required by their children, their wives primarily performed all the care-related responsibilities and tasks.

Fourteen fathers stated that they contacted doctors, scheduled appointments and sessions with therapists, bore all expenses related to care, such as medical expenses, external care providers, and domestic help, and made insurance plans to secure the future of their children, wives, and other family members, as well as bringing medicine and other related support on time. “Caring about” and “caring for” motives were also observed when seven fathers mentioned that they had tried to care for their wives by keeping the child engaged by playing or by keeping a close watch on him/her so that the mothers (wives of the respondents) could get some time for themselves and to perform other household chores. Only nine fathers were observed to have affiliated with the “care-giving” components, and they were directly engaged in performing everyday care-related tasks. Figure No. 4.3 below represents the involvement of fathers in care work for their children with disabilities. Table (4.3), however, reflects the information on fathers’ involvement based on what Fisher and Tronto (1990, p. 16-17) have provided in their theory of care.

**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)**

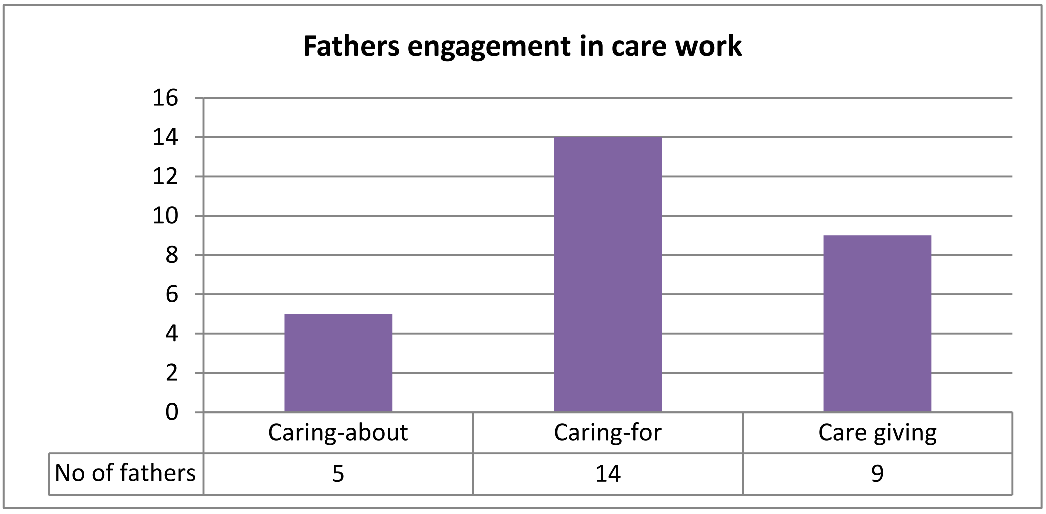


Figure No. 4.3 shows that most of the fathers (fourteen) in the research adopt the "caring for" role for their children with disabilities. Only nine fathers were found to be directly involved in caregiving functions in the household.

Mothers were observed to have been actively engaged in all the four phases of the components of care as mentioned by Fisher and Tronto (1990, p. 16). In-depth conversations with the mothers reflected their adherence and acceptance of the socio-cultural constructions of motherhood that had considered childcare to be an exclusive domain of responsibility for the mothers.

It had been observed that the mothers in my research had adopted an intensive mothering role for themselves and had confirmed that such an ideology and construction of motherhood were also mirrored by other family members, including the husband (father of the disabled child). This kind of gender ideological affirmation by the family members, who considered intensive mothering ideology to be the ideal mothering role and recognized care as a mother’s responsibility, had constructed a closer relationship and bond between the mother and the child. The relationship, however, was observed not only to be characterized by love, empathy, care, and responsibility but also to have defined burden, pressure, anxiety, and stress experienced by the mothers out of such a compact and condensed relationship. Thus, “the prominence of women in care then emphasizes their ‘natural aptitude’ and creates different relationships between mother and child and others in the family, including the father” (McLaughlin et al., 2008, p. 163). The ideological framework against which the family members and husbands were found to have affirmed the ideology of intensive mothering was the belief that “women are better at these forms of care and skill” (McLaughlin et. al., 2008, p. 164).

Interviews with mothers revealed similar affirmations to this type of gender ideology when they stated that fathers were unable to take on care responsibilities and had limited knowledge about what to care for. Thus, a mother’s gender ideology was noticed to have determined how she had 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, and they expressed that it was natural for their husband to identify himself with the work commitment he had towards his job. A mother said:

“*My work is to care for my baby and handle all the duties I have towards my home. My husband fulfils his responsibility by providing us with the necessary financial security.”*

In these instances, mothers had internalized and accepted the disengaging role of the fathers in care work as per the expected and accepted standards of gender division of care work nurtured within the family. Six mothers were noted to have performed the responsibility towards care and chores single-handedly, out of which five mothers did not believe in the traditional gender ideology of the division of labour between men and women. They had confirmed that it was their husbands, family members, and the wider cultural context they lived within that had driven them to accept the traditional ideology of gendered division of labour within the household. A mother of a four-year-old boy with ADHD narrated:

*"It is really tough to manage the house and my son simultaneously. My son needs my constant attention and supervision. I become exhausted juggling all the chores and carework. Some days are harder than others. It would have been helpful if his father (husband of the respondent) had shared some of the care responsibilities, if not the domestic chores. But I know that won't happen. After work, he demands some time for himself to watch television, read the newspaper, or even meet friends or colleagues. He takes care of our well-being by fulfilling all our needs and requirements. However, when it comes to sharing the burden of care, he says, "That's not my cup of tea". Earlier, I used to fight, but with time I have accepted that it won't change."*

Fifteen mothers reported that their responsibilities of care and chores were jointly shared by their husbands. In these instances, the mothers did not believe that fathers could not share the care tasks for the children or could not handle the chores because they were men and it did not fit their traditional gender roles. In such instances, fathers were observed to have openly accepted and adopted the role of caregiving. These household units, where both mothers and fathers believed that childcare and domestic chores should be shared equally and jointly by both parents, were observed to have adopted an egalitarian gender ideological position. Many of these household units were even observed to have taken the services of external care agencies by hiring paid care workers to look after their children during their absence.

Among the six respondents, mothers who were in paid employment had domestic help for sharing the chores and had hired care workers to care for the child during their absence, but at the same time considered child-care to be the sole responsibility of a mother. These mothers believed that their identities as employees or ambitious women were equally important as their identities as mothers. However, they believed that parenting was the domain of a mother, and when the child required exclusive support, constant supervision, and attention because of their disability condition, the mother was more capable of fulfilling those demands than a father would have done. These mothers, thus, have adopted a transitional gender ideology in justifying their indispensable positions both as mothers and caregivers.

A thorough analysis of the responses revealed that mothers were less confident in entrusting the child-care tasks of their children with disabilities with their husbands (fathers of the children). These mothers had expressed low confidence in their husbands as far as taking care of children with disabilities was concerned. Many of these mothers had reported that the way fathers had performed the care tasks was not the correct way of caring for children, particularly those children whose needs and requirements were exclusive and required more empathy and understanding of their emotions. Conversation with the fathers had revealed that in many such instances, even if the fathers were willing to share the care-work, mothers chose to perform those tasks themselves because they had perceived that their husbands would not be able to manage them the same way their mothers wanted to get them resolved. In fact, in a few instances where the fathers had performed the caregiving activities for their children with disabilities, it was thoroughly done under the supervision and direction of the mothers. Thus, a kind of "hegemonic motherliness"[8] (Ruby & Scholz, 2018, p. 78) was observed among the mothers, and the father becomes the "junior partner", the "everlasting trainee", or the "guilty student" (Behnke  & Meuser, 2012, p. 131).

With regard to child-care and the involvement of the parents in employment, I have adopted the "male breadwinner/ female caregiver model"[9] and the "dual breadwinner/female caregiver model" (Bruhn & Rebach 2014, p. 19) for this research. According to the first model, males were the primary earners in the household and were considered to be responsible for bringing financial security to the family. The contribution of women to household chores, care-work, and outside work that was not associated with any monetary exchange or wage was considered to be non-productive. Here, women's domestic contribution was considered as care instead of work, and this contributed to the overall invisibility of household work for women. Thus, women's work in the household was seen as a part of their role as caregivers to the family members. Thus, care-work included not only child care and other dependents (aged or ill) in the household, but also other domestic chores such as cooking, washing, cleaning, and other chores designed to meet the needs of the family members. In short, care was the umbrella term that included all the chores, care-work, and caregiving activities that were directly or indirectly related to the needs of the family members, including the children with disabilities. In this research, in the family units, where mothers were not employed in paid sectors and fathers were the only earners (twenty-three), the "male breadwinner/ female caregiver model" had been found apt to explain their realities concerning care and chores.

In family units where both parents were employed in paid economic sectors, the "dual breadwinner/female caregiving model" has been employed to get an overall understanding of the everyday realities expressed by these parents having children with disabilities. According to this model, women looked at 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. Instead, they had chosen to take part-time jobs to balance their commitments to work, home, and children with disabilities. These mothers were the ones who were observed to have adhered to the cultural expectations related to the ideologies of motherhood that were constructed around the social reality of which they were a part. Most of these ideologies were observed to follow the norms associated with intensive mothering, which exalted child caregiving and care-work over paid employment. Thus, mothers who believed in the ideology of intensive mothering but wanted to remain engaged in the paid labour force sought part-time employment. It was also noticed that in family units where both parents were employed, it was mostly the mothers who performed the role of caregiver for their children with disabilities. Though in many of these units, the mothers had received assistance from other family members and hired paid care workers to manage the caregiving tasks during their absence at home, overall, it was the mothers who were held responsible for the care-work responsibilities of their children. However, it is important to note that the mothers were not held responsible for caregiving only by their husbands or by any significant others outside the household; in many instances, the mothers themselves held them responsible as the primary caregiver.

### 4.3. 6. Parenting Children With and Without Disabilities: Context of Having Siblings

Choosing and prioritizing between the roles and identities turned out to be more complicated when the parents had another child (siblings of the children with diversity). Parents' roles, duties, and responsibilities toward their disabled and non-disabled children differed greatly. The needs, requirements, and care demands of the child with disabilities were not similar to the care requirements of his/her sibling without disabilities. Hence, parents were observed to remain in a constant flux between choices and responsibilities of care. A mother of a thirteen-year-old daughter with ADHD responded that:

*“My elder son has always complained, and still complains sometimes, that we don’t give him enough time or support him in his school activities and work. Though he is very sensitive towards his sister and loves her a lot, at times when he asked us to provide some time to accompany him to any friend’s place or for a movie or an outing, it was not possible for any of us to manage that time for him. He used to get angry and cry. Even at times, he shouted at us, saying we don’t love him anymore. But these were moments! After some time, he is used to getting back to his normal self. But these moments, though we knew they were temporary, had many times turned us down and made us feel guilty as parents. "*

The research found five instances (household units) where parents had another child, generally an elderly child, with no potential diversity. Having two children with completely different needs posed challenges for the parents to fulfill their duties and obligations as parents. Having a child with disabilities at home had a huge impact on the brothers’ or sisters’ lives and needs. 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. There were days and moments when their older children complained about not getting their parents' attention and support whenever they needed it, like while doing homework, making their favourite dishes, taking them to their friends' places, and so forth. In India, and particularly in Kolkata, where the care-work responsibility remained inclined towards the mothers and taking care and fulfilling the material demands, as well as emotional needs that were completely separate for children with and without disabilities, fell solely upon them, immense emotional turmoil, physical stress, and anxiety among the mothers were observed.

### 4.3. 7. Raising a Daughter with Disability: "After all, She's a Girl !"

In my research, thirteen girl children possessed certain diversities in their intellectual, developmental, and cognitive functions of body and mind. 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. The mother narrated:

*"One day, my maid rushed into my room, held my hand, and took me in front of the door where my daughter was having her physiotherapy. I saw the man was holding my daughter's breast and was rubbing another hand on her thighs".*

The shocking part of the story was that the girl used to find this comfortable without understanding that she was just being utilized as a sexual object; and when the parents had sacked him and he was absent for consecutive days, she started to turn violent and expected him to provide the comfort she used to get with him. 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. Even the maid did not know about her husband's misdeeds and was unaware of the fact that the parents of the child had installed a CCTV camera inside their daughter's room. The father narrated:

*"I saw the footage in the evening. We were shocked and immediately filed a police complaint. I clearly told my wife that whatever happens, one of us has to leave our job. So my wife did! We decided that since my income was more than what my wife used to earn, there was no point in me resigning from my job. No maids were kept for my daughter from then on."*

### 4.3. 8. Juggling Between the Roles: Scrapes of Rigid and Inflexible Schedules

Intense and continuous care work demands in managing the special needs of their children meant parents had to juggle between the many different roles and identities that characterized and recognized them as social individuals. 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 their routines and remained organized as far as practicable. 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. A mother of a thirteen-year-old boy with cerebral palsy stated:

*"Pablo (her son) has a fixed daytime schedule. We need to follow the routine exactly, in the same manner, every day. Any distortion of the routine and order of activities makes him scream loudly. He then does not listen to anybody, just screams like anything. It sometimes becomes so unbearable that I lock myself in the bathroom and I promise myself not to deviate from the daily scheduled routine ever again in the*

*future. I feel that following the same activities within the stipulated time and order will keep my son and me both in peace, even though monotony grasps me.”*

The parents were observed to juggle not only fulfilling the care needs of their children but also accomplishing other related activities like scheduling appointments for their next session of counselling or therapy; taking them to schools (mostly, special schools); discussing and consulting with the expert and special teachers about the scope of improvements or related issues of their children; and so forth. The primary care work responsibility was fulfilled mostly by the mothers in comparison to the fathers. Mothers were solely responsible for child care in households where fathers were the only earning members and mothers were homemakers. However, mothers (eight) acknowledged that fathers did spend quality time with them and shared the care work burden as much as possible for them once they came back from work.

Some mothers (sixteen) pointed to the fact that primary care work burdens, including carrying the children to the therapeutic centres and schools, fell solely upon them without any assistance from their husbands other than providing for the expenses required for running the house and the activities related to the special needs of their children. In some instances, mothers who were earlier employed in paid work sectors had to leave their jobs because the formal work patterns and timings did not suit the care work schedules of their children. Some of these mothers (three) had chosen contractual work arrangements, primarily project-related, that allowed them to work from home and with flexible hours. A mother, who was a civil engineer and a single mother of a child with autism, exclaimed that:

*“I left my job just to provide better care for my son. I had no family support to share the care work. Whatever I earned was not sufficient to hire a professional care worker (aya) along with the medical and therapeutic expenses for my son. So I chose to leave my earlier job and took up contractual project-based employment options. I am a civil engineer and I plan, make the designs, and create blueprints for new houses or buildings for some companies that work as proprietary agents.”*

The storyline was similar for a mother of a child with ADHD, who had left her full-time job for some independent venture that could be continued and sustained by staying at home and following flexible work schedules. In her words:

"*My child has ADHD with borderline OCD, which makes him so violent at times that it goes beyond the capacity of the care worker I have hired for him. He only calms down a bit when I hold him in my arms and cuddle him back. I understood that he needed me.*"

However, there were eight instances where fathers shared childcare responsibilities with their children. A father of a child with Rubella syndrome took care of his fourteen-year-old daughter in every possible way. He owned a business of his own related to filmmaking. Despite having busy work schedules, he had never skipped his lunch and dinner with his "sweetheart" (as he called her daughter by this name). An important thing to note here was the connection the father had with his daughter, which he believed to have existed with his own destiny or fortune. The father believed that his daughter was a blessing from God and he owed all the flourishing and prosperity of his business to her. He even stated:

*"She is the 'Lakshmi' (a Hindu deity of wealth and prosperity) of my house, and I don't go or sign a new venture unless I see her face."*

### 4.3. 9. Limited personal space

Being a parent of a child with diverse needs requires excessive emotional, mental, and physical organizational skills to fulfill their complex and continuing needs. Interviews with the parents revealed a higher emotional investment in providing the required care work in comparison to the physical and mental exhaustion. Raising a child with disabilities consumes most (if not all) of the quality time that the parents earlier used to define as their 'me-time' or 'we-time' (between couples). The planning, organization, and execution of the tasks associated with their children's needs left little or no quality time for parents. 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. In some cases, the daily care work responsibilities of the child, in addition to the usual chores of running the household, multiple and consecutive days of sleep deprivation took a toll on the mothers' health, particularly for those who did not have professional care workers as support (hired maids).

In my research, there were fifteen families who did not have access to hired care workers, out of which six mothers were solely burdened with the care work without the support of their husbands or other family members; and nine families where care work was extended by both parents. In these household units where care work was shared by both parents, it was the mother who took the primary responsibility of care due to the professional engagement of the fathers in their paid work domain.

In household units (thirteen) where the care work was supported by hired care workers, parents were required to monitor and supervise their disposal of care for the best interests of their child. Only two units were able to hire a full-time professional care worker for their children, and parents from these two units reported having some time for them, albeit limited in both time and scope. A father of a child with cerebral palsy narrated:

*"Thanks to our 'mashi' (care worker), who takes good care of our son, just like his own. My son, too, feels comfortable in her company. Sometimes we (husband and wife) go for dinner together, and sometimes we attend a few social occasions with family and friends. With 'mashi', I know my son is in safe hands".*

Hiring a full-time care worker was not only a matter of choice but also about affordability. Parents (both mothers and fathers) from these two units were employed and received handsome remuneration to hire the services of a full-time professional care worker for their children. This, however, was not accessible for all household units or parents due to their inadequate fund allocation. Thus, the economic positions of the parents were found to have influenced their access to support systems.

The continuous care for the children demands handling pressures at work, along with making arrangements and organizing the day-to-day needs of the children. Carrying the child to special schools or attending special therapeutic sessions consumes the whole day for the parents. They hardly got any time (if they got any at all) to spend with their partners. Even if they got some time out of the rigid schedule, it was devoted to discussing their child's needs, arrangements, progress, and discussions related to the medical issues and expenses. Parents' accounts of their daily lifestyles and schedules reflected stories of marital discord and strains. In a study undertaken by Bristol et al. (1988), it was observed that parents of children with disabilities had lower levels of satisfaction and tension in marital adjustments.

Raising children with disabilities has caused serious lifestyle alterations for the parents. It had impacted the frequency, intensity, and patterns of social interaction the parents had encountered. Seven parents had reported that they had not attended any social functions or gatherings for years and had not visited any relatives' or friends' places. The only time they were out was either taking their child to medical experts, to special clinics, or to special schools. A mother agreed that her life was surrounded by doctors, clinical therapists, special trainers, and educators who provided care work for her child and the house. Constant engagement with the care-work and continuous therapeutic and special follow-ups as per medical and clinical recommendations both at home and in clinics meant that it was difficult for the parents to keep in frequent touch with their friends and relatives. However, in addition to their daily rigid routine lifestyles, the "felt stigma" or "perceived stigma"[10] associated with the disabilities of their children often hindered the parents' ability to socialize. Thus, parents were observed to have gradually shrunk into social isolation. Social isolation results from the absence of common platforms, grounds, issues, or topics of discussion that they used to share with their peers and in social circles. Few parents had reported responses of sympathy from friends and family members, which had driven them towards withdrawing themselves from such interaction situations. This is supported by what Link and Phelan (Yousof, 2016, p. 96) proposed in their understanding of stigma. The parents of the children with disabilities had been observed to have possessed all the five components of stigma[11]- whereby the children were found to have been labelled based on the social recognition of the diversities, followed by stereotyping of the diversities with negative attributes that extended feelings of negativity towards the parents. This was further followed by a feeling of separation by the parents from the wider social networks and relationships, which finally generated negative feelings among them towards their children's disability and added to their feeling of stigmatization.

## 4.4. Confronting Disability at the Systems Level

### 4.4. 1. Parents’ Encounter with Schools: Contradictions Inherent in Inclusion

The first step towards extending an inclusive society to children with disabilities and diverse backgrounds is to adopt and implement the policy of inclusive education. Schools are the primary site where the ideology of inclusive education has received its pragmatic accomplishments, and they are also, after the family, the most important site for connecting the child with the larger social network. The basic ideology behind inclusive education has been to bring changes, alterations, and modifications to the existing education system to include every child within its umbrella and, to make children with diverse needs (physical, cognitive, intellectual, developmental, and psychomotor) "fit" into the pre-existing education system, which was structured without keeping the special and diverse needs of these children into account.

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 to put their children into a special education structure 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 because the regular schools did not have adequate arrangements to accommodate their children with disabilities. The existing inadequacies, both within and outside the curriculum, had reproduced disabling social-environmental barriers that constructed disability based upon the diversities of the children. 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 impossible and out of reach in two instances, not just because of the excessive cost that was directly associated with the admission and maintenance of the school education but also because of the allied costs that were found to be high to take their children to these schools.

A mother of a thirteen-year-old boy with Down syndrome said that:

*“I continued it for two years, and then I finally decided to discontinue the special school. He has become very heavy now and cannot withstand the loud noise of traffic. Travelling to and from the school made him more tired, and he was turning more violent with me. I used to avoid public transport to avoid such disruptions and had to travel by taxi. With my humble income, it was difficult to carry the cost of any private special education school near to my home, and the government one with which we are associated (Manobikash Kendra) is located at a distance of around twenty kilometres.”*

The family was staying near the Dumdum airport, and Manobikash Kendra is located near Ruby Crossing in Kolkata, which is almost 19 km apart.

Within the school curriculum, the structure of the syllabus and the pedagogy followed by the teachers in a regular school setup were not found compatible with the learning and comprehending capacities of the children who had intellectual, developmental, and cognitive diversities. The evaluation mechanism in regular schools spins around the numbers, grades, and information about different subjects learned and memorized, which most of the time compensates for with the actual knowledge gained. School curriculums, despite having subjects like SUPW (Socially Useful Productive Work that included art and crafts), were found to have continued their evaluation of a child based on their progress made in the mainstream subjects like literature, language, mathematics, science, history, or geography and the grades they earned during the exams. Many parents reported that their children were good, if not excellent, at creating artworks such as painting or sculpting. Though these were well recognized in schools, the overall progress always highlighted the lack of learning capabilities in their children. A father of an eleven-year-old boy with learning disabilities said that:

*“In every parent-teachers meeting in the previous school, I was told that my child should improve his performance in the subjects and should be more attentive in the classroom. Although the teachers accepted that he was excellent at painting and was better than the children in his age group, they still maintained that he should also perform well in other mainstream subjects.”*

In the above narration, the use of the word “mainstream subjects” by the school teacher reflected the teacher’s attitude in dealing with children with disabilities where he/she herself believed that painting or crafts were not mainstream subjects and hence performance in these areas of education should not be taken as yardsticks in recognizing the mainstream development of the child. These were the small occasions when the exclusion of children with disabilities began.

Outside the curriculum, the structure and planning of the school buildings, classrooms, library, and toilets constituted primary barriers for the children with disabilities. Furthermore, the lack of special educators in schools, teachers with insufficient training to deal with these children, and the absence of trained care workers and staff in regular schools made it difficult for children with potential disabilities to survive in the regular school environment. A father of a child with autism spectrum disorder claimed that the school principal often called his wife (mother of the child) whenever they found it difficult to attend to him. He narrated that:

*"The teachers often called and told us that he was very unmanageable, disobedient, and hurt other children when he got violent. But the real picture was different. One of his classmates told us that he was irritated by other children and sometimes they chased him by pulling his hair or shouting bad names at him and calling him 'mad'. Loud noises made him shout and scream and made him violent. The teachers did not make a note of it as my son could not complain about it himself. When we told them about the reality, they said that we should put our child in a special school as they could not provide the required special care and attention."*

Parents of children with disabilities have encountered a hard choice in selecting the right and appropriate school for their children, where the child would have received appropriate attitudes and behavior from the teachers, staff, and other children. What many (parents of twenty-one children) parents feared most about putting their child into the regular school system was the stigma that the child would be experiencing in their encounters with teachers, staff, and other children both within and outside the classrooms. Most of the parents (parents of six children) who took their children to regular schools complained about the strange and doubtful stares they used to receive while carrying their children in and out of the school.

Almost all the parents had reported that schools, particularly the regular schools, could not manage the medical issues that might have been confronted by their children at any point in time. Parents had faced a situation where they were being called by the schools to take their children to doctors. A mother of a twelve-year-old girl with Autism narrated an incident when she was called by the school to take her daughter to the hospital as she became severely ill:

*"It was twelve o'clock in the afternoon when I received a call from school that my daughter was ill and required immediate medical attention. I ran hurriedly and saw that she was having breathing trouble. We already knew that she had breathing trouble and an inhaler was always present in her bag. I gave her the inhaler and, after some time, she was feeling good. When I asked them why they didn't give her the inhaler, they said she was not a regular child, and they feared that if anything went wrong, then the entire burden would fall upon them. Moreover, they said that they did not have any specialized medical personnel to deal with such an incident. I too thought that they were right to some extent."*

When I asked the parents how far they thought mainstream education and the school system would benefit their children, I got a mixed bag of responses. There were some parents (parents of nine children) who felt that accessing regular education and the school system would have helped their children to feel 'included'- to be a member of mainstream society and social structure in general, and a member of the mainstream education system, schools, and peer groups in particular. Some parents (parents of twenty-one children) had pointed out the fact that the special, exclusive, and complex needs of their children would have remained unattended by the teachers, staff, and management of the schools. These parents also feared that their children would have felt stigmatized in their encounters with the peer group. Some of these parents (parents of six children) also believed that the complex needs of their children required specialized and trained professionals, which was not possible in schools with regular teachers and staff. Table No. 4.7 shows details about parents' responses to their perceptions of what kind of schooling would have helped their children as part of inclusion.

**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 |

Parents' accounts of the pedagogical and structural barriers that hindered a child from his/her participation in the wider social world in general and schools in particular, carried a close lineage to the social model understanding and conceptualization of disability. The social model perspective on disability has highlighted that it was the social-cultural barriers at large that created disability by producing a socially disabling environment for individuals with diverse abilities.

### 4.4. 2. Limited Social and Public Access

Parents have expressed their inconvenience and anxiety while taking their children out in public places. Parents exclaimed that going out with their children or taking them for walks or visits entailed a good deal of planning and organization on their part. For children who had difficult mobility issues (like cerebral palsy, multiple disabilities, and rubella syndrome) or in instances where the children were very heavy, carrying them out became a physically demanding task for the parents. A mother of a child with cerebral palsy exclaimed:

*"It has become harder these days. He has turned thirteen (age), and making him move and change his position is a real physical task for me. It has become difficult to take him to school even. I ask the auto driver to lift him up into the auto."*

Another father of a fifteen-year-old daughter with rubella syndrome narrated that:

*"We (husband and wife) take her to places like shopping malls and restaurants. Accessing shopping malls is easier for us because we move in a wheelchair and we visit only those restaurants where there are provisions for privacy and to slide the wheel to and fro or chair up and down. We go out when I am there. It is not physically possible for her mother to deal with her or carry her in public places."*

The above-mentioned instances speak a lot about the reality of the structural and architectural accessibility of public places for disabled people in general and for children with disabilities in particular, in the context of Kolkata. Most of the restaurants, cinema halls, parks, and transport facilities did not accommodate the needs and flexibility required for these children.

Among the external factors that had created conditions of disablement based on the children's diversity, inadequate transport and conveyance facilities topped the list. A major hindrance that the parents and their children with disabilities had encountered was accessibility. Whether it was regular schools or special schools; going to special therapeutic sessions, hospitals, and doctors; or taking the child for a walk to nearby parks or for entertainment in public places like shopping malls and restaurants- the basic requirement remained the availability of the means to access them. In Kolkata, the transport and conveyance systems were not adequately equipped to accommodate the easy and comfortable movements of these children across places. Parents reported several obstacles they encountered regarding the disabilities of their children while accessing public means of conveyance. The list included the absence of a ramp in the buses or cabs; an improper arrangement of seats with no space for grabbing support; and a lack of space and means to accommodate the wheelchairs, in the buses. The absence of a ramp had been the primary reason that had restricted the free and easy movement of the wheelchairs which was found important for most of the parents to carry their children, particularly after they had reached a certain age.

Parents conveyed that many doctors and counselors had recommended taking the children for walks or visiting in the open air as a means to maintain a healthy mental and emotional state for these children. However, limited or lack of accessible means of transportation made it difficult for the parents to put the recommendations into practice. In some cases, the parents preferred to take their children out for a walk or to have dinner or lunch in restaurants in their personal cars. This, however, was not possible for most of the parents who did not have a personal car or whose father was so busy with his professional commitments that it was almost impossible for the mother to manage the movements alone.

Following Lisa Baraitser (2008b), mothers' experiences with their children with disabilities could be explored well by their encounter with the material world and objects outside. Parents' interaction with the architectural planning of roads, and public buildings and with the articles and objects that were required in providing care to their disabled children in the public sphere (like a wheelchair) had assisted them to reproduce the meaning of disability, which got diffused into the wider existing literature of disability in general. Most of the parents in my research had supported the idea that disability was created and evolved. When the children's disabilities and their different ways of functioning had failed to comply with the architectural planning of the roads, buildings and transports, their diversities then were then labelled as disabilities. Thus, disability was created, on the ground that the children with diversities were "misfits"[12] (Garland-Thomson, 2017, p. 593) in the public sphere due to their inherent differences from the socio-culturally accepted normative standards upon which the public sphere, in its structural material form, had been designed. Thus, using a wheelchair or wearing corrective shoes created the context of "misfits". According to Garland Thomson (2011), misfit "emphasizes context over essence, relation over isolation, mediation over origination" (p. 593), and hence the scope of alterations or modifications remains undefended. Thus, instead of attempting to make the diversities fit through interventions or treatments, Garland (2017, p. 593-594) advocated for revisions of the architectural gap that failed to fit the diversities. If this had happened, diversity would have been recognized as diversity rather than disability. There were many accounts in this research where the parents and their children with disabilities had 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.

### 4.4. 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. However, parents were aware that most of these comments were made unintentionally, without much in-depth insight or understanding of the issue. A mother of a child with learning disabilities once encountered such an experience when she attended a parents-teachers meeting in the school (he was then in a regular school). After the teacher finished her discussion-regarding her child's performance in class, the 'issues' he created in the class, his inattentiveness to board works, and the areas in which she required improvement-and the mother was about to leave the classroom, she heard someone say, *"poor child! What will he do with his life? I wonder what future he has!"*

As a response to this instance, the mother commented during the interview that:

*"Even if I was there before, I too might have commented, if not directly, in the same manner. I feel unless you are not in the same situation, you might not understand the difference. People don't always think before they speak. However, it is true that I was hurt by the comment."*

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 other people. 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. In cases where parents had introduced wheelchairs to their children (for easy and comfortable movement) after they reached a certain age, they experienced diversity in attitudes and perceptions of people that the use of wheelchairs had caused. In cases where the child had diversities marked as multiple disabilities, cerebral palsy, rubella syndrome, and autism with locomotory dysfunction of the legs, the parents had introduced them to the use of a wheelchair because of factors like weight and age of both the children and the parents. Parents of a daughter with rubella syndrome stated that they used to carry their child themselves for any kind of movement or locomotion required. However, with age and increasing weight, it was not possible for the mother to carry out even the normal day-to-day activities like bathing. So a wheelchair needed to be introduced. Similar experiences for the same reason have been cited by some parents who use wheelchairs. A parent of a child with autism, whose child faced difficulty in walking, expressed her feelings of stigma when she stated that:

*"Earlier, when he used to walk by himself, though there was less coordination in the movement of the legs, he still did it. Our neighbors, relatives, or friends who knew about his condition did not have much to react to, as there was no visible diversity in my child at that time other than his slow and unsteady movements. But when we bought him a wheelchair at the age of twelve, certain rumours and stories circulated that my child was basically disabled, and we had been concealing this fact for all these years."*

It seems important to mention here that, generally, children with autism might not need the assistance of a wheelchair for their movements. However, in the above case, along with the traits of a typical autism spectrum syndrome, the child had been developing difficulties in locomotion. Thus, at times when the parents took the child outside for some shopping, for a lunch/dinner, or just for an outing, they preferred to take him in a wheelchair as he was unable to walk continuously for a longer duration.

Parents were frequently "subjected to thoughtless comments" when they came across comments that were neither negative in the literal sense of the term nor carried any positive attributions for the children and their parents. (Hewitt-Taylor, 2008, p. 152). The descriptions of the two incidents illustrate this. The first instance involved a fourteen-year-old boy with multiple disabilities who had excellent singing skills and was used to perform using karaoke. At local functions and programs, he was invited to perform. In one such program, he was performing along with other performers. When his performance was over and they were about to leave, an old man gave him a currency note, and, keeping his hand over the boy's head, he said, *"What you have done is really commendable; how did you memorize the whole song?" "How did you manage to keep up with the beats?"*

In another incident, the mother of a six-year-old girl with autism was asked, *"She looks so beautiful! Such a pretty girl you have! How did this happen to her? Nobody will say that this beautiful angel could have this kind of destiny!"*

Both the incidents narrated above reflect how people perceive disability. In both instances, the excellent song performance of the boy and the beauty and prettiness of the girl mismatched the image and idea of people with disabilities held by the old man and the other man.

## 4.5. Conclusion

The parents' accounts reflected their critical position regarding the model of disability they had adopted in understanding and comprehending their children's differences. In the Indian context, in general, and in the context of Kolkata, in particular, parents did not stick to any single perspective or model in conceptualizing diversity. During the initial stages of the detection and diagnosis of the disability, parents began to perceive the disability from the angle it was then presented to them by the doctors and medical professionals. This had made the parents conceptualize the diversities based on the medical model, and they were found to have exercised the belief by conceiving 'disability as a personal tragedy' or 'disability as a problem within an individual'. This made them follow the prognosis based completely upon medical recommendations or corrections (behavioral, speech, and sometimes physical) and interventions. Gradual and constant exposure of the parents to the special medical and professional interventions and to the daily management and organization of the special needs of their children made them realize the precarious existence of the diversity within the medical and social preview of disability. When parents encountered larger social structures such as schools, hospitals, medical systems, transportation systems, public buildings, and roads, they were exposed to the state's faulty and unattended policy and planning. Thus, they were found to have been inclined to adhere to the social model of disability in comprehending their children's lived experiences.

It is important to note that the binary of the medical/social model did not operate exclusively in contextualizing or conceptualizing disability on the part of the parents. In-depth interviews and narrations revealed that different models of disability - medical (interventions and therapies), social (barriers that cause disability), relational (assistance from spouse, extended family members, friends, and neighbors), and minority models (exclusion from inclusion in schools and limited public access) - operated at different points when parents had encountered with the micro individual the macro structural levels of interaction. Parents' accounts of raising their children with disabilities and managing their diversity reflected wider social and economic contexts that influenced their personal responses and actions regarding the context of diversity and disability. It was, however, noteworthy that, though parents had expressed their immense challenges, stress, and stigma, it was part of their lived experiences and should not be understood as an end in itself. There were instances where parents chose to challenge the dominant discourse on disability by forming an agency to speak for themselves and their children. We will explore this theme in detail in the next chapter.

# Chapter-5

# Coping and Development of Agency among Parents

> ***"The management of the internal tension of opposing forces between loving the child as he or she is and wanting to erase the disability, between dealing with the incurability while pursuing solutions and between maintaining hopefulness for the child's future while being given negative information and battling their own fears"***
>
> ***- Larson (1998, p. 865)***

## 5.1. Introduction

Encountering the disabilities and raising the children with diversities was found to have generated an array of emotional reactions, responses, and reflections among the parents. A multitude of emotional responses had been exhibited by the parents, which could be understood under the broad spectrum of stress[1]. In-depth understanding and analysis of the narratives and responses from parents had reflected diverse sources of stressors[2] that signified their everyday encounters and experience with the diversities. Continuous care demand, organization, and management of works that were not related to the diversity (household chores and /or office works) arranging for social and financial resources to meet both familial and medical expenses, battling with interpersonal marital discords, juggling with the multiple roles and most importantly thought of the future of the children with diversity had exposed the parents to immense stress, anxiety, and emotional distress. In India, where childhood disability has been comprehended as a tragedy (Gupta & Singhal, 2004, p. 23), parents' perceptions of disability remained clinched to a negative portrayal of their lives and experiences. An enormous and huge amount of literature, research works, and reports were found to have existed which reflected good data on negative emotional distress experienced by the parents having children with disabilities. Narratives and lived experiences of the parents suggested that parents had devised various coping techniques to reduce or at least channel their stress towards things or events which generated positive reinforcements and rewards for them. Many recent research works were noticed to have started highlighting the positive emotions and perceptions that parents had developed in raising and caring for their children with disabilities. Much of these studies had focused on how positive perceptions were developed among the parents as a coping mechanism (Behr, Murphy, & Summers, 1992; Scorgie et al., 1998; Scorgie & Sobsey, 2000; Hastings & Taunt, 2002; Gupta & Singhal, 2004).

This chapter has attempted to show how the parents in Kolkata have adjusted and coped with their daily struggle in managing and dealing with their children's diverse needs.

The chapter has been divided into four broad themes, followed by a general conclusion based on the narratives and responses of the parents retrieved during the interviews. In the first theme, I have attempted to explain parents' access to coping resources. This theme was discussed in the light of Pierre Bourdieu's theory of capital. The second theme has been an endeavour to analyze the coping mechanisms that were adopted by the parents based on the positive and negative perceptions they had developed about disability and diversity. The third theme was centered on the importance of and access to both formal and informal support networks by parents. And the final theme of the chapter discussed the agency and advocacy roles adopted by parents as a critical response to the inadequate services and facilities they have been receiving from the wider social institutions, structures, and systems.

## 5.2. Understanding Parents' Resources to Coping

### 5.2. 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[3] 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. Bourdieu discussed three forms of capital: economic, cultural, and social. Economic capital was anything and everything that was directly convertible to and extracted from monetary transactions (Bourdieu, 1986, p. 81–82). Thus, parents' income, their existing material assets, and properties in the form of houses, land, insurance, or bonds that involve direct monetary transactions, formed their economic capital. Individuals' embodied and objectified cultural forms were defined as cultural capital (Bourdieu, 1986, p. 82). Variables like educational credentials, intellectual and cultural skills (dance, music, art, culinary, etc.) learned, and the possession of cultural practices, say, the habit of reading books in leisure time, form the cultural capital possessed and acquired by the parents. Bourdieu (1986, p. 86) defined social capital as the social contacts, connections, and relationships that one has developed over time and that can be used to achieve different goals or meet certain ends. The parents' social networks and relationships, as well as their professional and social support networks (physical and virtual), had contributed to the formation of their social capital. 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.

### 5.2. 2. Economic Capital and Parental Coping

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. Refer to table No. 5.1 for detailed information on the income of the parents.

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. In contrast, parents in the lower-income bands had to compromise, to some extent, on the medical and interventional services for their children. For instance, among eleven children who had been recommended for speech therapy by medical experts, only five could access speech therapy sessions.

### 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 |
| **Total** | **32** | **100** |

The household units, where the income of the units lay between Rs. 11,000 and 30,000, were managed by single mothers. In household units where the monthly income of the family lies between Rs. 31,000 and 50,000, only two units were found where both parents were employed in paid labour sectors. In household units where the monthly income of the family lay between Rs.51,000 and Rs.70,000, there was only one unit where both parents had been working in paid labour sectors. In household units where the family monthly income was somewhere between Rs. 71,000 and Rs. 90,000, only two units had both parents working in paid labour sectors. In the rest of the household units, the family was managed by the single-earning parent. In such cases, it was the fathers who were seen to have earned in the single-earning parent household units, and the mothers were mostly found to remain busy in their role as homemakers. Thus, among the thirty-two household units, only five households had dual-earner parents. Moreover, among the twenty-seven remaining units, four were run by single mothers. While the rest were single-earning twenty-three household units, in which the fathers were the single-earning members.

A special educator specializing in speech therapy confirmed this finding and claimed that he had been charging Rs. 1500 per class for one-hour sessions of speech therapy. This meant that if a child was required to attend two sessions a week as per the medical recommendations provided, then the total expense of speech therapy turned out to be Rs. 12000 a month, leaving aside the expenses related to other medical costs, fees for special or regular schools, medical consultation fees, and costs that were involved in other intervention procedures. Twelve parents agreed that in order to manage the overall financial monthly budget based on the household income, they would have to compromise on certain needs and recommendations regarding their children's disability condition. A single mother of a child with multiple disabilities with an income of Rs 11,000–30,000 per month said that:

*"I know his condition will deteriorate over time. Doctors have already warned me that he would not be able to walk after a few years if he does not receive a regular session of physiotherapy. So I have to choose between taking him to a special school cum intervention centre where his overall social and behavioural development would happen, and providing him with the most required physiotherapy sessions that would stop him from becoming permanently impaired or handicapped. I cannot provide for both of them with my little income. I chose physiotherapy over the special school."*

Parents, who were in a better economic position to deal with the high financial stress of managing the disabilities of their children, were observed to have coped positively with the life strains they had been experiencing. Parents who had limited financial resources were seen to have developed negative perceptions of the diversity in their children and perceived their children's disabilities from a personal tragedy angle, blaming their own fate or destiny for such misery (five). It was not that these parents did not love or care for their children, but it was the interaction with their previously learned beliefs and perceptions (which they internalized through socialization) towards disability that had a counter-impact on their interaction with the existing social circumstances that had been shaping their approach towards disability. In the absence of resources, accessibility, and the consequent helplessness and acceptance of the situation, the parents had tried to cope with the negativity by transposing their helplessness to destiny, fate, or karma. Some parents (thirteen) have even resorted to religious and spiritual healing as a coping mechanism to reduce their stressors.

### 5.2. 3. Cultural Capital and Parental Coping

The acquisition and possession of cultural capital among parents was an important indicator of how they perceived disabilities and dealt with the challenges posed by their children's differences.

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

| **Last Attended Degree** | | **No. of parents** | **Percentage (%)** | **Mothers** | **Percentage (%)** | **Fathers** | **Percentage (%)** |
|---|---|---|---|---|---|---|---|
| **Higher secondary** | | 3 | 4.99 | 1 | 3.12 | 2 | 7.14 |
| **Graduation** | B.A./B.Sc./ B.Com | 20 | 33.32 | 15 | 46.87 | 5 | 17.85 |
| | B.E. | 9 | 14.99 | 2 | 6.25 | 7 | 24.99 |
| **Post-Graduation** | 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 |
| **Doctorate** | | 1 | 1.66 | - | - | 1 | 3.57 |
| **Post-Doctorate** | | 1 | 1.66 | - | - | 1 | 3.57 |
| **Total** | | **60 (N)** | **100** | **32** | **100** | **28** | **100** |

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. Tables 5.2 and 5.3 provide a detailed 3nderstanding of the distribution of education and profession among the parents, respectively.

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. Parents who were teachers and doctors expressed their positive perceptions in a more instrumental manner as compared to the parents who were engaged in other professions.

**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 |
| **Total** | **60 (N)** | **100** | **32** | **100** | **28** | **100** |

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. 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.

Table No. 5.4 gives a detailed picture of parents' acquiring of cultural capital as a positive coping mechanism. Thirty-six parents had decided to acquire further cultural capital based on their existing cultural potential, among which twenty-six were mothers, and five of them were the fathers of children with disabilities. Two mothers were found to have undertaken a special education program; eight parents undertook short-term courses on disability and management of differences, and eighteen parents reported attending different seminars and workshops based on disability and diversities to gain an additional expert understanding of disability. Five parents said that they had subscribed to certain disability-related journals and articles to enhance their understanding of disability. DeRoche (2015) in her study showed that parents referred to their education and social connections while advocating for their child, whether it was for diagnostic reasons, receiving required services, or deciding the interventions to be employed (p. 15-16).

**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 |

### 5.2. 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. For parents who had children with disabilities, the presence of good social networks was observed to have provided them with identity and purpose (Chenoweth & Stehlik, 2003, p. 67). Bullen and Onyx (1999) had suggested that social capital referred to the exchange of resources and reciprocity of support (material, informational, and emotional) and services between people (Chenoweth & Stehuk, 2003, p. 67). Responses from the parents reflected mixed emotions about their experience with the support networks they had been encountering. There were nineteen parents who had reported that access to support networks and community groups of parents having children with disabilities had enhanced their positive perceptions of disability and diversity. Twenty-seven parents had disclosed their dissatisfaction and displeasure with social networks that were related to family, extended relatives, and friends who did not have children with disabilities or who did not have any prior association with disability in general. Almost all parents, regardless of gender, education, profession, or income, and regardless of the type or severity of the disability, 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 in 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 the diversity.

Access to existing or development of new social capital has provided a significant coping mechanism for parents. However, there were some instances where parents' access to social networks was limited, and the existing networks began to generate negative feelings and perceptions among them. These parents were observed to have coped with this negativity by socially isolating themselves from these contacts. Friedrich et al. (1985) claimed a positive proportional association between coping and the presence of strong social support networks. He mentioned that "better copers may have more social support and more social support facilitates coping" (Sloper et al., 1991, p. 672).

Following Bourdieu's analysis of capital, it came to light that managing and dealing with disabilities had reproduced different and unconsciously woven patterns of inequality by which parents who possessed more economic, social, and cultural capital were in a better position to negotiate or bargain for the best services for their children. In contrast, parents who had limited economic, cultural, and social capital had less access to services and interventions for their children. Thus, it was discovered that children's possession and acquisition of economic, social, and cultural capital created inequalities in receiving much-needed services and interventions for managing their diversity. The social-cultural context (field) within which parents thought, felt, acted, or interacted, and the manner in which they acted, making meaningful interactions (habitus), were observed to have manipulated the acquisition and utilization of the resources (capital) parents had at their disposal.

## 5.3. Coping with the Disability

### 5.3. 1. Coping Resources for Parents

Coping could be understood as the strategies, mechanisms, and resources that people adopt to adjust to or overcome conditions of stress. People embrace diverse coping mechanisms to limit or reduce the impact of the stressors that gave rise to stressful conditions. The kind and extent of adopting coping strategies were found to have depended upon the coping resources that the parents possessed within a definite social-cultural context. In this research, coping was referred to as the efforts and attempts made by the parents to minimize the life strains that had emanated from the extensive care responsibility coupled with the varied forms of social encounters in which the parents were engaged in managing the disabilities of their children.

Pearlin and Schooler (1978) defined coping resources as the social and personal attributes of a person that are utilized by them to reduce the influence of stressors (p. 5). They had classified resources as "social resources," "psychological resources," and “specific coping responses”[4] (P. 5) and concluded that the extent and forms of coping relied heavily upon the social resources one had and also upon the psychological make-up of a person. The social resources included the social and support networks and relationships to which people had access. The psychological resources referred to the attitudes of pessimism or optimism, self-efficacy, and self-confidence that characterized the personality traits of people. It was found that accessing social resources had assisted in coping with the disability of their children and in reducing stress among the parents. 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. Parents' responses were found to be varied when it came to issues related to assistance and social support from family members (other than spouse) and relatives. While some (six) parents agreed that assistance from family members, both materially and emotionally, had contributed to stress reduction, such as feeding the child in the afternoon and making him/her sleep or accompanying him/her in their regular activities for some hours helped the mother to get some rest, sleep, or read a book; some (nine) parents complained that assistance from other family members (for parents who live in the joint household or family) had constrained their ability to get some rest, sleep, or read. A mother of a child with Rubella syndrome described how her mother-in-law used to force-feed her daughter in order to instill good and healthy eating habits in her daughter, whom she believed would boost her immune system. This was turning her more aggressive and violent, which was becoming difficult for the mother to deal with. She said that:

*"After every forceful feeding session with my mother-in-law, my daughter bit me to express her anger. Some days I feel like crying as she continues to scream and bite me, and sometimes she even hurts herself. "*

Another father narrated the way his father (the grandfather of the child) had treated their son (with ADHD) by locking him in the bathroom for two hours as a form of punishment when they went to attend a marriage ceremony of one of their very close friends. *"When I asked him why did he do so?" He answered that indecent and ill-mannered children like this need to be disciplined in a strict way.* Thus, parents who had accessed external support and professional networks outside their family were found to have experienced a decreased level of stress as compared to people who relied on their family support systems (Mancil et al., 2009, p. 534). Instances like these have explained how assistance and support from the family members added to the already existing stress quotient of the parents.

The psychological resources of the parents in the form of their internal psychological constructs of attitudes and perceptions towards the disabilities of their children were observed to be an important factor in determining how these parents had developed positive and negative perceptions of their life circumstances. Parents in my research have been observed to have subscribed to both negative and positive perceptions of disabilities in their children. Negative and positive perceptions of the diversities were generated among the parents not just out of what they knew or conceived about the diversities but also shaped by the way they perceived and experienced the social encounters relating to the children and their diversities.

### 5.3. 2. Formation of Negative Perceptions in Coping

Parents, whose narrations had reflected negative perceptions of the disabilities and their consequent life strains, were found to blame their fate or destiny. They believed that it was the result of their past karma or certain misdeeds that their children were born with certain disabilities. Connecting diversities in children with concepts relating to Karma, fate, or destiny was necessarily the result of conceiving the diversities as a tragedy or an unfortunate and undesired event in someone’s life. In India, where childhood disability has been comprehended as a tragedy (Gupta & Singhal, 2004, p. 23), parents' perceptions of disability were found to have remained clinched to a negative portrayal of their lives and experiences. In this manner, five parents explained their perceptions of their children's disabilities. In some cases, it was observed that conversations with relatives, neighbors, and friends often elicited negative comments; the use of words that reflected feelings of sympathy; or anything that included unwanted exaggerations of parental suggestions made the parents feel further stressed. On many such occasions, parents felt stigmatized. Though they agreed that their relatives, friends, or neighbors' actual intention was not to make them feel bad or stigmatize them, it was their own perception of stigmatization that made them feel bad about their situation.

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. "Secondary stigma" or “courtesy stigma” has been discussed by Erving Goffman, which has helped in explaining the experience of stigma felt by the parents of children with disabilities because of their affiliation and association with disability and diversity of their children. The parents were observed to have experienced the courtesy stigma when they had internalized the stigma extended towards the disability condition of their children and the corresponding stigma extended towards them as caregivers. In recent research, the public stigma directed at caregivers has been dubbed "affiliate stigma"[5] (Mak et. Al, 2008; Patra & Patro, 2019; Chang et al., 2020). Affiliate stigma was observed to have more serious consequences than courtesy stigma for the parents and their mental health. Mak and his co-authors (2008) differentiated courtesy stigma from "affiliate stigma" (2008, p. 532). Mitter, Ali, & Scior (2019) claimed that caregivers perceive courtesy stigma that causes "internalizations of the negative evaluations and subsequent development of affiliate stigma". As a consequence of such internalization, parents were observed to have withdrawn socially. Thus, social withdrawal and concealment were the consequences of this internalization of stigma, which had a negative impact on their use of coping resources (Mitter, Ali, & Scior, 2019, p. 03).

Fourteen parents in the research had subscribed to this kind of social withdrawal behaviour. It was noticed that after learning their children had certain diversities, parents were observed to have denied the medical reports and findings with regard to the disability conditions. The denial resulted from negative perceptions that parents had attached to the disability conditions, as well as negative images that the parents had formed about the social and cultural acceptance of diversity. The initiation of early intervention procedures further worsened the existing complications associated with the diversities. When the parents had begun to observe and experience extreme challenges as a result of the complications, and when the disabilities turned out to be unmanageable for the parents, they realized the need for intervention. But in almost all the instances of this kind, parents (five) were noted to have regretted their decisions to deny the disabilities earlier. A father of an eleven-year-old boy with ADHD along with learning disabilities narrated that:

*"When my son was three years old, his school teacher told me to consult a doctor about some of his irregular behaviour patterns she noticed in school. We decided to change his school after five to six repeated recommendations from the school. We*

*admitted him to a good private school. After four months, we were summoned to the school and informed that our son had been observed to have irregular concentration and communication patterns; and that he had been closely observed by the school's mental health counselor, who reported that our son displayed symptoms of ADHD and that we should seek medical attention as soon as possible. This time, my wife convinced me to see our paediatrician, who, after a preliminary check-up, recommended we see a developmental paediatrician. He was diagnosed with ADHD with highly prominent symptoms of learning disabilities. The doctors and the concerned medical panel had reported that improvement would be very gradual and would take a very long time as his condition would turn complicated with time in the absence of the required interventions. Now I feel that his primary school teacher was right with her observation that she made three years ago!"*

Whether parents relied heavily on fate, chose to withdraw from existing social networks, or denied their children's disabilities, all of these represented coping mechanisms that parents had adopted to reduce stressors and strains in their lives. Closer scrutiny and in-depth understanding of the responses by the parents revealed that all of these coping strategies were associated with the negative perceptions that parents had with regard to the diversity of their children.

### 5.3. 3. Development of Positive Perceptions among Parents

It was observed that all the parents had gone through phases where they had developed both positive and negative perceptions regarding the disabilities their children had. But for parents who had psychological resources associated with a pessimistic or tragedy-oriented understanding of the diversities and had limited access to social or familial assistance and emotional support, they were observed to have retained their negative perceptions associated with the disability for a longer duration of time. The negative social-cultural and psychological aspects were attributed to the persistence of the negative perceptions among these parents. While in some parents, such long-term persistence of negative perceptions has been observed in their children, there were many others for whom the negative perception was generated out of the initial social and interventional challenges they had encountered, and the negative emotions towards the disabilities were found to have been retained for a shorter duration among these parents. These parents were among those who had gradually developed different avenues for devising strategies and implementing coping mechanisms that assisted them in reducing stressors and limiting life strains. These parents had developed positive perceptions of the disabilities of their children. A thorough analysis of their narratives revealed that this attitude of positive perceptions had been highly influenced by the positive or optimistic psychological aptitude they had possessed. It had also been noticed that individual possession and acquisition of cultural, social, and economic capital had contributed much to the development of positive perceptions among parents. In a study conducted by Luther et al. (2005), it was observed that in the presence of assistance from different parent-based social support groups, families and parents could successfully cope with the stress that they had been encountering in managing the disabilities of their children (Mancil et al., 2009, p. 534).

Thus, instances were not rare where parents disclosed their positive perceptions about the disabilities of their children. In my research, parents who had developed positive perceptions of disabilities had adopted a variety of coping strategies, such as connecting to external social and professional support networks outside the family, being affiliated with parent-based non-governmental NGOs, being connected to or creating community groups in their locality or near vicinity, and participating in various virtual community groups of parents through social media platforms (mainly). Engaging themselves in the positive coping strategies mentioned above, parents expressed their agency as a conscious reflection on the life strains and challenges. Some parents were found to have furthered their potential and capacities for developing agency both among themselves and also for other parents, which took the form of advocacy depending on the social, cultural, and economic resources they possessed.

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. The responses from the parents revealed that inadequate (if not absence) and limited access to the required services for their children had directed and driven them to find hope for themselves. Thus, it was the negative perception of society and the systems that had diffused an aura of negativity among the parents with regard to their children's diversities. It was because of this negativity and pessimism that parents felt compelled to express their agency and work toward advocacy.

### 5.3. 4. Impact of Positive Parental Coping

Conversations with the parents and extracts from their narration revealed stress, anxiety, and intense frustration among them. But instances were not rare when parents reflected positive emotional vibrations while caring for their children with diverse personalities and overcoming the hurdles they had been encountering. According to research and studies, families have positive perceptions of raising their disabled children (Taunt & Hastings, 2002, p. 116). The findings on parenting have conformed to the observation of positive emotional reflections expressed by the parents. In their study, Mullins (1987), Hornby (1992), and Meyer et al. (1993) stated that parents had expressed their stories of personal growth and an enhanced sense of enrichment and meaning in their lives, which had resulted due to their association with and experience of raising their children with disabilities. A mother of a fourteen-year-old boy with cerebral palsy expressed similar views by saying:

*"I was never this confident as I am now. I did not even know how to talk back to my elders or strangers. I was a shy kind of personality. My in-laws did not like me and accepted me because it was a love marriage and I was not of their caste. Even when my son was born and detected with cerebral palsy, my mother-in-law blamed me for this and said that it was because of the curse that we had entered into an inter-caste marriage. I was silent and had accepted all the humiliations as I was a very introverted person. But look at me now. I run an organization single-handedly (a creative and craft-making organization named "Ankibuki"), and around twenty-five girls and boys work under my supervision. I even take orders for well-known puja committees in Kolkata. And this all happened because of my son. I understood that I had to stand by him when nobody else stood by us. I know that my son won't live much longer, but he has given me a new life; I have emerged into a new personality-*

*one significant among many, and it is all because of my son. Raising and taking care of him makes me feel special and confident. I often feel that I and other mothers like me are special! "*

Through a thorough understanding of the interviews, diverse coping strategies were adopted by parents to adjust to their intense stress and anxiety in dealing with and managing the diversity in their children, both at the micro and macro level. It has been observed that parents prefer to look for positive aspects in their lives. Parents always maintained that they wanted to give positive meaning to their constant effort and struggle to manage the diversities. It had been noticed that while parents expressed negative emotions while narrating their lived experiences in dealing with disabilities, at the same time they expressed their adoption of ‘positive perceptions’ as a coping strategy to fight back the intense phases of the negative emotional turmoil they had been encountering for a long time.

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” (p .115-116)[6]. Positive reappraisal was seen among parents when they had attempted to groom themselves into experts to understand, comprehend and manage their children’s disabilities in a more systematic manner than just giving in to the situation which was socially hurdled and dictated by the medical professional gaze. Many parents (nine) had taken short-term courses or workshops, which were organized by different non-governmental NGOs, on disability in general and the specific diversities that their children had, to gain an overall understanding of the disability discourse in India and Kolkata, in particular. There were some parents (five) who took this effort of gaining knowledge on diversities to the next level by assisting other parents who could not access the existing knowledge and information resources reacted to disability due to various personal and wider socio-economic hurdles. There were seven parents who worked on their personal growth through professional consultation and psychological counseling to cope with phases of intense stress and frustration. In these instances, the parents could control negative emotions arising out of the constant exposure to care-burden and personal encountering of the disabilities in the children. These parents had chosen to regulate their own emotions by taking professional help and psychological counselling. Thus, parents' emotional regulation to cope with the negative feelings and thoughts could be traced to the "problem-focused coping" (p. 116) category of emotional adaptation as was claimed by Folkman and Moskowitz (2000).

This type of positive emotional coping was found to have helped many parents channel their negative emotions into positive and productive self-development. A mother of a son with severe symptoms of cerebral palsy, who could not walk, see or talk, claimed that it was during the negative, intense phase of her life when she had decided to clinch upon her previously nurtured creative self and had decided to do something meaningful with her long-buried passion for art and craft. In her words:

"*My son never called me 'ma' and he will never say it. He does not even recognize that I am his mother; he does not even understand what a mother is! I am just like any other caregiving person in my life. As such, I don't know how it feels to become a mother. My experience of motherhood is associated with pregnancy and giving birth to my son".*

She had expressed her intense pain and displeasure over her identity as a mother, which she thought had not been recognized by her son. After six years of dealing with severe negative emotional upheavals, she could finally decide to start her own business using her skills in art and crafts. To this day, her business has been run by the families of many others who worked in her workshop. She even started exporting her craft materials outside India, which had gained wide popularity within Kolkata.

Her story indicated that she had tried to cope with the displeasure by diverting her negative thoughts toward working on her passion for crafts. Discontent and non-recognition of her identity as a mother made her derive contentment from her identity as a successful businesswoman. Folkman and Moskowitz (2000) call this the "creation of positive events" (p. 116). Seven parents mentioned that despite exhibiting extremely rigid and inflexible schedules of daily care responsibilities, along with the intensive burden of managing and organizing the household chores, they could bargain and celebrate moments of joy, humor, and happiness out of the little spaces they received.

I remembered how excited and happy the mother was when she heard that I would be visiting her place in the afternoon for the interview. She said, "*Yes, the afternoon will be great! We shall be having our tea together on the balcony, with long hours of conversation. It feels extremely good to witness the sunset from my west-open balcony. I love having tea here every day."*

A father said, *"Reading books makes me feel good anytime. Reading books provides the space where I don't get worried about our daughter; where thoughts about her future do not scare me; where I don't find the time to see or talk to her doctors, therapists, and special educators."*

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. This had enhanced the sense of self among the parents and had directed them towards making meaningful and productive contributions towards enhancing the perception of self for other parents who were sailing in similar boats.

### 5.3. 5. Coping Strategies Adopted by Mothers and Fathers

Coping strategies that were adopted by parents revealed a gendered dimension in perceiving and adjusting to the stressors. In earlier chapters, we had a detailed discussion on how mothers and fathers reacted differently to the reality of their children's diversities and how the challenges involved in raising and caring for their children and dealing with their disabilities took different forms for mothers and fathers. Since mothers and fathers were found to have perceived the diversities differently based on their different socio-cultural orientations (both internal and external), the coping strategies devised and adopted by them were thus observed to be markedly different. The different socio-cultural orientations of the mothers and fathers, reflected through their narratives and responses, have been analyzed under the lens of existing motherhood and fatherhood ideologies that have shaped their personalities, behavior, and actions. In India, motherhood and fatherhood ideologies have made a wide shift from their traditional religious clutches as encoded in the religious texts of ‘Chaturasharama' or ‘Purushasukta’, which said a lot about the duties of a man and woman in society and within the family; where fathers were seen as providers and disciplining agents (Sriram & Navalkar, 2012, p. 208) and mothers were made responsible for the care of children and households (Valk & Srinivasan, 2011). However, empirical and qualitative research has revealed that little has changed in reality from what was predicted theoretically. There were a few studies in India that observed that even women who were engaged in paid employment had considered men as the primary providers of the household and were found to have seen and accepted their passive homemaker roles (Sriram & Navalkar, 2012). Husbands and fathers were seen as the “providers and protectors” within the family (Sriram & Navalkar, 2012, p. 211). Studies on contemporary fatherhood and motherhood ideologies and practices have reflected a dichotomy between the existing perception of motherhood and fatherhood ideologies and the real images that were portrayed in actual research findings.

Responses from the parents confirmed that the burden of care still fell upon the mothers. Mothers’ constant exposure and continuous care work related to managing the disabilities and diversities in their children were the main sources of stress for them. Stress among fathers was observed to be related to finances, strategic planning of household expenses, and securing the future for their family, especially with children with disabilities.

In households where both parents were employed, a gendered division of tasks was also noticed in caring for and managing the diversities. In nine households the continuous care demand was met by an external care provider (aya or mashi), and mothers were observed to have handled tasks relating to the medical and professional needs of the children, like making appointments with doctors and professionals, discussing improvements and potential with the specialists, directing and supervising the kind of food to be prepared for the child, and monitoring other household chores. Fathers were seen to be engaging more in planning the finances and insuring for the future or emergency needs, going through the medical and improvement records, and sharing certain household chores with their wives. The tasks included taking the child to specialists, intervention sessions, and doctors. When it came to providing quality time and play-based learning time to the children, the parents were found to have shared the responsibility among them. In these households, employment and professional engagement had contributed to the parents' coping with their life strains. These parents accepted that dual employment provided them with the financial security they believed was most important to bear the expenses of the intervention procedures for their children. A couple responded that:

*"We earn well. And surely this is our strength. At least we know we can afford the best care, professional services, and required interventions recommended for our daughter. With limited economic resources, it would have been difficult for us to meet the high expenses required for accessing the medical and professional interventions for our child."*

Coping strategies did not differ much along gendered lines in households where both parents were employed. In households where mothers were homemakers and fathers were the only earning members, the care work burden was totally managed by the mother along with the organization of her household chores. The coping mechanisms for the parents thus differed in these households. Constant exposure to the children made the mothers emotionally closer to them as compared to the fathers. However, this should not be understood as negligence, ignorance, or lack of love and care from the father's side, but rather that this had happened because of the situational and circumstantial context of the family and economic system of production that left little or no time to contribute to care work and household work. Thus, mothers were exposed directly to the child-related stressors and were observed to have adopted different coping strategies to reduce them—like joining different professional and information support groups, community parent groups (both physical and virtual), creating groups in the locality, attending various courses and skill development programs, and even providing voluntary services to NGOs where their children went for special educational needs.

**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.

Fathers who were the sole earners and got limited time to share the care burden have been observed to have more emotional distress as compared to their mothers. In my research, fathers expressed that talking to their close friends or childhood friends had provided them with positive emotional reinforcement. The inexpressiveness among the fathers was another stressor that added to their own emotional distress. The fathers sought out positive marital relationships as a coping strategy for the life stresses they were experiencing in balancing their roles as providers and caregivers. A father narrated:

*"I am satisfied when my wife and son are satisfied and when I am able to meet their needs and demands. When I see my wife is running things well, when she does not complain about my part of the responsibility, I feel content".*

## 5.4. Role of Support Systems for Parents: Network Matters

Raising children with disabilities requires continuous monitoring and supervision by the parents, which sometimes takes a toll on their physical and emotional health. Any kind of support or assistance has helped them in adjusting and coping with the daily challenges. Social support was found to have existed in varied forms—like spending some quality time with the parents; sharing a piece of advice or information that might have proven to be beneficial for them; just listening to their thoughts without making any judgements; or just spending time with the family for some time.

### 5.4. 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 perceived or felt stigma by the parents. Most of the interactions that parents had with the expectation of receiving pleasure and breaking free from the monotony of their rigid and inflexible lifestyle resulted in questions and queries that made them uncomfortable. As a consequence, parents were observed to have isolated themselves from such social circles, which restricted their scope of socializing with people. These parents were observed to have developed negative perceptions of their children's disabilities and life situations as a result of their constant interaction with diversity.

The mother of a four-year-old boy with Down syndrome responded that she had many friends, many of whose children were almost the same age as her son. She said:

"*Whenever we all met, I was asked about the recent development or improvement that I had (must) noticed in my son. Gradually, I stopped receiving any calls or invitations from them.*"

She felt ridiculous every time she was asked these kinds of questions regarding her son. She could sense a feeling of sympathy and felt stigmatized. The findings were similar for many other parents.

In Kolkata, no professional institutions or organizations were noticed to have existed which could provide expert care-work services for children with disabilities at times when parents needed them the most. There were abundant provisions that extended crèche services, but none of them were professionally equipped to provide care to children with disabilities, nor did they readily agree to keep these children. In the absence of social support both at a personal and professional level, parents felt heavily burdened with the care work of their children. At times, parents become so emotionally driven that they wish they had never had children. The only support system that parents could get was the services of a hired care worker, which was accessible to families who had a good financial position.

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. Other than these few of the above cases, the rest of the parents reported that no one from their family extended assistance, even for some hours. Assistance and support from close friends and neighbours were still available in some instances. A father expressed his relief when they could leave their elder daughter (fifteen years old) at a neighbor's place because they had to take their son (a seven-year-old boy with autism) to NIMHANS Bangalore for his check-up and interventional follow-ups. However, incidences of this kind where assistance was received from the neighbours were limited. Only in four instances did we see that neighbours had extended the required support needed in occasional emergency situations that did not relate to caring for the children with disabilities in a direct way. The help was extended in an indirect form by assisting the parents in some other ways other than getting involved in the care work directly.

**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** |

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. Interviews with the parents and the two clinical psychologists in my research revealed that the presence of a strong social support network had a significant impact on the lives of the parents who had children with disabilities.

The presence of a strong social network was observed to have been important not only for sharing the burden of caregiving but also for providing emotional support that could have provided the necessary motivation and encouragement during times of stress, anxiety, and depression. Parents responded by having good social networks with friends, family, and neighborhoods with whom they had strong emotional connections. The parents had agreed that at times when they suffered from any kind of emotional issue, they could receive the material, social, and emotional support from these social networks. A mother (single mother) who was a teacher at a government school and had a five-year-old boy with Down syndrome expressed that it almost took two hours to travel from her home to school. Her son used to stay with his maternal grandmother, grandfather, and a hired care worker for nearly eleven hours a day. She said,

"*I can keep calm throughout the day because I have such wonderful people around me to assist. Otherwise, it would have been impossible for me to manage everything alone.”*

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. The mothers in these households were homemakers, who, due to limited financial access to resources, could not afford to hire paid care workers to assist in managing the special needs of the children or even to hire maids who could assist in sharing the household chores. A father of a four-year-old boy with autism spectrum disorder narrated:

“*I work for a private company. My salary is just enough to maintain the three of us. The medical expenses and special therapeutic sessions required for my son are out of the monthly budget we have. So I took a few tuition classes for junior years in my area.”*

In such a context, the excessive workload of the father left him with limited time and energy to share the care burden with his wife.

### 5.4. 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 understand their circumstances of life and with whom conversations could be continued on a positive note. In households where both parents were employed, the care work responsibility was extensively supported by the material support systems to which they had access. In these cases, the care work responsibilities were completely taken care of by a hired care worker. In some joint households, the extensive hired care services were assisted and supervised by other family members who were present in the house. These parents had experienced a few instances of depression and anxiety with regard to the care of their children with diverse abilities.

An in-depth conversation with the parents revealed that in households where the fathers were the only earning members and mothers were assisted by a hired careworker to share the care burden of their children, mothers got time to socialize with their friends and families, both over the phone and also by physically meeting them at their own place or outside. These parents expressed that frequent social interaction with family and friends provided them with much-needed space outside of the monotony of fixed and rigid care-work schedules.

It was observed that the parents who had received good material and emotional support had a lower incidence of emotional desolation that led to stress, anxiety, and even depression. Existing and working social networks had helped them to vent out their emotional turbulence. For parents, the presence of a strong social system has a significant and positive role in parenting. Depression and an intense level of anxiety were reported in parents who had the least number of social contacts and scope to socialize. This could well be understood through the concept of the "cycle of rejection"[7] (Chenoweth & Stehlik, (2003, p. 67). The parents who remained over-burdened with care demands found limited exposure to accessing social networks, particularly when they received no assistance from the existing social networks. Lesser exposure of these parents to social networks was observed to have lost the required reciprocation that any kind of relationship could demand, and gradually the parents got isolated socially. Isolation from social networks and relationships caused greater negative emotional turmoil among the parents.

### 5.4. 3. Role of Support Groups in Parental Coping

A survey, conducted by Clifford and Minnes (2013), found a connection between access to support groups and the coping strategies adopted by parents. They could recognize three groups of parents: i) parents who were engaged with support groups and could adopt better-coping strategies; ii) parents who believed that access to support groups would have been beneficial for them but had not been able to get involved with any support groups due to the absence of far-flung establishments of such groups they knew about; and iii) parents who were involved with support groups earlier, but had left them due to non-fulfilment of their needs. 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. Sharing concerns and experiences assisted the parents to come out of the negative emotions that surrounded them on occasion. Support groups were observed to provide much-needed emotional support and often material assistance to parents, but some parents (eleven) were unable to access the support groups due to the lack of such groups in the 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, formed and organized a community of parents among themselves that could provide support to each other. Another group of parents (eight) were there who had earlier been members of certain support groups but had stopped accessing the groups because they felt that the membership of such groups was not yielding the results that they had expected. Though the groups had been organizing workshops and sessions for the parents, those were more inclined towards therapy and learning techniques to be applied to the children. The parents had expressed that they had decided to join the groups to receive emotional reinforcements and to cope with the daily challenges they had been facing, but the workshops further trapped them along with the clinical and medical complications with which they were already dealing through their encounters with various interventions and special therapeutic programs. A father of a child with autism had shared his negative experience with one of these support groups, which he later stopped accessing. He narrated:

*"It had been seven months since we (father and mother) had attended each and every meeting they had organized. During these seven months, we were connected to many parents like us. From our parents, we definitely got that support for which we became associated with the group. But the programmes and workshops that were conducted by the group were more inclined toward developing the learning, teaching, and training techniques among the parents than attempting to empower them through exposure to different kinds of information. We had already come across such learning sessions during various meetings and workshops arranged for parents in the special schools where my child was affiliated; even the doctors made us learn certain training and teaching cues via special sessions as part of the intervention procedure. We were receiving nothing new; rather, my wife was getting more depressed and anxious with the constant exposure to medical procedures, interventions, clinical therapeutic sessions, and the ongoing professional nagging. We were not getting any emotional assistance from the group to cope with our everyday stress, anxiety, and monotony in raising our children and managing their diversities".*

### 5.4. 4. Parent's Access to Virtual Support Groups

The extensive care burden reduced the capacity for reciprocation among the parents, which formed the basic foundation for the successful operation of any community or informal group. The parental informal groups functioned well when all the parents shared their capacities and agencies to uplift each other from life strains. In such a context, the capacity for some families to reciprocate or contribute by attending the group meetings or sharing their experiences was reduced by the daily burdens of care and chores. A mother said:

"*I got so tired after completing the daily tasks of the household and taking care of her everyday needs of feeding, bathing, etc., that I could hardly motivate myself to attend the group meetings or gatherings.*"

This has been observed to have reduced parents' capacity to build social networks for themselves, which would provide the necessary emotional and social support whenever they need it. Chenoweth and Stehlik (2003, p. 67) called this "the cycle of rejection" by which the care work demand had restricted the capacity to develop social networks, which further directed them. In such circumstances, parents have looked for access to virtual social and community parental groups that could help them to balance their physical tasks and emotional needs. Thirty-four percent of the parents in my interview had subscribed to different virtual, social, and professional networks.

In-depth interviews and detailed conversations confirmed that parents seek assistance and support from groups to receive information and attain emotional reinforcement to advocate for the needs of their children. Accessing support groups and arranging schedules to attend the meetings, campaigns, special counselling sessions, and other parent-related gatherings that were organized by these groups required an investment of time and resources on the parents' part. To attend the services from these groups demanded rescheduling of the everyday fixed routine that parents used to follow with regard to their care and chore-related responsibilities. This has been found to be difficult for parents who did not have hired care-workers at home or who did not have any other familial or social assistance to share the care burden of the parents who could attend to their children with disabilities during their absence. For these parents, virtual support groups (also known as internet support groups) provided the necessary platform to draw upon their informational and emotional resources in dealing with their children's diversities. 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 were associated. Eleven parents 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 those groups and the services they provided. In such instances, the internet and virtual support groups were found to have facilitated the parents with their requirements.

During the interview, parents expressed that the phase followed by the detection of disabilities in their children created confusion and helplessness among them regarding the diagnosis and prognosis. In order to adjust and cope with the feelings of helplessness that parents experienced while planning their future course of action, they used the internet as a source of detailed information and knowledge about the disabilities of their children. In doing so, the parents came across information about different parents' groups and got connected with them. Parents agreed that connecting with parents with similar experiences and interests had helped them to come out of confusion and provided them with much-needed emotional support. In his study, Fleischmann (2004, p. 35) found that after the detection of disabilities, parents had undergone periods of readjustment and that interacting with other parents had helped them to feel connected and less isolated. Gathering relevant and adequate information about the disabilities and sharing parents' experiences helped in building up a "sense of self-efficacy" among the parents (Webster, Cumming & Rowland, 2017, p. 207).

### 5.4. 5. Access to Parent Support Groups: "We Care for Each Other!"

Narratives revealed that parents had received positive emotional and mental support from their families and 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 this kind of support network, parents feel comfortable and understood. 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. A single mother of a fourteen-year-old boy with multiple disabilities narrated an incident where the boy had serious breathing troubles and was required to get hospitalized at 2:00 am:

*"I was scared and clueless. My son was shivering in pain and having difficulty breathing... While holding me tightly, he looked and stared at me as if he was asking for help... It was a forty-minute journey to the hospital from my place... and I was alone. I called Mr. Sinha (a father of a child with Down syndrome) who stays near to my place. He immediately arranged for a car and took us to the hospital. He even paid the admission charge, which I did not have at that time. He was an angel for that night".*

Mr. Sinha and the single mother mentioned above were members of a community called "Disha", founded by Dr. Ranajit Mondal. The community included parents of children with intellectual disabilities. This community acted as a strong support network for these parents. "Jagori", founded by Amrita Mukherjee, was another such parental community group that was developed by a parent for other parents in the locality having similar life challenges with regard to disabilities and diversities in their children. Another parent-based group, ASWB (Autism Society of West Bengal), is now registered as a non-governmental organization. In all these groups, parents' decision-making capacity and their agency found their expression through different campaigns, awareness programs, and strategies for improving the living conditions of their children. 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.

## 5.5. Agency, Capacity Building and Advocacy

### 5.5. 1. Organizing Local Level Advocacy

Parents have been able to express their agency in improving living conditions for themselves and their children by adopting various coping strategies to reduce the stressors and potential life strains caused by constant exposure to, the encounter with, and management of their children's diversity. In this research, parents' agency has been clearly expressed through the different strategies that the parents have adopted in altering their life conditions. Narrations and responses from the parents reflected the active agency of parents in making decisions for their children; decisions that 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 had to exert considerable effort in communicating with various macro-societal stakeholders involved with their children's disabilities. Connecting with appropriate authorities and officials and negotiating with school administration, medical professionals, and special trainers required a significant investment of time, energy, organizational skills, and commitment on the part of the parents.

Some parents had expressed their concerns about the inadequate existence of care and intervention facilities for children with disabilities in their vicinity, whose parents were not adequately equipped with the much-needed financial and material resources to support the professional and special interventions for their children. In such instances, support groups and networks were found to have played a significant role. Parents, who had received professional and informational exposure with regard to the diversity of children, came forward to support other parents in every way they could. In some instances, though few in number, these parents arranged parents' meetings at regular intervals to talk, discuss, and provide information regarding the diversities and consequently tried to enlighten the parents with innovative ways of parenting and managing the disabilities. However, these kinds of advocacies at the local level context could hardly make their way towards advocating for their children's actual needs, which the parents had encountered while parenting in a real-life scenario and which were often not very similar for all children and their parents, as had been accounted and assumed by the law and medicine. Most of these local-level advocacy programmes worked to provide support to parents to deal with their everyday encounters with a disability and also to overcome and cope with the challenges they had encountered as an individual, other than being a parent.

Voluntary activity within the organizations or groups was appreciated by many parents, and they found this to be rewarding for them. Presently, a good number of parents' groups could be identified who chose to advocate for the needs of their children. Many parents tried to connect with many of these groups in order to remain associated with people who shared similar life experiences. These parents reported that connecting to these parents' groups had helped them not just to receive significant information regarding the disabilities that their children had but also drew emotional and social support from them, which could help them to deal with unpleasant periods while managing the disabilities in their children. In all the above instances, parental advocacy and agency have been prominent in voicing the needs of their children and getting them fulfilled through various individual and community-level efforts.

### 5.5. 2. Development of Parental Capacity

Parents' expression of agency and their consequent development of advocacy were understood in the light of how Emirbayer and Mische (1998, p. 962) had conceptualized agency. They had defined agency as the constitution of three interrelated components-"agency as iteration" or extension of habitus, agency as encompassing "projective capacity", and agency as "practical evaluative capacity" (p. 962)[8]. Parents in my research had reflected all the three components in their actions with regard to managing the disabilities of their children. Parents had planned and oriented 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. The past experience and habitus of the parents were found to have shaped their perception of disability, and the possession of the cultural capital had influenced the development of positive or negative perceptions of the disabilities in their children. Thus parents' iteration and reiteration, which were shaped by their habitus, had directed them to adopt coping strategies based upon the presence of and access to resources they had at their disposal. Based upon the 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 programs 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 own experiences; and thus, developing advocacy. The potential capacity of the parents to alter and challenge the given reality of strain and anxiety had been expressed as the "projective capacity" (Emirbayer & Mische, 1998, p. 983) of the parents. The projective capacity of parents was seen to have transformed into “practical –evaluative capacity” (Emirbayer & Mische, 1998, p. 994) when they were seen to have expressed and mediated their agency. Instances were not rare where the parents had institutionalized their capacity of the agency to voice the needs of their own children and that of the others. The calculated absence and inefficiency at the systems level to meet the needs of their children, and evaluation of the social and political reality with regard to the services their children had received, had urged the parents to mediate their agency based upon the resources they had at their disposal. Thus, parents were noticed to have developed their own critical and creative responses to the complicated, strenuous and challenging reality, by utilizing the cultural capital and resources which they had acquired in the past. The following narration of a mother (government high school teacher with a Master’s degree in Bengali) with a five-year-old boy with Down syndrome made it further comprehensive:

*“When my son was five months old, he had been identified with Down syndrome. My husband and all the in-laws blamed me for this. My love marriage and inter-caste marriage were blamed for my son's disability. Every moment was a struggle for me to fight against the cultural odds that were nurtured in my in-law’s house. My son was seen as a curse to the family, one that would bring misfortune to the entire family. My education and cultural exposure made the situation more complex as there were real fights to give my son the respect and dignity that every child deserves. I was dropped from school and told that my son would be my sole responsibility from that point on. I was not allowed to go out, consult doctors, or disclose anything to anyone about my son. After a few months, I decided to leave my husband and filed for a divorce. They readily agreed, as if they wanted to get rid of me and my son. I joined my school. It was the second round of fighting then, and this time the fight was with the system. There were no special schools or intervention centres near my place. I could not afford the time to take him to schools that were distantly located along with my professional commitment. So, I converted my personally run recitation training workshop into a community and parent-based special school for children in my region who could not access special schools at a distance or intervention centres due to a lack of resources. The fight continues, and we see it every time we apply for disability*

*cards and have to wait months or even years to get one; when we struggle to get our children to school and don't have access to facilities like ramps on public transportation; when we apply for counselling sessions and early detection camps in local schools and health centres for all children but receive no attention, and so on."*

The story of this mother showed how she had challenged the conventional, stereotypical, and negative portrayal of disabilities and chose to live independently as a single mother after coming out against all the odds that were present in her societal context. Based on her education and professional experience, she has been found to have negotiated with different stakeholders related to disabilities to receive better services for all the children who were associated with her school.

In Emirbayer and Mische's language:

*"By increasing their capacity for practical evaluation, actors strengthen their ability to exercise agency in a mediating fashion, enabling them (at least potentially) to pursue their projects in ways that may challenge and transform the situational contexts of action themselves* (*p. 983*)."

### 5.5. 3. Advocacy as a Medium to Access Service

Parents' participation in decision-making, interventions, and planning that were associated with managing and dealing with the diversities of their children had proven to be effective for these children in receiving quality and need-based support (both material and legal) and in accessing the appropriate education and health services they required (Trainor, 2010a, p. 245). At this juncture, the parents were observed to have stood in the juxtaposition between the entitlements that their children (with disabilities) were provided via legal provisions meant for them and the actual needs and requirements that these children deserved. In most instances, parents (seven) complained that the legal entitlements did not fulfil the requirements that they had been encountering in their everyday lives while managing the diversities. For instance, we could talk about the provision of inclusive education, which has ensured the admission and continuance of education of children with disabilities in regular schools, but in writing only. In actual reality, this provision was not well coordinated with the infrastructural facilities that were required to access these schools, like proper arrangements and organization of the roads, buildings, and public transportation system, making it easier and more comfortable for parents to take their children to schools. Though the Bill of 2014 (Rights of Persons with Disabilities) mentioned structural changes that were required for inclusion, it did not address the real-life barriers that parents and children faced in accessing schools, whether regular or special.

Interviews revealed that inadequacy and limited accessible resources had been the primary thrust among the parents to develop agency and engage themselves in advocacy. 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.

A father of a five-year-old child, who had been running a medical store and a doctors' chamber attached to it, had thought that it was necessary to bring doctors to his chambers, who specialized in developmental pediatrics and other psycho-motor and neurological disorders, to counsel and detect the disability conditions in the children of his locality, which would have helped to guide them further. He said:

*"My son has autism. I showed him many renowned doctors across the city and even took him to Chennai. We understood how important the early interventions were for*

*improvement in their condition. I knew some parents in the vicinity who had children with certain disabilities but who could not take their children to good doctors or could not afford the high expenses. Some of them did not pay heed to the diversity and thought that it would go away naturally once they grew up. I thought it was necessary to make people aware. Since I owned a shop and had a running chamber, I contacted some doctors in the city to have their chambers in my shop. I even arranged three awareness camps with the help of these doctors in the open ground near my shop with the help of the local councillor. He even allotted a room in the local club to conduct special intervention classes, like speech therapy, for the children in and around the locality. Right now we have eleven such children, including my son.”*

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 they could provide the required push to the authorities to improve the living conditions of their children. In my research, such systemic changes have been observed when, for example, parents forced private school authorities to admit their disabled children when they refused and suggested they go to a special school for the purpose. Another such instance was observed when the parents convinced the local political body to construct ramps in a park that was situated at an elevated level from the road.

However, it was observed that parental advocacy could hardly reach the legal and medical systems of operation. It was highly characterized in terms of the operation of medical systems and professional knowledge by a sense of possessing expert scientific knowledge and a biological understanding of disability, which had conferred decision-making power upon them. Discussing the legal system would have necessitated a reflection of reality as an insider and direct participant in government decision-making. Indrani Basu, Director of the Autism Society of West Bengal (ASWB), provided a holistic understanding of government, policy, and legislation perspectives, which were discovered to coincide and crosscut parent perspectives. She had maintained that it was the question of intention that counted the most. The government and concerned departments were not separate bodies that were independent of society but comprised of people who belonged to the society in question. She believed that the wider understanding of disability in Indian society in general and Kolkata, in particular, was a “repertoire”. She believed that people's common understanding of disability revolved around the medical model, as evidenced by the frequent use of the word "diagnosis" by doctors, parents, and officials in positions to devise policies and programmes for these disabled children. She had pointed out that the state concerned departments had been more oriented to looking after whether the policy recommendations got fulfilled or not. A narration made by her explained this clearly:

*“To observe World Disability Day (details), all the NGOs are invited to participate and are given a maximum of ten-minute slots to perform. Participants from each NGO come on stage, perform, and then leave. The programme thus begins and ends by celebrating the performances of the children with disabilities. During the planning of one such event, I suggested that it would be better to have the children and adults who had disabilities and their parents speak before the audience about their experiences and needs. This would help the authorities to understand the gap between the law and reality. But it was outrightly rejected and, instead, requisitions for dance, song, and recitations were accepted.”*

Thus, the state and the concerned departments were found to be more inclined to see whether the promises made in the law and the theoretical assurances made for improving the living conditions of these children were implemented in reality or not. However, the quality and practicability of such implementations were never taken into account. Even the role of many NGOs has been questioned by Indrani Basu. She said that she was considered arrogant for posing questions as compared to the members of other NGOs. Indrani Basu had argued that it was the wider understanding and perceptions of disability in our country, which remained embedded in comprehending diversity and disability as illnesses that required a drastic change. And it was this understanding that laid the groundwork for medical interventions, policy recommendations, and legislation to be written, passed, and implemented. In the face of this kind of passive involvement from the state, parents choose their own path to advocate for their children and develop agency among other parents to improve the living conditions and opportunities for their children rather than sit back and wait for the government to act to do the same.

### 5.5. 4. Parental Involvement in Effective Social Advocacy

In a study, Trainor (2010b, p. 40) observed that parents' agency and advocacy for their children with disabilities took diverse forms in their respective contexts and functions. Trainor (2010b), thus, classified parental involvements into four categories- "intuitive advocacy", "disability experts", "strategists", and "agents for systematic change"[9].

Twenty-seven (twenty-two mothers and five fathers) parents in my research fell within the intuitive advocacy category, who agreed that constant and continuous encounters with the diversities, had turned them to understand their children's different behavior, expression, and actions better than anyone else. Many of them maintained that their understanding and knowledge about the respective diversities in their children were sometimes even better than the professionals they had encountered. This was particularly true when the diversities in the children had interacted with the social environment in their everyday lives, which often remained apart and far from the medical technicalities of the diversities concerned. 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 the fathers. Mothers, in their narrations, used the phrase "I know what is best for my child", and this sense of knowing the best for their children emanated from the continuous encounter with the disabilities and fulfilling the demands of intensive care and exclusive needs for their children.

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 detailed conversations with the paediatricians and other disability-related medical and professional experts—to illuminate themselves with regard to the diversity present in their children.

Gathering information and acquiring knowledge had led the parents to comprehend disability, drawing perspectives from two existing realities: first, being parents of disabled children; and second, being conscious social agents who had gathered an expert understanding of disability and diversity in order to act effectively for the betterment of the lives of their own children as well as other children who had been detected with disabilities. Knowledge of disability and diversity has linked these parents to other parents who had children with similar differences (Trainor, 2010b, p. 41). Parents who acted as disability experts received special education training to understand the diversities from a professional standpoint and attempted to apply this knowledge in dealing with the differences their children had. These parents were among those who had extended their knowledge, information, and understanding towards managing the disabilities of other children who had been facing similar challenges due to their diversities. Parents confirmed that they took part in various parental programs, training, and counselling sessions provided by various NGOs and disability associations in order to gain a better understanding of diversity. There were instances which revealed that being disability experts, parents were able to negotiate and guide the teachers, school management, and even professionals to achieve the best outcome for their children. A mother of a daughter with ADHD explained how she had convinced the school authorities to change her classroom, which was small, dark, and devoid of natural light. Being a special educator and getting constantly updated about the latest evidence-based techniques, she believed that her daughter felt claustrophobic, which triggered her restlessness within the classroom. She said:

"*I asked the teacher to change her section into another; into a classroom where there is adequate space and access to natural light as possible. I convinced them about the latest evidence-based research on it. The principal was convinced and made her sit in a classroom that was big and that was beside the playground, open and wide. I am grateful to her that she shifted the class section of my daughter to a room where such exposures were available, just to make her schooling comfortable and accessible".*

### 5.5. 5. Advocating for a Wider Cause: Extending Individual Agency for Other Parents

The development of advocacy and agency was observed in parents, both at the individual and system levels. Conversations with the parents revealed that offering advocacy for the children with disabilities, both at the system and individual level demanded an extensive investment of time, energy, and emotions. And this copious investment of time, energy, and emotions required the parents to have access to diverse resources at their disposal. Parents who chose to organize their advocacy at the system level, either through the formation of an NGO or the establishment of special education or therapeutic centre, had adequate financial resources to balance their work related to care and chores as well as adequate exposure and access to information and knowledge about the diversity of children, in particular, and disability in general. At the individual level, parents took different measures which reflected their self-involvement in the decision-making process for their children with regard to the suggested intervention procedures, special sessions, and therapies, like speech therapy, and in making decisions about the kind of education and schooling that would have been appropriate for them.

Parents were required to have possessed and developed resources and knowledge, respectively. In this research, we found three cases where parents had institutionalized their capacity for agency and advocacy and created organizations that included parents who had children with diverse abilities. The organization provided the required support network for the parents by providing them with necessary information and updates about the diversity of their children. The organization helped in generating positive reinforcement for the parents and recognized the agency within every parent with regard to the disabilities they had been dealing with.

Amrita Mukherjee was one such example, who herself became empowered to ensure that her son (with Down syndrome) received the best service and similar life opportunities as other children. She had questioned the effectiveness and efficiency of the different systems and stakeholders associated with managing the diversities of her son. As a mother, she herself had to undergo diverse challenging periods and moments. When she applied for a disability certificate for her son, she had to face the bureaucratic medical maze to prove that he had met the eligibility requirement of possessing forty percent disability to receive the certificate. It took almost one and a half years of her time, energy, and emotions to receive the certificate, which came with limited provisions for the future as far as the disability condition of Down syndrome was concerned. The certificate only provided her son with concessions on public transportation, 3% reservations in education (which includes all disability categories combined), and 3% reservations in employment (which includes all disability categories combined and where employers tend to see people with physical disabilities, blindness, or deafness as more appropriate candidates than people with autism, Down syndrome, or other developmental disabilities). Being a teacher in a government school and being a single mother, it was difficult to cater to all the care services that were needed for her son. The only familial assistance she received was from her parents, who lived in their ancestral house around sixteen kilometres from her workplace. She chose to keep her child with them and travelled every day from there to school. Her employment and professional engagement in school, travelling sixteen kilometres to and fro and taking her son to doctors, hospitals, and for other associated clinical interventions, left no time to put her son in a good special school. Moreover, the place where they resided did not have any special schools nearby. It was impossible for her elderly parents to manage the care and schooling of their grandson in distant schools. For Amrita, as a single earner and a single parent, it was difficult to juggle all the roles mentioned above. So she decided to do something herself that would help her son and also other children in the locality who had similar differences and faced similar social challenges. She used to run a recitation training school, which she gradually turned into a community of parents and finally into an organization for parents' advocacy and agency. She named it "Jagori" and at the time of research there were more than forty-five parents who received service from "Jagori" for their children with disabilities and where many parents worked voluntarily in different roles, based on their capacities and resources. Amrita's story revealed how a parent advocated and fought for her son's needs and how she gave recognition to the agency and capacity for advocacy among other parents.

Mr. Goswami was another example who extended his agency and developed advocacy for children with disabilities in his area. Access to governmental hospitals, special education schools, or intervention centres was difficult for some parents in his area (Garia), and commuting long distances every day with these children required an extensive investment of physical strength, time, and financial resources (as for many children, buses or trains were not an accessible option). Mr. and Mrs. Goswami then decided to form this community and dedicated a section of their own house for this purpose. The father of the child had encouraged his wife to take short-term training courses in special education. He believed that as a primary caregiver, it would benefit her in dealing with autism in their son, and her expertise in understanding diversity would benefit other parents in the community and would have enhanced their understanding of the same. With time, the mother, with her expertise, knowledge, and skills, could help other mothers in the community who had children with disabilities. However, all the children in the community did not necessarily have autism; there were also children who had Down syndrome, learning disabilities, and ADHD. The father kept constant contact with the doctors at NIMHANS. He even used to send reports and diagnoses of the other children in the community to NIMHANS and could receive detailed prescriptions and recommendations for them. He even arranged video calls with the doctors of NIMHANS on certain occasions when it was found necessary for the children in the community. These parents, thus, engaged themselves in advocacy not just to retrieve benefits for their other children but also for other children in the area who required them. As a result, the parents' economic, social, and cultural capital contributed to the social and cultural capital of the other parents in the community. These parents had informed other parents about the inclusive education and other related policies of the state and even advocated for the admission of these children to local private regular schools that had earlier denied their admission. By creating a local parental community, the parents provided emotional and material support to other parents, which assisted them in coping with the stress that these parents underwent in the absence of resources in the locality. The community had offered them a much-needed platform to vent out their negative emotions, fears, and stress and helped them to share their experiences and feelings with each other.

The story of Dr. Ranajit Mandal was another exemplary case in my research. Dr. Mandal is a renowned ENT surgeon. His daughter was detected with severe ADHD symptoms along with symptoms of certain other psycho-motor diversities. His response was a critical reflection of the medical system and state responses to disability and diversity. Being a doctor, he had agreed that in Kolkata there were no standard provisions that were required for early detection and intervention. He had argued that the therapeutic interventions that existed in the city were not well updated and did not follow any evidence-based procedures for therapeutic interventions. There was no standardization of the quality and services provided in the special schools. There were no written standards for the procedures, techniques, or quality improvisation to bring out the effective outcomes for these children. He used to read national and international articles, books, and journals regarding disability and diversity and could gather updated information about the possible effective means for the betterment of the lives of these children as well as their parents. After many years of hard work, he established the "Barasat Vision Charitable Trust"[10] to build an integrated residential community area for parents of disabled children. It was comprised of a residential parent community where parents with children with disabilities had been staying. It had provision for a special school that was primarily run by the parents of these children, with a few mothers who had been trained as special educators. The engineering and architecture of the flats and the whole campus had been designed keeping in mind the needs of these children, which were backed by evidence-based research studies. A civil engineer mother, with a child having disabilities, was one of the few members of the board of engineers who could effectively include her opinion and experience as a mother in the engineering of the flats. For example, having glass covers on the uppermost walls of all the flats to make the entry of natural light possible when the doors or windows were to remain closed was one such inclusion that required not just engineering skills but the experience of a mother of a child with a disability. There was a big community hall, where children used to practise dance and sports according to their choices. The singers and dancers from the parents' group took the initiative to teach the children these skills. Parents were offered regular training programmes and short-term courses online to gain skills and learn strategies to direct their children. Professional experts in the field have been employed to guide the overall operation of the intervention procedures and sessions. The playground and game rooms had been prepared, keeping in mind the interventional recommendations for the diversities. Arrangements for emergency primary health care needs had been made with ready and emergency access to oxygen and medicine. All the flats were connected via intercom to get assistance at times of emergency or other occasional needs. The parents who were engaged with this organization had expressed their content with the overall management and planning of the project. Parents felt a reduction in stress after getting involved in this integrated residential community project for parents with children with disabilities. Dr. Ranajit Mandal stated that:

*"After the parents' demise, the responsibility for life and care of the children will be ensured by the trust and they will work for a sustainable rehabilitation."*

Dr. Ranajit Mandal's story is an exemplary case for understanding effective and constructive parental advocacy with regard to children with disabilities.

## 5.6. Conclusion

The responses, actions, and behaviors of individuals within specific social and cultural circumstances were found to have heavily relied upon the emotional organization of the person in question. The emotional organization of an individual was learned and acquired through long years of encounters with micro and macro-level agencies of socialization. This had contributed to the acquisition and accumulation of the "emotional capital"[11] of a person (Stets & Turner, 2014, p. 374) which has been utilized as a resource to cope with situations or circumstances that led to emotional arousal in parents. The economic, social, and cultural capital along with the emotional capital had resulted from and had been shaping the field, within which parents expressed their actions, behaviors, responses, and thoughts. The capital and the habitus that had emerged and thrived within the field provided the individuals with the necessary resources that "constitute an embodied matrix of generative action" and "open up possibilities for mobilization and change" (Stets & Turner, 2014, p. 374). Parents' responses to the stressors and challenges, which they had been encountering in raising their children and dealing with their diversities, had been well comprehended in the light of resources (economic, social, cultural, and emotional capital) they had possessed and the consequent coping mechanism they had adopted to deal with the disabilities. It had been observed that parents' response to the stressors, with regard to the diversity in their children, was varied in kind and intensity depending upon the availability of capital that these parents had at their disposal. Thus, based upon the socialization and socio-cultural context within which parents grew as social individuals and which shaped their habitus, had an insignificant impact on the emotions that they had attached to disability in general and diversities in their children, in particular. There were some parents who had developed negative emotions and perceptions toward disability and some had developed positive emotions and perceptions towards the same.

Positive or negative emotions and perceptions were found to be predisposed by social networks to which the parents had access; at the same time, they assisted other parents in coping by connecting to various social networks, which provided them with the necessary positive emotional motivations and rewards. Findings of the research confirmed that parents derived positive coping emotions and reinforcement from professional, parental, and community support networks, most of which were outside the family and close relatives.

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

# Chapter- 6

# Conclusion

> ***"The difficulty, in Sociology, is to manage to think in a completely astonished and disconcerted way about things you thought you had always understood."***
>
> ***- Pierre Bourdieu & John B. Thompson (1991: 207)***

## 6.1. Introduction

Viewed through the lens of social construction, knowledge and truth are created, i.e., they are products of social constructions of events, interactions, and any social process that occurs within a given reality. As Berger and Luckmann (1966) have explained, reality is socially constructed and defined through the subjective experiences of the individuals who live, experience, and interact within a given reality. Based on these subjective experiences, actors perceive the wider social world—the world that they have encountered in the past and also the world that has remained outside the periphery of their interaction. This research has attempted to look through how parents' subjective experiences of having children with intellectual and cognitive disabilities have contributed to the understanding of the reality related to the disability of children. The research has attempted to see how far parents' perceptions towards and interactions with disabilities, before and after encountering the diversities in their children, respectively, have contributed towards the construction and re-construction of realities with regard to the intellectual and cognitive diversities among their children. 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.

The findings of the research on "Parenting children with disabilities: A sociological exploration in Kolkata" have been discussed in detail in the following section of the chapter.

## 6.2. Research Findings and Discussions

In every society, there are certain constructed socio-cultural standards based upon which a healthy child is defined, measured, and evaluated. These socially constructed and culturally informed standards define the boundaries between what should be accepted as ‘normal’ and what should not. Disability as a social category does not show any exception to this. The cultural, social, and political histories relating to disability literature have reflected a dual tendency in India, through which disability has been constructed and conceptualized in the country in light of religious, cultural, and social understanding of the same. The socio-religious and cultural understanding of disability among the mass was found to intersect with the biological and medical knowledge of the same. While there is a noticeable impact of bio-normative understanding through which disability has been comprehended by people in Indian society, the religious connotations of disability relating to karma or bad deeds of previous lives, as well as cultural connotations that connect disability with incapability, dependence, tragedy, and thus undesired, cannot be denied outright. In Kolkata, the parents of children with disabilities have shown similar patterns in their attitudes and understanding of the diverse nature of their children.

The medical understanding of disability was central to the way parents comprehended the diversity in their children and, consequently, they considered medical rehabilitative procedures and treatments as solutions to the ‘problem in their child’. Narratives have reflected that parents looked at the diversities in their children as a ‘biological problem’ or as an ‘undesired health condition’ which made the child seen as someone different, and these diversities became prominent when they were compared with the behaviours and interactions of other regular children who did not have any diversities. The understanding of disability as a ‘biological problem’ was framed, to a large extent, by the interactions parents had with medical professionals. Right from the time of disclosure, parents engaged themselves, mostly unconsciously, with the medical model understanding of disability. Constant interaction and exposure to clinics, medical explanations, diagnoses, and discussions about reports, results, treatments, and rehabilitative procedures had enfolded the parents into a medical gaze. 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. Most of their everyday challenges in managing the disabilities were beyond the generalized rehabilitative recommendations, which were suggested by medical experts and professionals. It was during the course of raising their children with diversity that they realized the need for structural and socio-cultural reforms in society relating to disability and diversity. 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 taking 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.

With regard to different disability models, parents' understanding of disability in Kolkata did not reflect strict adherence to any single model or categorization of disability perspectives. Accounting for the lived experiences of the parents through the lens of any single disability model would have resulted in a partial projection of the reality of their lives relating to raising their children with disabilities. No single disability model was understood sufficiently to explain their everyday experiences in dealing with and managing disabilities. Conversations with the parents and analyzing the narratives revealed that parents' perception of disability, their encounter with the challenges, managing disabilities and dealing with care, and resisting the confrontations that they might have encountered in relation to their children's disability, expressed affiliation with almost all the models of disability that have been discussed in this research. 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. Thus, it was found that both medical and social model perspectives on approaching disability had shaped parents' understanding of the same.

In this research, parents were found to have struggled with the social stigma. Many parents had associated themselves with the status of being "discreditable" because of their children's disability and had experienced feelings of "felt stigma" or "perceived stigma". Even instances where such feelings directly or indirectly drove the parents to choose social isolation and, as a result, breaking the much-needed social networks they required due to a lack of reciprocation in such relationships, were not uncommon. The cultural model of disability was found to be relevant in explaining such experiences of social isolation and stigma among the parents. It was the cultural model of disability that could explain how 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. On one hand, while the cultural model of disability has the capacity to explain the significance of understanding the cultural context through which socio-cultural constructions about disability have been comprehended by the society that has shaped the perception of parents, on the other hand, it helps in explaining how disability has worked as a "site of resistance and a source of cultural agency" (Snyder and Mitchell, 2006, p. 10) through which parents could express their agency, advocacy, and activism. While social networks and relationships were observed to become sites of emotional and social repulsion on the part of many parents due to feelings of stigmatization, in many other contexts, it was these very social networks and relationships that became the strength for the parents in managing the everyday challenges they had been encountering in dealing with their children's disabilities.

How and in what way did such social networks turn out to become important social facets in managing care and means of acting out their resistance could be well explained by engaging in the transactional and relational model of disability? 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 influence the experience of disability for both 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 to a single model of disability in analyzing their lived experiences and encounters with disability.

In India, the birth of a child is seen as an important life event as well as an institutional and social obligation. In the families in which children were born with certain diversities, the initial reactions and responses of the parents to the disability were observed to have varied and reflected mixed emotions, which included feelings of joy and despair. Parents have been found to have experienced a variety of emotions during the initial phases when they encountered the reality that their child was detected with a certain diverse health condition. The initial reactions of the parents included denial, anxiety, shock, trauma, grief, guilt, confusion, fear, and helplessness. The primary reactions of denial and shock were observed to have been connected with the inability to accept the counter reality of the child’s health against the desired and constructed knowledge of a child they had earlier. Thus, encountering the counter-reality of giving birth to a child with disabilities acted as an emotional stimulus for parents. And it was such emotional arousal that caused them to express diverse emotions.

Parents were part of a social relationship in which they learned to look, conceive, and comprehend the social world around them before their child was born or before they encountered the diversity of their children. The world of social reality is the product of the constant creation and recreation of meanings and interpretations of the various social events and phenomena with which people engage. The parents of children with disabilities have been observed to have a pre-existing world of social reality through which they comprehend and interpret different social categories, including disability, in their own meaningful terms. At the same time, the comprehension of the meanings which they had attached to any social event, category, or phenomenon was observed to have been grounded upon a given meaning of such a reality that was presented before them before they could comprehend it in their own meaningful terms. This given reality had been presented to and learned by the parents through the process of socialization they had received earlier, and likewise, they had certain ready-made socio-cultural constructions regarding disability already presented to them, even before they had encountered the reality of their children being born with disabilities.

For parents, the birth of a child is a moment of immense happiness, fulfilment, and pleasure. For all the parent respondents, pregnancy, conception, and childbirth were celebrated as positive life-changing events, and everyone had different expectations and future conceptions of how they wanted to see their child. Parents never expressed disability as an expected reality in their future constructed image of reality in which they would have liked to see themselves with their children. With such images and expectations, their encounter with an alternative reality, where their children were detected with certain diversities, made them enter into a different reality than what they had expected. In this new, unexpected, and alternative reality, meanings and interpretations relating to disability and diversity were required to be adjusted to the pre-existing meanings that the parents had constructed earlier.

At this juncture, the interaction of the parents with the doctors, other medical professionals, and staff played an important role in adjusting to this new, unexpected, undesirable, and altered reality. It was found the 'art of disclosure' about the diagnosis and detection of the diversities in the children had a significant impact on the way parents reacted and responded to them. The communication skills of the medical professionals were noticed to be one of the determinant factors in understanding parents' reactions to the diversities. A more informative and detailed discussion of the diversities made it easier for the parents to understand the diversities and made it easier for them to adjust to the new reality by attaching alternative meanings and interpretations to the medical explanations and recommendations. In contrast, in instances where the disclosure of the diversities was made following a typical medical professional attitude of objectivity, that rarely provided space for the subjective understanding of the social, cultural, and economic positions of the parents to whom the diagnosis had been revealed, parents were readily found to have developed a negative conception about the diversities in their children and expressed their feelings of fear, anxiety, confusion, and helplessness.

Parents have encountered the reality of their children's diversity either shortly after birth or during the early years of development. Their reactions and responses varied depending on whether the parents had encountered the different reality just right after birth or later. Diversities like cerebral palsy, congenital rubella syndrome, multiple disabilities, and, in some instances, Down syndrome, were said to have been detected right after birth or during the initial few days after birth. Conditions like Autism, SLD, ADHD, and Down syndrome were all discovered during the early years of a child's development. The expression of the different behavioural and functional patterns was expressed during the first five years of child development. In the first instances, where the diversities were detected at the time of birth, expressions of shock, grief, distress, guilt, trauma, and denial were common among parents. Denial, shock, and trauma among parents stemmed primarily from disbelief in the diagnosis. It was hard for the parents to accept that their children were born with certain diversity, and the resistance to accept the alternative reality was expressed in the form of shock, grief, trauma, and denial. Many parents were observed to express guilt as an initial response to the diversity. The feeling of guilt was associated with the preconceived socio-cultural conceptions regarding the causes of diversity and disability, according to which the wrong deeds of the past life, karma, or faulty lifestyle during pregnancy and negligence were held responsible for the diversities into which the children were born. In instances where the diversities gradually found their expression during the formative years of the development of the children, reactions of confusion and helplessness prevailed among the parents. In these instances, since the children were born with no suspected disabilities, the parents did not expect any diversity in their children, and they believed them to be like any other regular child. But, gradually, when they could notice certain diversities in behaviours, responses, and functionality in their children, and the diversities were confirmed through medical procedures of detection, expressions of confusion and helplessness were retrieved from the parents. Confusion among the parents was primarily found to have emerged from limited knowledge and exposure to disability and diversity.

Parents in the research were observed to blame their fate and destiny for giving birth to a child with diversities. Disability, perceived in this way, coupled with the existing medical gaze of bio-normative understanding of the body, health, and mental functioning (which measures ability based on social productivity and capability), was observed to have paved the way for constructing disability as a 'problem'. Looking at disability as a 'problem' has recognized the need for rehabilitation through medical procedures and treatments as a solution to the 'problem," so constructed. This has been well reflected in the responses extracted during the interview. Parents have reported that after knowing the detection of disability in their children, they were unable to accept the reality and repeatedly asked the doctors about the cure for such conduction, even when the doctors maintained that there was no known cure for them. Parents have reported the insecurities and fears that they felt after learning of the disabilities of their children. Some parents believed that their children's disability would have affected their earlier social presentation. Parents who were engaged in professions that were attached to comparatively higher social prestige were observed to have subscribed to this kind of response, conceiving fear, anxiety, and insecurity regarding the disability of their children. Most of the parents reported having feared the socio-economic impact of the disability both on their family and their children. Parents from different socio-economic backgrounds were observed to have feared the high expenses that would have been incurred for initiating and continuing medical treatments for managing the diverse health conditions of their children. The high cost involved in managing the disability of their children—which included not only direct medical and therapeutic expenses but other allied services like physiotherapy, speech therapy, carrying the child to clinics, schools, other places in private conveyance, and so forth—contributed to parental anxiety and stress.

Parents were observed to go through phases of confusion after learning about their children's disabilities and various conditions. Confusion was observed to have stemmed from a limited understanding of disability in general and from a lack of knowledge about the diverse functioning conditions of the body, mind, and emotions of the children detected with disabilities. The state and extent of confusion among parents were higher in instances where the disabilities were revealed much later after birth, mostly during the formative years of development. As in the case of autism, parents reported having noticed changes in the behavioural and response patterns of their children at around three to five years of age. In cases where the child has ADHD, parents have noticed behavioural changes and hyperactivity in their children when they were around four to seven years of age. Specific learning disabilities were identified by parents when their children were around seven to ten years of age. In all these instances, where the diverse condition in their children was not present at the time of birth but was gradually revealed and identified by the parents during the early years of development, parents’ confusion about the condition creating disability was observed to have heightened. The primary source of such perplexity was discovered to be a general lack of awareness about intellectual and developmental disabilities among parents.

Almost all the parents confirmed their absence or limited knowledge of disability, in general, and intellectual disability among children, in particular. It has been discovered that parents' lack of knowledge and general awareness about disability conditions in children has contributed to the delayed identification of the various conditions in the children. Lack of disability awareness and knowledge hampered the visibility and recognition of children's hidden and gradual development of disability conditions, causing them to go unnoticed by their parents for an extended period of time. Narratives have reflected that, in some cases, when children were taken to doctors after parents had recognized certain changes in their development, intellectual, and behavioural patterns, they were sometimes accused by the medical professionals of being late for settling down to interventional negotiation. In many cases, the parents were told that had they brought their children earlier for diagnosis, they would have had better hopes for improvement in the disability condition as interventions have proved to have worked well in the early stages of the development of the condition.

Parents' responses to denial and rejection were found to be closely related to a lack of awareness and limited knowledge about disability. When a child's disability was discovered shortly after birth or within the first six months of life, parents were found to be more absorbed in shock, denial, rejection, and helplessness. Diverse conditions like cerebral palsy and Down syndrome were detected just after the birth, while Rubella syndrome and multiple disabilities were detected within the first six months after the birth of the child. The realization that one’s child has a disability that has no permanent cure, other than intervention and therapies to ease the level of difficulties, is a life-changing one. The primary cause of parents' denial was their disbelief about their child's disability condition. It was for them a sudden encounter with an unmatched reality. It has been discerned that though, initially, the parents expressed reactions of denial or rejection of the diagnosis, gradually they accepted and learned to cope with the reality that their children had certain intellectual, developmental, psycho-motor, or neuro-motor diversities that can and should be negotiated within the wider social-cultural contexts they live within. This shift in perceptions and comprehension regarding disability among the parents was observed to have resulted from their everyday and wider levels of interactions with the health system, regular and special schooling systems, and social and public infrastructure systems including public roads, buildings, and transportation.

Parents had a limited understanding of how diversity was labelled and constructed as a disability prior to their encounter with a disability in general and diversity in their children in particular. Their understanding of disability revolved around the concept of ‘biological normativity’ of health, illness, and functionality of the body and mind. Such understanding of disability through an exclusive medical model perspective has shaped their perception of disability. Parents' narratives have revealed that everyday encounters with the wider social structures (health, education, and public infrastructure) in managing the diversities of their children have directed them to recognize and subscribe to a social model understanding of disability.

The feeling of shock or trauma among the parents primarily emanated from a kind of disbelief over the diagnosis, which engulfed the parents at the moment they learned about the disability in their child. In this research, it has been observed that there were both ‘internal’ and ‘external’ inducements that stimulated the responses of shock among the parents. I have referred to them as' ‘dual-stimuli’ of shock or trauma. The internal inducements of trauma could be traced to the way parents perceived the disability of their children. The perception of disability, which built their internal inducements of trauma, depended on the kind, type, and extent of the diverse conditions and relied on how parents’ earlier understanding of disability, in general, was connected with it. In this context, parents’ possession of emotional capital and previous knowledge of and encounter with a disability deserve special mention. In instances where parents’ emotional capital and previous knowledge relating to disability provided them with positive perceptions of the same, the extent and intensity of trauma were observed to have been managed and dealt with within a shorter duration of time. While for parents, whose emotional capital and previous knowledge relating to disability provided them with negative perceptions, the phases of trauma and post-traumatic periods were found to be more intense and non-manageable. In many such instances, parents have reported having sunk into phases of depression for which they are compelled to seek medical consultations and counselling sessions. The ‘internal inducements’ of trauma among the parents were observed to have encompassed a ‘perception of rejection’. The ‘perception of rejection’ was seen as an acuity with which parents tended to perceive the diversities in their children under the lens of accepted socio-cultural standards of a (bio)-normative definition of body and mind functioning. When the diversities in the children were evaluated against such standards and were found to have deviated from the accepted normative definition of health (functioning of body and mind), parents were found to have rejected the reality they had never expected.

‘Internal inducements’ were evidenced in the personality systems and emotional capital of the parents, which were associated with their earlier knowledge about disability. But, the ‘external inducements’ were mainly associated with the socio-demographic positions of the parents in society. The parents’ educational qualifications, job profile, and economic position were evidenced to have impacted the extent of trauma experienced by them. With regard to educational qualifications, it was noted that parents with comparatively higher credentials could overcome the trauma within a shorter period of time after learning about their children’s diversity. Intense phases of trauma were witnessed among parents whose educational credentials were comparatively lower in the educational demographic ladder devised in this research.

The reason for such variation in the intensity and duration of trauma among parents may be attributed to the ‘cultural capital' possessed by the parents and the 'field' around which their lives have been contextualized. Similar findings were affirmed with the income of the parents. It was noted that parents who had a higher income and knew that they could manage the medical and related expenses were noted to have managed the initial shock subtly. In these instances, the parents remained secure as far as the affordability of managing the disabilities was concerned. However, parents from relatively lower-income groups have reported struggling with the high expenses involved in raising their children with disabilities. High expenses, which included both direct and indirect medical costs, made it harder for these parents to meet the needs of managing disability and the requirements of their households. In some instances, the parents were found to stand at a crossroads where they had to choose to fulfil some needs at the expense of others. For example, there were a few parents who could not access special speech therapy sessions outside of the special school hours for their autistic children, even when it was highly recommended for them by medical experts. It is known through various research that speech therapy involves high expenses, which makes it an inaccessible, unaffordable, and luxurious service for many parents in India (Mahapatra, Pati, Sinha, Chauhan, Nanda, & Nallala, 2019). Higher incomes were also associated with high occupational commitments, as per the demographic information provided by the respondents in this research. But interestingly, when parents who were working in the occupational and professional profiles that attach higher social value and prestige in our society, were asked about their experience after knowing the detection of their children with disabilities, responses of shock and trauma were noticed to have been narrated by them. Feelings of shock and trauma as a result of knowing the disability of the children persisted deep and long among parents with higher income profiles. Parents working in higher-income jobs and having higher incomes were identified to have responded variably concerning their incomes and jobs. Narratives of these parents working in high-profile jobs have reflected long durations and intense phases of trauma, but concerning affordability and meeting the high medical expenses of managing a disability, these parents showed a lesser degree of stress and anxiety related to financial security. Financial stress due to the high cost of medical recommendations was found to be higher among parents with limited financial resources. Thus, ‘external inducements’ of trauma were found to be rooted within a ‘perception of challenge’. This occurred when parents feared whether it could have been possible for them to employ the recommendations and suggestions made by the medical experts as a part of the treatment and therapies for their children, considering their limited access to the economic resources required to meet expenses for such recommendations.

Research findings have discerned a commonality of guilt among parents of children with disabilities. It was noted that parents have been struggling with guilt when they felt that it was due to their mistakes (which they might have committed before or during pregnancy) that their children were born with a disability. From the responses, it was evident that feelings of guilt were predominant, mostly among mothers. Mothers confirmed that after knowing about the detection of disability in their children and overcoming the initial trauma of encountering the unexpected reality, they repeatedly tried to put their whole pregnancy period under self-scrutiny to get a clue about the mistakes they might have committed then. The occurrence of guilt among parents was observed to have varied depending on the kind, type, and extent of the diversities in mind and body functioning that created disability in the children. For example, a child born with Congenital Rubella syndrome or with cerebral palsy was detected with an exceptional health condition right after birth. Hence, possession of inadequate knowledge about the diversity and limited access to information about the causes of such conditions urged parents, particularly mothers, to review their pregnancy and find out the probable mistakes they might have committed while being pregnant. But, in instances where disability conditions were not detected at birth but were gradually revealed and detected in the early years of child development (in cases like Autism, ADHD, Down syndrome, or SLD), guilt among parents was observed, which made them scrutinize their current practices of parenting their children with disabilities.

Mothers were found to have blamed their mothering skills and practices which they had employed in dealing with and raising the children in their early years of development before the disabilities were detected. The conversation revealed that the feeling of guilt was more intense among parents who had little understanding of what autism was, what ADHD meant, or how a learning disability appeared out of nowhere! Parents were seen to have believed that lack of attention to the child and heedlessness in caring was responsible for the development of such diversities in their intellectual, developmental, neuro-motor, or psycho-motor functioning that were not present at the time of birth. Comprehending the cause and development of disability in this manner was observed to have directed the parents to alter their daily life routines and parental practices that they had been following. For example, a father is reported to have stopped watching television or getting occupied with any other form of entertainment media after returning from work because he started to believe that his son was becoming aggressive as he was not having adequate quality time with his father. There were numerous instances where mothers were seen to have quit their jobs in order to pay more attention and care for their children because they believed that their prolonged absence from home was causing a lack of care and attention for their children. They were discovered to have believed that a longer period of absence from the children caused the disability in their children, and they may have felt neglected or unprotected by their parents. Such alternations in parental practices were observed to take a toll on their physical, mental, and emotional health. Instances were not rare where parents sought assistance from professional psychological counselors.

Grief was seen to be another common response from the parents. Grief among parents was found to have resulted from an inconsistency between expectations and reality. Conversations with the parents confirmed that their expectation for the birth of a child was associated with a constructed image of a child; an image constructed in their minds through interactions and encounters with children they knew in their social circles. In this context, parents were found to have referred to children they knew in their circles of relatives, friends, and neighborhoods. All the children whom the parents had referred to in their conversations were observed to be children without disabilities. Thus, their expectation of a child was associated with the image of a child they constructed, i.e., a child without disabilities. Therefore, the birth of a child with intellectual and cognitive diversity was observed to be a distant and unexpected reality for them. As a result, the birth of a disabled child or the gradual development of the disability in their early stages of development resulted in a lag between expectation and reality. It was from this lag, or inconsistency between expectation and reality, that grief was expressed as a common response among the parents. Though the feeling of grief among parents was not evidenced to have varied across kind, type, and extent of disability in the children, it was observed that parents who had children with conditions like cerebral palsy, multiple disabilities and Rubella had extended phases and persistence of grief. Parents with children having autism, ADHD, Down syndrome, and SLDs were observed to have intense phases of grief in the initial periods after they had encountered disabilities in their children. But gradually, with constant exposure and interactions with experts and various other support systems, parents could manage their grief by holding on to the positive perceptions of disability.

Grief was a common expression among the parents. Responses and narratives relating to grief were seen to have affected mothers and fathers differently. Even though both mothers and fathers communicated about their intense emotions, it was discovered that mothers found it more difficult to accept the diversities in their children's personalities. The reason for such skewed findings based on gender may be attributed to the inexpressiveness of the fathers during the interviews. During the interviews, mothers were observed to be more involved in the conversation in comparison to fathers. Moreover, greater proximity to the kids made it harder for mothers to deal with the plethora of emotions. Grief among mothers was identified to have emanated from two kinds of thoughts, or to be more practical, fears, which has been recognized in this research as ‘double mourning’. On one hand, the mother's expectation of a child is based on her earlier perception and knowledge of children in general, making it difficult for her to accept the reality of having a child with a disability. On the other hand, their perception of the future image of herself as a mother of a child with a disability made her comprehend that mothering might not be a smooth journey for her. It was evident from the narratives that mothers had perceived and feared their future image as mothers who would have nothing left in their life other than providing continuous and intense care work to their children. However, constant exposure to interventions and counselling sessions was noted to have assisted the mothers in coping and organizing themselves towards a more adaptive role.

An in-depth analysis of the narratives and lived experiences of the parents revealed that the phases following the detection of disability and the phase before an intervention programme was required to be initiated had been the most stressful interval for the parents. The level of stress was noted to differ across the varying socio-economic contexts of the parents. The extent of parental stress was identified to have emanated from a diverse range of factors which included the kind of disability, 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 centers by parents. Concerning the type, extent, and degree of vulnerability related to disability, stress was found to be more intense among parents who had children with conditions like cerebral palsy, multiple disabilities, and congenital rubella syndrome. In such cases, the extreme levels of physical and emotional dependency of the children were noticed to have exerted a strain on the physical, emotional, financial, and social resources of the parents. However, although stress was not completely absent among the parents who had children with conditions like autism, Down syndrome, SLD, and ADHD, the intensity and persistence of stress were identified to be relatively subtle in comparison to parents who had children with disabilities like cerebral palsy, multiple disabilities, and congenital rubella syndrome. Narratives reflected that the scope and promise of rehabilitative therapeutic measures, which were recommended for children with autism, Down syndrome, learning disabilities, and ADHD, generated positive perceptions among parents looking at the disability of their children. Many of such therapeutic programmes were viewed by the parents as opportunities improvement in their children's intellectual and developmental limitations. These parents were observed to believe that, with the aid of interventions and rehabilitative therapeutic programs, their children would be able to function in the journey of life, performing almost all the daily life activities required for living, given their own diversities in functioning. This kind of belief was found to be nonexistent among parents having children with conditions like cerebral palsy, multiple disabilities, and congenital rubella syndrome. Findings have evidenced higher levels of stress among the mothers. Mothers were observed to have shown a perception of higher responsibility and caregiving role in fulfilling the needs of the disability condition in their children.

This study attempted to highlight parents' emotional responses in the form of an emotional crisis model based on Kandel and Merrick's (2007, p. 1802) classification of the “crisis of change”, “crisis due to changes in social contexts”, and “crisis of reality”. All three categories of the crisis were observed among the respondents. Confronting an unexpected reality of disability (crisis of change); making alterations and modifications of their earlier knowledge and perception about disability and simultaneously adjusting and adapting to the new realities of life with regard to their children and parenting (crisis due to alterations in social contexts); and encountering the mundane reality of the socio-economic contexts of the parents and social structural limitations that were put before the children and their parents (crisis of reality) - was found to have created an intense emotional vacuum among the parents. Parents of children with conditions like cerebral palsy, congenital rubella syndrome, and multiple disabilities were seen to have expressed significant levels of emotional crisis in their interviews. In these cases, a ‘perceived sense of futility' over the interventional procedures was evidenced among the parents, and a ‘perception of higher levels of vulnerability' was observed among them.

In raising and caring for children with disabilities, parents were observed to have encountered two identities relating to the child and his/her needs of care. Firstly, the parents had to understand and perform the child-care tasks that were noticed to be similar for children without disabilities. Care performances associated with this identity include bathing, feeding, washing clothes of the child, providing toilet training, disciplining, teaching, playing, carrying the child to school, and assisting the child to sleep. Here, the parents were found to have encountered the child’s identity as being a ‘child’. Secondly, parents had to perform exclusive child-care activities that they thought they have been able to execute if their children had no state of disability. Here, the parents were observed to have encountered the child’s identity as being a ‘child with disabilities’. Care activities associated with this identity include booking appointments and consulting with the experts, carrying the child to different therapeutic and rehabilitative sessions and programmes, respectively, practicing and playing prescribed game activities with the child, and providing constant attention and physical and emotional support to the child, continuous, monitoring of the improvement and narrating them to the experts in the next sessions, keeping track of their medicines, nutrients, and cooking foods as per the recommended charts given by the experts; and all other care activities related to the first identity mentioned above with certain variations in their functional operations depending upon the extent and type of disability in the child. While caring for a child with a disability, parents were observed to confront both of these identities of their children: being a ‘child’ and being a ‘child with disabilities’. Caring for these children and their association with a ‘dual-identity’ was observed to have extended towards the formation of a ‘dual-identity’ among the parents- identity of being a ‘parent’ and identity of being a ‘parent having children with disabilities.

Findings related to caregiving practices have revealed that parents with disabled children face daily challenges related to caring. In-depth analysis of the narratives and experiences expressed by the parents has pointed to several dimensions of such challenges, which remained embedded within both macro and micro levels of social interactions encountered by the parents and their children. Confronting the health system as a whole and interacting with medical experts, medical staff, medical boards, and health professionals, in particular, has reflected the difficulties parents have had to face in managing their children's disabilities. Parents were observed to have recognized a medical gaze in the professional interventions and the way disabilities in their children were portrayed before them. Several instances and incidents of their interaction with the medical system have revealed an inadequate understanding of the socio-demographic profile of the parents by the doctors and medical experts. One common dimension of such confrontation was observed in the way parents narrated their experiences relating to the process of applying, following up, and receiving disability cards for their children. Research findings have observed parents getting enmeshed within a bureaucratic gaze where they find themselves moving from one table to the other to get their children certified with forty percent of the disability criteria, which is required to receive the disability benefits and reservations from the state. Non-coordination among the departments and staff working on papers made the parents run hither and thither across hospitals and various state departments related to disability.

Medical gaze has also been revealed in the approach and attitude through which parents experienced their interactions with medical practitioners and professionals in dealing with their children’s disabilities. The findings revealed a two-sided understanding of children's disability in particular, which was found to have a broader impact in shaping disability discourse in general. On one hand, the medical practitioners were observed to have assumed that parents’ knowledge of understanding disabilities in their children was limited because they were not imparted with any medical information or technical training required to understand or deal with the disabilities, both in terms of detecting and deciding upon the interventions that would have been required. On the other hand, constant and continuous exposure to the functional and behavioral diversities in their children and fulfilling their exclusive care demands made the parents kind of experts in understanding the disability, particularly in the context of their own children. Findings could show that parents had claimed to be the best care provider for their children, and as such, they had claimed to have possessed the best knowledge about their children’s diverse functional and emotional needs. Instances were provided in the earlier chapters where it has been shown that children’s responses to doctors or professional medical administrators were not always very comfortable for the children and did not always turn out to be positive in terms of the expected result. For example, there were cases where children did not respond when doctors called them by their name, but the same children when they were called by their parents or any other professional in a different setting, say in their home or in a park, they were found to have responded. Thus, children's responsiveness before the doctors in the hospital setting was mandatory, and any kind of unresponsiveness in such contexts made these children become labelled as having 'no improvement in their attention-deficit tendencies' and so forth. However, conversations with a few clinical psychologists and doctors have reflected that the evaluation of a child in terms of his diversities was both natural and significant to have performed in a hospital setting or doctor's personal chamber because, firstly, it was not possible for doctors or psychologists to identify the correct location, time or people to whom the child could have responded. Secondly, they pointed out that it was not only important but was immensely necessary for children with intellectual and cognitive diversities, to respond to anyone from the generalized other social categories, in any general location or place at any point of time to evaluate their 'normative pattern of responsiveness' found in other children without disabilities. It was found that parents had reported non-recognition of their observations in relation to the rehabilitative measures administered to their children and the respective improvements they could notice.

Thus, research findings have noticed a difference in perception between doctors and parents regarding disability and diversity among children and their corresponding interventional recommendations. The current research has attempted to understand the diversity of perception by employing Pierre Bourdieu's concept of "habitus", "field", and "capital". The doctors' and medical professionals' long acquired training, their context of working with several disabilities and diversities together, their interaction with several parents from various backgrounds, and, most importantly, their bio-normative perception of a child and his/her body and mind functioning, have caused them to stick to their own scales of evaluating, classifying, and detecting diversities. Their recommendations of interventions required in managing the diversities, which also included prescriptions for modifications in parenting and caregiving practices performed by parents, were observed to have derived from their bio-normative medical understanding of disability. On the other hand, parents’ perception of disability was associated with their daily context of caregiving and parenting practices, which they had actually performed in their everyday lives. The parents’ perceived inconsistency by the parents between the theoretical recommendations provided by the medical practitioners and the practical caregiving practices conducted by the parents was significant.

The research has revealed both positively and negatively affirmed relationships between medical professionals and parents of children with disabilities. It was observed that in cases where a positive relationship was cultivated between the medical professionals and the parents, the parents developed faith and optimism towards such ongoing medical procedures. Parents recognized the medical procedures as being constructive and productive in managing the diversities. In some of the instances where the relationship between medical practitioners and parents was evidenced to be positively affirmed, mutual recognition of knowledge and observations was found to have worked well, and vice versa. However, there is no denying the fact that such observations of positive relationships between parents and medical practitioners are rare.

In terms of detecting and intervening in their children's differences, the most common responses obtained from the parents during the interview pointed to deficiencies in the infrastructure's existence and functioning. A lack of coordination between the health departments was unearthed, particularly for Kolkata (as per the scope of the study). In conducting the research, it was found that most of the interventional and therapeutic services related to childhood disabilities were generally operated by different non-governmental organizations. Parents were observed to have pointed out their unintended disengagement with the services of these NGOs because of the varied difficulties encountered by them at a strategic level. These included their inability to bear the expenses for the services; high costs incurred in accessing the locations with personal arrangements for conveyance; timings of the sessions; dissatisfaction with the services provided; dissatisfaction with the services provided by the professionals; location and distance of the centres, and so forth. All these factors, along with inadequate infrastructure for early detection and intervention, have resulted in delayed identification of the diversity in the children. This was true in cases where the disability condition in the children included Autism, ADHD, and Specific Learning disabilities that were evidenced to have visible expressions in the early years of their life.

In-depth conversations with medical professionals and clinical therapists have revealed that early detection of the disability condition and corresponding early interventions for the same could yield significant results. Detection of the disability condition and extent of diversity at a very early age was observed to have produced better results in the degrees of improvement as compared to instances where it was detected later and interventions started late. Conversations with medical professionals and clinical psychological practitioners confirmed that delayed detection and intervention of the disability condition always had a chance to develop further behavioral, cognitive, and psycho-motor complications, which could only be resorted to with the aid of early interventions. Instances were found in the research where the non-recognition of the parents’ observation of the child’s changing behavioural and developmental expressions resulted in delayed identification of the disability condition, and this led to a corresponding delay in the implementation of the interventional recommendations. In this kind of instance, parents were found to have developed negative affirmations towards medical practices and procedures.

Another dimension of challenge, which the parents had encountered in raising their children and managing their diversities, was associated with care. The socio-cultural ideology relating to the functions and significance of family in Indian society, coupled with the legal framework and policies about disability, particularly childhood disability, was found to have located parents (as operators of the household units or family) at the center of discourses related to care. In India, family and care agencies were given their due recognition in the legal discourse for the first time after the implementation of the Rights of Persons with Disabilities Bill 2011, and the Rights of Persons with Disabilities Bill, 2014. But still, there remained no clear definition of home and family in those bills, as if it was taken for granted that parents and family members would perform the primary responsibility of care (Sen, 2016, p. 69). Thus, with regard to caring for children with childhood disabilities, parents remain the sole agency responsible for caregiving.

Parents' responses towards perceptions and beliefs related to care varied across gender, income, education, occupations and professions, the complexity of the disability condition, and the accessibility of support networks.

In terms of gender, parents perceived and practised caregiving activities based on their familial and gender ideologies, which had shaped their knowledge of reality and habitus about the same. Findings have shown parents' affirmations of all three ideological classifications related to the gender division of care and household chores provided by Arlie Hochschild (1989) in the form of "traditional", "egalitarian", and "transitional". Parents who had subscribed to the traditional ideology considered caring to be a mother's work. These parents were found to have believed in caring practices as a motherly act that was natural for them to express and perform as women. This kind of belief was observed to have been acquired and expressed by both fathers and mothers in this research. Fathers who had adopted a traditional ideology, considered their wives to be the best caregivers for their children. Even in a few instances, these fathers were observed to have convinced their wives to leave their earlier involvements in the paid labour sector despite having good performance records and good income history. However, in the instances where fathers had adopted a traditional ideology, not all mothers were asked or convinced by their husbands to leave their paid work. These were true in families having relatively lower income and financial resources where husbands' single earnings were calculated to be inadequate for meeting the family's survival needs along with other household expenses and caring for their children with disabilities. In the majority of such cases, fathers were observed to have taken a transitional gender and familial approach to care and chores, despite adopting a traditional approach in terms of caring for children with disabilities. These fathers were transitional because, on one hand, they considered the mother as the sole caregiver for their children with disabilities like the traditional fathers; while on the other hand, they recognized their wives' paid work sometimes as the families' need for financial support and sometimes as recognition of women's empowerment. In cases where fathers had adopted a traditional approach towards care and chores, they were not always supported by the mothers in the households. While some mothers expressed their dissatisfaction with the traditional approach to care that their husbands had affirmed, others were seen to have perceived it as a rightful approach to care and had accepted that they were responsible mothers who had been caring for their disabled children alone. In households where transitional gender and familial ideologies were practised by the fathers – where care responsibilities were believed to be a mother's sphere of activity even when they were working in paid labour sectors and had commitments outside the periphery of care- mothers were found to adhere to the transitional ideology, sometimes because of their similar affiliations with transitional ideology, or sometimes because they had submitted to the gendered power negotiations within their family and marriage.

Parents were also found to have adopted an egalitarian ideology toward caring for their children with disabilities. In these instances, the care responsibilities were demonstrated to be equally shared by both mothers and fathers, even when the mothers were not engaged in paid work and the fathers were the only earners in the households. In most of the instances where both the parents were engaged in paid sectors, care workers were found to have performed by hired care workers. However, findings suggest that when one or both parents adhered to traditional or transitional familial and gender ideological frameworks, care responsibilities were shifted to the mothers. In most of such cases, mothers reported feeling excessive pressure related to care, which often made them feel burdened, both physically and emotionally. This pressure has been felt on a higher note by mothers who work in paid sectors. This mostly happened in households where fathers had adopted the traditional gender ideology of division of labour related to care and expected their wives to perform care activities for their children, and the mothers believed in an egalitarian ideology while expecting their husbands to share the care load. However, in households where transitional gender and familial ideology were nurtured by both husbands and wives, mothers were noticed to have expressed their excessive burden of care, but they never complained about the disengagement of their husbands about the care-load. These mothers thought that care was their domain of work, which they believed could not have been done well by their husbands, even if they were given a chance. Findings have also directed the research to reflect mothers' dominance over care work, which they did not want fathers to get involved with, particularly for care activities related to direct care work. In the household, where mothers were found to have nurtured a transitional familial and gender ideology and fathers had affiliation towards an egalitarian ideology, care work related to the children with disabilities was completely found to have been managed by mothers. In such instances, mothers did not like fathers' involvement or engagement in direct care work and were seen to have been convinced that care works was not meant for men. In such cases, fathers have stated that they are only involved in specific jobs related to indirect care work. Few mothers were evidenced in the research to have internalized the ideology of 'intensive mothering' and had decided to leave their highly paid and rewarding jobs to take care of their children, as they believed it was their responsibility and no one would have performed it better than them, not even their husbands.

Research findings have suggested that, even when many fathers were observed to have shared the care responsibility, they were mostly observed as an aid to mothers' work related to care. Mothers were observed to have played multiple roles in caring for their children with disabilities and managing their diversities on a day-to-day basis. Ranging from spending quality time, keeping in tune with the recommendations of specific play and activity engagements, practising the speech recommendations, carrying the children for regular medical follow-ups, attending different intervention and therapeutic sessions, and cooking food for the children according to the prescribed nutritional limitations, washing and cleaning children's clothes and stuff, and other direct and indirect work related to care, kept the mothers on their toes. Constant and continuous care demand had been reported by the mothers to be overindulging for them. Many mothers have complained about their restricted social life and lack of personal space for themselves. This was expressed on a higher note by mothers who were not engaged in paid work or had left their job for the sake of care.

According to research findings, mothers who shared physical, emotional, and social space with their disabled children lost their identity as individuals or as anyone other than mothers. For these mothers, their parental identity was seen to have overshadowed any other identity that they might have possessed before encountering disabilities in their children. This has often resulted in long-term depression and other mental and emotional issues among the mothers. As compared to mothers, fathers were not found to experience such emotional trauma and anxiety. The absence or limited experience of emotional pressure and anxiety by fathers, as per the findings of the study, might have been embedded in two probable realities. First, the fathers might not have expressed their actual feelings or they might not have wanted their personal feelings to be revealed. The fathers might not have felt comfortable emotionally expressing their anxiety and burden in front of the interviewer. Secondly, fathers might not have felt the emotional distress but have been able to cope with the resulting stress and anxiety through their involvement in projects, work, and interactions with their social circle within the office and outside. Few fathers and mothers who were engaged in paid work agreed that remaining engaged in work commitments provided them with an individual space where they could interact with their other identities outside of being a parent of a child with disabilities. They had also confirmed that work engagements had been providing them with opportunities for social interaction with people who were not related to disability. In contrast, parents, particularly mothers, who were homemakers and had to spend every moment and every day throughout the year with their children having disabilities, and who shared their physical, emotional, and social spaces in managing and encountering diversities in them, found themselves ambushed in a care-maze.

Parents' income was found to be a significant factor in managing the care of children with disabilities. It had already been discussed earlier that managing disabilities in children entailed huge costs, some of which were directly associated with the medical costs and rehabilitative expenses, while others included the indirect costs of continuing the treatments and managing the diversities in everyday life. In household units where both parents had been working in the paid sectors, care work was found to have been managed by hired care workers. But in cases where expenses relied on the humble income of a single parent, hiring an external care worker was not a possible or accessible option for them. In these households, mothers had to shoulder the whole burden of care upon them, irrespective of their gender-ideological adherence related to care. Thus, husbands, despite having an egalitarian ideology, could not equally share the care-load of their wives; or wives, despite adhering to an egalitarian ideology, could not complain about the unequal presence of their husbands in care work. The whole situation has become more and more troublesome for single mothers. Whether it was traditional, egalitarian, or transitional, the household had two heads to share the care burden, even when they were not equally shared. But for single mothers, the stress of managing expenses was coupled with the care demands, which multiplied their physical and emotional burden. Their only shoulder to bear was the informal support of their maternal grandparents.

The care-maze turned out to be more complicated when the parents had another child without disabilities. The care demanded by the children with disabilities differed in different ways from that of the children without disabilities. Parents felt that it was difficult for them to manage the needs of both. Parents reported that siblings without disabilities were affected in various ways because a major share of the parental time was absorbed in caring for their other siblings with disabilities. Narratives from the parents also reflected an additional fear of sexual abuse when they had a child with disabilities. Almost all the parents of a girl child, who had certain diversity, expressed their fear and feeling of insecurity regarding their daughter’s vulnerability towards getting sexually abused or exploited. The current research has evidenced a few instances where girls with disabilities were abused by their physiotherapists or their professionally hired caregivers.

Being a parent of a child with disabilities requires intensive emotional, mental, and physical organizational skills to fulfil their complex and continuing needs. Parents have revealed their extensive emotional investment in managing the diversity in their children and adjusting themselves to the constant alterations in parental practices to remain in tune with the exclusive demands of these children with disabilities. Parents have reported having no personal time or space for themselves. Lack of quality ‘me-time’ for the individual parents and ‘we-time’ for the couples generated diverse emotional complications, which were reflected in their behavioural changes that included long-term depression and sleep deprivation.

Research findings have directed us to observe the influence of support network systems in managing the mental, physical, and emotional exhaustion among the parents of children with disabilities. Raising and caring for children with disabilities was found to have made serious changes in lifestyle and parenting practices. Constant and continuous care demand was noticed to have affected their quality and extent of social interaction. Parents of children, who had conditions like cerebral palsy, congenital rubella syndrome, and multiple disabilities, were observed to have experienced extreme levels of social separation. They had very limited social interaction among circles that were not related to their children’s disability. Restricted social interaction in these cases resulted from a sense of ‘perceived stigma’ or "felt stigma’ and vice versa. Parents were observed to have developed a sense of separation as a result of 'felt-stigma' within social groups. Instances have shown that, in cases where interactions within particular social groups had generated negative perceptions of the diversity and had extended sympathy to the parents, parents chose to maintain social separations from such groups or networks to avoid their perceived sense of stigmatization. In contrast, intense feelings of stigmatization and a perceived sense of stigma had led many parents to isolate themselves from the social circles they had earlier. Thus, it was observed to be a vicious circle within which parents chose to isolate themselves, and this gradual withdrawal from social networks, which resulted in social isolation in the absence of reciprocation, further intensified their experience of stigmatization. Most of the mothers have expressed their unwillingness or lack of time and energy to get involved in different social circles, like friends, family, and the neighborhood, after performing their daily exhausting routine of care-related tasks.

Conversations with the mothers suggested that their lives remained surrounded by and succumbed to interacting with doctors, clinical therapists, special trainers, and educators. Constant engagement with the care-work and continuous therapeutic and special follow-ups as per medical and clinical recommendations both at home and in clinics left the parents, particularly mothers, to keep in frequent touch with friends and relatives. These kinds of findings were more frequently observed among parents having children with conditions like autism, Down syndrome, and ADHD, where it was essential for the children to attend regular sessions of therapies, like speech therapy or occupational therapy, depending upon their kind and extent of diversity. Attending these sessions and therapies was a part of their interventions, which were expected to be followed without any disruption to achieve improvements in the behaviors, functions, and expressions of the children. It has been evidenced in earlier research that continuous interventions help in improving the state of behavioural and developmental functioning of children with intellectual and cognitive diversities, while disruption or discontinuation of the interventions could result in further deterioration of the condition (Jacob, Olisaemeka & Edozie, 2015). Thus, parents having children with conditions that required continuous and non-disruptive interventional follow-up had to invest all their time, energy, and resources towards managing and dealing with the diversity of their children.

The above findings have cast parents’ encounters with disability at micro-societal levels of interaction. But the findings reflected several dimensions of challenges and contestations that the parents had experienced at the systems level of interactions within society. The macro-social systems encountered by parents in this study were the health system, education system, legal system, public transportation system, and infrastructure system.

Parents' encounter with the education system was explored through their everyday interactional experience in schools, both regular and special. Based on the type and extent of diversity, most of the parents were observed to have opted for special schools in order to access the special teaching and learning services recommended for these children. Many parents expressed that they wanted their children to continue their classes in a regular school setup, even when they knew that their child would not have adjusted to the lessons taught and despite earning poorer grades because they had desired to access the benefits of 'inclusive education'. But in reality, many of these parents had to shift their children from regular schools to a special schooling system. Incompatibility of the curriculum and pedagogy followed in the regular schools that could sustain the learning and comprehending capacities of children with intellectual and cognitive diversities were observed to be a significant cause that triggered many parents to withdraw their children with disabilities. Instances were found while conducting the interviews where few parents reported that their children were good at drawing, singing, or in general interactions but lacked the required level of attention for other subjects, for which they had earned poorer grades in mainstream subjects, and hence the parents were convinced by the school authorities to shift them to special schools. In addition to that, the absence of special educators and teachers with inadequate training in handling children with intellectual and cognitive diversity made the whole system of education non-accessible for these children.

Other than the curriculum, another difficulty that these children had encountered in regular schools was associated with the architectural and infrastructural settings of the school buildings, classrooms, playgrounds, and bathrooms. The absence of a ramp, the absence of an elevator, small and compact classrooms, inaccessibility of natural light within classrooms and corridors, and the absence of attendants in the bathrooms made the choice of regular schools difficult for the parents. Thus, the idea of inclusive education was found to be non-functional with the given realities of the structure and function of regular schools. Findings have suggested that parents who had children with conditions like learning disabilities, ADHD, autism, and Down syndrome, desired to put their children in regular schools so that they could get the scope of interacting with children without disabilities and learn within the mainstream environment of education. But, inadequate infrastructural facilities in the regular schools, therefore, directed many parents to access special schools for their children with disabilities.

Admitting children with disabilities to special schools, however, was not an easy solution for many parents. Findings have suggested that a number of special schools and their respective locations are almost inaccessible for many children on a daily basis. There were many instances where parents had to admit their children to local regular primary schools because they could not find a special school in their vicinity, and carrying the children to special schools located at a distance had turned out to be an expensive affair. Not all parents had enough financial resources to bear the cost of personal conveyance on a regular basis. Moreover, the cost of continuing classes and sessions in special schools was also very high, and it was found difficult for many parents to arrange the cost, leaving aside the direct cost of care. In some instances, it was evident that parents were left with choices between continuing special schools and arranging special home-based sessions for their children, which was recommended by experts. In a few cases, parents had to choose any one of them.

At this juncture, the parents were observed to have encountered the legal system of the Indian state, which talked at length about the importance, significance, and implementation of the inclusive education policy. The schools in India were found either to have adopted the recommendations of the inclusive education policy of the state or to have resisted them on the grounds that they did not possess the necessary arrangements, both in terms of pedagogy and structural accessibility, to include children with disabilities with their exclusive demands of special education. To reach an overall understanding of the accessibility of education for children with disabilities, I interviewed three teachers from regular schools along with their parents, to get their perspective on the current discourse. Conversations with teachers mirrored inconsistencies and contradictions in the state policies. They had pointed out that including children with disabilities, which indirectly asked these children to share similar pedagogical and curricular structures along with the regular children, was far from practicable. Moreover, providing special attention to these children in a class of sixty to seventy regular students was unthinkable for teachers in regular schools with inadequate training and knowledge. Parents had questioned the role of inclusive education policies for children with disabilities where none of the provisions mentioned in the policies had been found to have been implemented in regular schools. A few parents reported that though government schools did not deny admission of their children, this, in reality, did not help these children in any productive way because there was no permanent trained teaching staff or special educators. Parents had claimed that many of the reputed private schools in Kolkata had outrightly rejected the admission of their children on the grounds that they did not have the essential facilities required for these children, both within and outside the curriculum.

Accessing public transport and public buildings or places was another dimension through which parents' encounters with macro-societal systems were explored. In-depth analysis of the parents' narratives and lived experiences has suggested that accessing public places like parks, restaurants, theatres, shopping malls, museums, etc. required a good deal of planning and arrangements on the part of the parents. The absence of ramps in public buildings, roads, and footpaths made the movement of wheelchairs difficult for children who had conditions like cerebral palsy and Rubella syndrome. Inadequate and inappropriate transport and conveyance facilities were marked as the most difficult challenge for the parents. Whether it was taking the children to school, special therapeutic sessions, hospitals, and doctors, or taking the children for a walk to nearby parks or public places such as shopping malls and restaurants, the basic requirement remained the availability of appropriate public transportation means. The absence of ramps in the local buses or cabs of Kolkata, improper arrangement of seats with no space for grabbing support, and lack of space and inadequate accommodation for placing wheelchairs in the buses were reported by parents. This has compelled most parents to access private modes of conveyance even when they cost more. This was found to be one of the reasons that drove parents to choose social separation from their families, friends, and other wider networks they had earlier.

Parents' accounts of the challenges, which emanated from their encounter with the health system, state policies, education system, and infrastructural and transportation systems of the state, have reflected stories that hindered the children from their participation in the wider social world that was closer to them. The findings were found to be very similar to the social model understanding and conceptualization of disability, which highlighted that it was the social-cultural barriers in general that created disability by creating a socially disabling environment for individuals with varying abilities. Though parents express their enormous challenges, stress, and stigma, it should be viewed as part of their lived experiences rather than an end in itself. There were instances where parents defended the existing discourses relating to disability and challenged both the macro and micro social systems, expressing their agency.

According to the research findings, parents' everyday encounters with disabilities through macro and micro-social interactions generated stress among parents. Depending upon the resources (physical, social, and emotional), parents were observed to have attached certain attributes and perceptions to comprehend and cope with the everyday encounter with diversities in their children. While some parents were found to have subscribed to the positive perceptions towards disabilities in their children, some others had developed negative perceptions towards them. The research has adopted Pierre Bourdieu's concept of "capital" to have a deeper and all-encompassing knowledge about the different coping techniques that the parents had adopted to overcome the stressors and to understand how such a choice of adopting different coping techniques was embedded within the social, cultural, and emotional resources of the parents.

Findings have shown that parents who had comparatively higher degrees of economic, social, and cultural capital were able to adopt positive perceptions of disability and diversity in their children. The parents' economic capital (income, assets, and anything directly convertible to money) had been identified as one of the pillars of their strength upon which they could face the stresses of life. Higher economic capital made it easier for parents to access outside services, which assisted them in dealing with stressors. For example, hiring professional paid care workers provided room for the parents—both for their individual space and for some time to spend together;

accessing the best home-based rehabilitative therapeutic services, like speech therapy or hiring physiotherapists, required higher financial resources for the parents. This was observed to be a necessary benefit of possessing more economic capital. Long-term retention of stress and anxieties related to daily care work were common among parents who had to perform all the direct and indirect care work by themselves. The cultural capital (educational credentials, any other cultural skills like dance, music, writing skills, or habit of reading books, etc.) of the parents was noticed to have influenced their coping mechanisms. It was found that parents who were in shock, anxiety, and stress after they initially encountered the reality of their children's disability condition, but who later mollified themselves were the ones who had possessed higher educational exposure or had higher exposure to diverse matters due to their professional or occupational engagement. Stress and anxiety continued to be immense and penetrating for the parents who could not understand the condition and who did not possess adequate information regarding the diversities of their children. Limited knowledge of and exposure to diversity, limited access to information, and internalization of stereotypical cultural perceptions about disability have led these parents to instill negative attitudes toward diversity in their children. Similarly, parents who had higher units of social capital (social contacts, social networks with professional or informal groups, and communities) were found to be more adaptable to the stressors. At both the macro and micro social levels, these parents were observed to have developed and directed their own paths of interaction with diversity.

The economic, cultural, and social capital could be seen as individual resources of the parents that they had acquired or learned and were necessarily connected with the external socio-cultural reality within which the parents lived. But parents' actions and responses to social facts and events related to disability were also connected to their psychological resources, which formed their emotional capital. The adoption of positive or negative perceptions of disability was found to have been not only influenced or impacted by the social, economic, and cultural capital of the parents, but the emotional capital of the parents had played a significant role in directing which socio-cultural perceptions were accepted, rejected, or modified by them given their daily reality of encounter with disability.

Parents who had subscribed to the negative perceptions of disability were found to have blamed their past karma or fate. Disabilities were viewed negatively and unexpectedly not only by society as a whole, but also by parents. These parents had accepted and internalized the traditional approach to disability, and were observed to have had limited familial assistance, emotional support, and social networks in managing the diversities. The experience of stigmatization and social isolation was profound among those parents whose physical, social, and emotional health was affected the most.

The parents were also observed to have developed positive perceptions with regard to disability and diversity and had attempted to incorporate diverse positive coping strategies to face the life strains. The positive coping strategies adopted by these parents included 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 joining different virtual community groups of parents; taking special short-term courses on parenting or taking special education programmes to enrich themselves; and develop skills to manage the diversities. Involvement with these sorts of positive coping mechanisms helped the parents to express their agency and assisted them in building a conscious reflection on the challenges of everyday life related to caring for children with disabilities.

Coping strategies among the parents were observed to have differed along the gender lines. Mothers, particularly those who did not work and were constantly engaged in childcare activities, were the ones who had to fight the stressors by constantly negotiating their physical, social, and emotional space with their children's disabilities and diversity. Many of these mothers adopted positive coping mechanisms to deal with the stressors, like forming local level community groups with other parents who also had children with disabilities; joining parents' and professional groups; and attending different sessions both online and offline to receive more information and knowledge about the diversities in their children and to learn about the different ways of managing the diversities in different social situations within and outside the home. It was observed that fathers who were the only earners in the household and possessed an egalitarian approach to share the care work of their children but were unable to perform due to higher responsibility and commitment towards work, were found to have experienced intense emotional distress. However, this did not in any way mean that fathers who had wives engaged in paid work or fathers who were affiliated with the transitional or traditional approach of gender ideology had a stress-free life, but the stressors were found to have been different for them. For fathers who had lower earning capacity, it was financial security and fulfilment of everyday expenses that mostly generated stress for them, while for fathers who were engaged in highly rewarding professions both in terms of income and social prestige, feelings of stigmatization in the form of "courtesy stigma" were a dominant stressor. Talking to a childhood friend, catching up with friends or colleagues, and spending quality time (even if only for a few hours) with wives were identified as coping mechanisms used by fathers. It was found that fathers relied on their wives to be emotionally stable. As a result, the good and positive vibes from the marital bond were an important source of positive emotional reinforcement for the husbands (fathers of disabled children).

The presence of and access to social support groups was observed to be an important coping mechanism for parents. Parents with limited access to social and professional networks found themselves entrapped within a "cycle of rejection" where being overburdened with care compelled the parents to isolate themselves and provided them with the least time to connect with friends and family. The absence of reciprocity resulted in social isolation from almost all informal networks, leading to the development of more negative perceptions about disability and diversity. The existence of social networks and regular access to them had helped the parents vent out emotional turbulence that had often led to anxiety and depression among them. Parents who remained connected to strong informal support groups (friends, family members, parents from local community groups) and professional social networks were found to have positively coped with managing the diversities of their children. Remaining connected to social networks and professional groups generated positive emotions among the parents because they could share similar social contexts relating to their children’s disabilities. Such social platforms that improve understanding of one another have given parents strength and support when dealing with disabilities at both the macro and micro social levels. Among all the formal and informal networks, parents’ support and community groups were observed to be the sources from which parental agencies and advocacies found their best and strongest expressions.

Research findings have suggested that within parent's support and community groups, those parents who had acquired professional training and had greater exposure to information and knowledge relating to diversities in children came forward to extend their support to other parents in the community who did not have the available resources to access the paid or distant professional groups. While doctors or medical experts and professionals guided the parents about the rehabilitative and interventional requirements of the children, which often modified their parental practices without accounting for the practical challenges in implementing them, parental support and community groups were observed to have enriched the parents with updated information about management of the diversities in their children and come up with practical solutions to their everyday parental challenges in caring for their children with disabilities. Parent support and community groups have provided a much-needed forum for parents to share their day-to-day experiences and encounters with disability. This greatly helped them cope with the life stresses associated with their children's disabilities.

Interviews revealed that inadequate and limited resources in dealing with the diversities of the children formed the primary thrust among the parents to develop agency and advocacy. The agency and advocacy among parents have been categorized into groups based on Trainor's (2010b, p. 40) classification of advocacy. Parents were found to have been involved in 'intuitive advocacy' where they believed that constant exposure and management of the care needs of their children with disabilities had made them experts in understanding their children's needs even better than medical practitioners and professionals. This kind of belief urged the parents to negotiate with the teachers, doctors, and therapists to get what they thought to be the best for their children. Instances were found where mothers had countered suggestions given by doctors and practitioners for certain alterations in the interventions and recommended parental practices. Involvement of mothers as intuitive advocates was shown to be higher as compared to fathers. There were also parents who took a step further and made themselves involved in acquiring expert and specific knowledge regarding the disabilities of their children by taking membership in different professional and community support groups; attending different seminars and sessions, and making direct contact with disability experts both within and outside their vicinity. These parents were found to have attended various workshops and sessions and taken part in discussions regarding upgraded or new intervention techniques. Few parents even take short-term training and workshops in special education. This did not just help these parents to update their individual exposure to a disability, but their expert understanding and experience helped other parents in the support groups to manage and negotiate their own encounters with regard to disability.

The research had the opportunity to involve "Jagori" and "Dishaa" as parental support organizations, where parents had formed a community to support each other in times of need and form a strong platform for parents to take recourse to whenever they would require. According to the findings, some parents have extended their capacity for agency and advocacy to system-level negotiation to obtain the rights and benefits deserved by their children. For example, there was an instance where a father wrote a letter to the local administrative authority asking for permission to construct ramps around a specific road or park so that he and his child in a wheelchair could access it in the morning or evening. These parents were the strategists who utilized their agency and advocacy to devise strategies to receive what they needed, particularly when the authorities who were responsible for the fulfilment of such services were ignorant. There were a few instances in the research where the parents had acted as "change agents." Those who acted as change agents were involved in organizing different programmes and campaigns to raise general awareness among people about childhood intellectual and cognitive disabilities. They took an active role in forming different support groups and organizations where parents of children with disabilities came together to deal with their challenges. These parents stood up for the cause of not just their children but for the children of other parents who were members of their organizations. However, there is no denying the fact that organizing advocacy for a wider cause requires the acquisition and possession of good social networks and cultural capital. In these three cases, it has been demonstrated how social encounters at both the macro and micro-societal levels created challenges for parents of children without disabilities; how parents refused to accept what society and the state had given them; and how much rejection led them to use their individual capacity within the agency to advocate for the needs of themselves and others in society about disability.

Right from the beginning and throughout the journey towards completion of this research, the questions that remained central were: how did parents react to the detection of their child's disability? What has been their journey raising these children? How did they adjust to the challenges of caregiving and parenting? And how did they express their agency in dealing with their children and managing their disabilities? This research was a deliberate attempt to address all such questions. The reactions of the parents were analyzed sociologically, engaging different theoretical constructs and drawing from perspectives of the sociology of emotions to look into how parents' reactions and expressions were part of the larger emotional culture of a society. It is through this emotional culture that people learn the expected emotional expression of a given situation and, thereby, construct the meaning of any social event happening before them. Parents' reactions to the disability of their children were a product of such constructions through which disability was comprehended by them and generated consequent emotional reactions.

The research has explored different dimensions of parenting and care in raising children with intellectual and cognitive diversity. The challenges were discussed and analyzed in light of the perspectives of the sociology of care. The research adequately accounts for and analyses the gendered dimension of care, the balancing of child-care and household responsibilities by parents, and the impact of the care burden on parents. The research was desperate in highlighting the gaps that were evident between the policy frameworks on paper and their real-life implementations in the lives of children with disabilities. This had a far-reaching impact on the parents of these children, who used to be their primary care-giver. The research thus employs a critical lens of understanding to show how disability has been created, recognized, and dealt with by macro-social systems like health, education, and infrastructure. The research demonstrated that functional limitations (both physical and mental) encountered by children with disabilities in general and intellectual and cognitive disabilities in particular when operating within mainstream socio-cultural contexts are the result of system-level dysfunction. The dysfunctions at the system level—health, education, and infrastructure—were unable to accommodate the needs and requirements of these children in order for them to function to their full potential. The parents, being subjected to the reluctance and indisposition of the state, had come up with their own solutions to address the challenges that they had been encountering in managing their children's disabilities. This has been elaborated well in this research in the form of parental agency, advocacy, and activism to voice for the rights of their own and other children.

## 6.3. Limitations of the Research

The research was conducted in Kolkata among sixty parents, employing qualitatively inclined mixed-method research. Since the research was conducted using the methods of qualitative research and was administered among a smaller number of samples, the generalizations of the research derived through analysis of responses and narratives hold true and right only for the given number of samples. Similar research within a broader geographical reach and a greater number of samples would have helped in generalizing the findings within a larger population. This would also have elevated the validity and reliability measures of the findings. However, the measures of validity and reliability have been addressed in this research as far as practicable. Limited access to various government departments and non-responsiveness from concerned authorities has hampered the multilayer reach to reality.

Many of the NGOs and special schools did not respond to the call for research and outrightly rejected participating in the interviews. Many such institutions mentioned that institutional information regarding the operations and services of the special schools was not allowed to be made public. Thus, the research analysis primarily depended on individual parental level data along with the views and opinions of a few doctors, special educators, and teachers. Institutional level data had remained outside the scope of research analysis due to limited access to information.

Moreover, expression of unwillingness was witnessed from many of the potential respondents, particularly fathers. While some of the parents readily agreed to the interview, many of the couples with children with intellectual disabilities, whom I had approached for the research, initially hesitated but later agreed to participate in the research. However, in the latter instances, few fathers were found comfortable having conversations regarding their children's disabilities. And a few of them just answered the technical questions related to their socio-demographic profile and insisted the mother have a conversation in detail. This made the sample selection phase of the research more complicated and time-consuming because I wanted to collect data from both parents in order to gain a better understanding of their daily realities.

## 6.4. Future Research Recommendations

The research has included diverse disability categories under the umbrella of intellectual and cognitive diversities to understand how parenting and child 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. Further research can be conducted to understand the parenting realities of caring for disabled adults within homes.

The study can be expanded to include parents who have children with physical disabilities or any other type of disability in order to obtain an intersectional reach that connects the type, kind, and extent of disability with age, gender, class, and other social categories.

The research has highlighted the gap which was found to have existed between the legal promises and the real predicaments through which children with disabilities and their parents had to struggle through. Further critical paradigmatic research can be conducted to unmask this non-existent link, which would help in shedding light on the role of the state in making the lives of these children and their parents more inclusive.

The research has reflected that parents were accorded the responsibility of care-burden for their children with disabilities and their role as primary caregivers was observed to have been taken for granted by the state. The state's policies regarding disability had very well reflected these tendencies. But despite knowing and recognizing parents’ central role in caregiving, the challenges of managing disabilities have never been talked about or discussed anywhere in the policies and provisions. Thus, further research in this area would help in designing policy frameworks that would address the question of community care and similar mechanisms for parents to ease their challenges and struggles.

The research was limited to an understanding and interpretation of the parents' accounts of their daily struggles and challenges in managing the disabilities of their children. However, there is no denying the fact that the family remains at the center of caregiving responsibility for people with disabilities. Further research can be conducted involving other family members, besides the parents, who directly or indirectly perform the caregiving tasks for the children with disabilities.

The research can be extended to understand the everyday realities of managing children's disabilities and diversity among families who have limited economic resources at their disposal. Thus, the research can be furthered by bringing the poverty dimension into understanding the disability realities of families and parents.

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# ENDNOTES

## CHAPTER -1

[1] Michael Oliver (1990) has discussed the "personal tragedy theory of disability" as the "grand theory" which underpins most of the existing literature on disability. According to this kind of conception, disability should be understood as an individual limitation. Oliver (1990, p. 1) in his book "The Politics of Disablement" mentioned "the personal tragedy theory of disability" (1990, p. 1) to show how disability has been conceptualized throughout western history as a personal tragedy that equates disability with suffering and the disabled person is seen as a sufferer. This view has been dominant in shaping most of the policies and practices adopted by different governments across the world and provided the rationale for introducing interventions and rehabilitative procedures for the required prognosis (French & Swain, 2000, p. 1-3). The medical model of disability is embedded in this very notion, which considers disability as a tragedy; as a problem, and hence requires a solution, preferably a medical solution.

[2] By ‘biological normativity’ I have attempted to focus on the ways in which medical professionals have distinguished disabled and non-disabled individuals based on the biologically accepted definitions of body and mind functioning. Disability is defined as any type of body; and model of disability is embedded in this very notion, which considers disability as a tragedy as a problem and hence requires a solution, preferably a medical solution. Mind functioning deviates from this biological definition and is primarily understood as an individual functional limitation.

[3] The Equal Opportunities, Protection of Rights and Full Participation Act, 1995 (or PWD Act), was enacted by the government of India in 1995 and was enforced in 1996. The act was enacted in favour of the "Proclamation on the Full Participation and Equality of the People with Disabilities in the Asian and Pacific Region." The Proclamation was published by the Economic and Social Commission for Asia and the Pacific Region in December 1992 in Beijing to launch the "Asian and Pacific Decade of Disabled Persons 1993–2002." The Act mentioned seven disability conditions, namely: blindness, low vision, leprosy cured, hearing impairment, locomotor disability, mental retardation, and mental illness. The proclamation defined mental retardation and mental illness and stated that mental illness was anything that did not fall under the purview of mental retardation. See Rao, Rights of Persons with Disability in India—A Study. A social welfare approach was clearly visible in the Act, with a focus on the prevention and early detection of disabilities. The Act includes a provision for a reservation of three percent in education and government posts. The enactment of the Act gave recognition and visibility to people with

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disabilities, both in educational institutions and government services. Also, see Kothari, 2012.

[4] The National Trust of 1999 is a statutory body of the Ministry of Social Justice and Empowerment, Government of India, set up under the "National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities" Act (Act 44 of 1999), which was enacted on December 30th, 1999. The trust had recommended providing opportunities for people with disabilities to develop their capacities along with those of their families. The Act suggested the creation of an enabling environment for people with disabilities, ensuring their rights and dignity. It had recommended providing comprehensive support systems for the disabled. The Act also included provisions to support registered organizations that provide need-based services to disabled people and to recognize guardianship appointments for people with disabilities. See, Ministry of Law, Justice, and Company Affairs, Government of India, 1999.

[5] 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 30th, 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.

[6] 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

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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.

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

[8] See the section on ‘Intellectual and cognitive diversities: conceptualization’ in Chapter 1

[9] ‘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, both are situated in their respective fields (which are separate) from where their respective habitus have been 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 diversity in children.

[10] See Annual Report, 2011, Kolkata Metropolitan Development Authority. Information was retrieved on 16 January, 2022, at 5:47 pm.

[11] See, Office of the Commissioner for Persons with Disabilities, Department of Women and Child Development and Social Welfare, Govt. of West Bengal. Information was retrieved on 17 December, 2021, at 9:40 pm.

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[12] See, Department of Health & Family Welfare, Government of West Bengal. Information was retrieved on 30 November, 2021, at 4:00 pm.

[13] 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 the 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). 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 files 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 (Grentell, 2008, p.52).

[14] The definition has been extracted from the official website of the American Association of Intellectual and Developmental Disabilities. https://www.aaidd.org/intellectual-disability/definition. Retrieved on 10 January, 2022, at 10:39 am.

[15] The definition has been extracted from the official website of the American Association of Intellectual and developmental Disabilities. https://www.aaidd.org/intellectual-disability/definition. Retrieved on 10 January, 2022, at 12:10 pm.

[16] The DSM-5 is the fifth edition of the Diagnostic and Statistical Manual. This is a manual for assessment and diagnosis of mental disorders published in 2013 by the American Psychiatric Association.

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[17] ICD-11 is the eleventh edition of the International Classification of Diseases. It is referred to as a global standard for coding health information and is updated and published by the World Health Organization.

[18] In India, the centrally supported scheme for Integrated Education for Disabled Children was launched in 1974 to provide children with disabilities with equal access to mainstream education. The Rehabilitation Council of India Act of 1992 established a training programme for professionals to cater to the requirements of disabled students. The Indian government has hastened the new inclusive education scheme in order to meet the aim of Education for All (EFA) by 2010. Inclusion is a strategy for ensuring that all children, including those with disabilities, are included in mainstream education. The Salamanca Statement calls on governments to make ensuring that education systems are inclusive a top priority. Inclusive education (IE) is a method of meeting the unique requirements of all students. See Singh, 2016 and Singal, 2006, pp. 351-369

[19] 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, paying fees to doctors or professionals, and paying 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 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

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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.

[20] When the units or samples in the study have unknown probabilities, or probabilities almost equal to zero, we call it a non-probability sampling technique. In social research, the non-probability sampling technique means all units included in the population do not have equal chances of being selected as samples. In qualitative research, non-probability sampling techniques are generally employed due to their smaller sample size. See Bryman, 2006.

[21] Purposive sampling is a type of non-probability sampling. It is also known as convenience sampling. In this kind of sampling method, the samples are chosen on the basis of the researcher's choice and convenient to units that he/she sees relevant to include in the research (Acharya, Prakash, Saxena and Nigam, 2013). See Bryman, 2006, 2012.

[22] The snowball sampling technique is a type of non-probability sampling where the researcher makes contact with few samples or a small number of people initially. Then, by using the contacts referred to by those initial numbers of samples, the researcher establishes contact with a larger number of samples, asking each of them for further reference. In this way, the researcher establishes his/her contact with as many numbers of samples as required by him/her in their research. See Alan Bryman, 2012.

[23] The semi-structured interview is a type of qualitative interview where the researcher has ample flexibility to include features from both structured and unstructured interviews. Like in structured interviewing, the researcher has an interview schedule that guides the topics and themes to be covered for the research. Some of the questions are organized to retrieve informative and confirmatory data, like the one I have used to retrieve data on social demographic profiles. On the other hand, it bears traits of an unstructured interview where the researcher enjoys the flexibility of asking probing and thought-provoking questions, which are subjective to the context and responses of the samples. Both open-ended and closed-ended questions are involved. In this kind of interview, the narrations of the respondents are given special importance. The semi-structured interview helps in providing illustrations, and questions should be so asked in this type of interview, that it allows the researcher to understand the way participants have been viewing their social worlds (Bryman, 2012). See Alan Bryman (2012), pp. 470-473.

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# CHAPTER - 2

[1] 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 are 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, pp. 33–53). The word ‘normal’ was introduced in the English language resources 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. In 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).

[2] See Illich (1976, pp. 13–43). In “Medical Nemesis” Ghosh (2016, p. 3) has adopted this term to denote that medical definitions impose a presumption of biological or physiological inferiority upon people with disabilities, and 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).

[3] Discipline and Punish: The Birth of the Prison (1975/1991) conceives 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

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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.

[4] 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.

[5] 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.

[6] 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

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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).

[7] At present, disability is classified and categorized according to the information provided in DSM-5 (Diagnostic and Statistical Manual, 5th Edition). In addition to this, ICD -11 (International Classification of Diseases), 2011 provides definitions of diseases and disorders and has been recognized as a global standard regarding information on health and diseases.

[8] Arlie Hochschild (1983) coined the term "feeling rule" in her book "The Managed Hearts" (1983), and expanded on it in her book "The Second Shift" (1989) to discuss the gendered nature of emotion and care. According to her theory, people are guided by certain rules to display their emotions in a given reality or context. These rules are guided by certain socio-culturally mediated guidelines and norms about how one should behave in a situation. These rules that guide the feelings and behavior of an individual are called "feeling rules". See "Emotion Work, Feeling Rules, and Social Structure" by Hoschschild (1979), pp. 551–575.

[9] Feeling rules are guided by certain socio-culturally informed and widely accepted norms of feeling. These rules are discovered to be embedded in a larger ideological framework that directs how people should feel in a given situation. This ideological framework is called "framing rules." Thus, "feeling rules" are always backed by "framing rules" (Hoschschild, 1979, p. 551-575)

[10] While the feeling rule explains how one should feel in a situation, "emotion work" refers to how one tries to feel in a situation. "Emotion work" is the "act of trying to change the degree or quality of an emotion or feeling." (Hochschild, 1979, p. 561). Read "The Managed Hearts" (1983) pp. 56-75.

[11] A system of societal expectations has been termed "emotion culture". When people experience and express their emotions in a specific socio-cultural setting, they create a system of societal expectations. Others in a community expect and judge specific emotional manifestations based on their social environment and cultural circumstances. Emotions in this context are more than just a response or reaction; they are a component of a larger cultural context that emerges from interactions with other people, institutions, or systems in society. Individuals' emotional manifestations in a society reflect the society's emotional culture, in which the meanings of such feelings are shared and reproduced.

[12] 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

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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). 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.

[13] Sociologist William J. Goode defines “role strain” as “the felt difficulty in fulfilling role obligations” (Goode, 1960). Goode suggested that every individual in a society is assigned certain roles to perform. In performing specific roles, people enter into different bargaining processes, prioritizing their different roles in different contexts and times, hence entering into what he calls role bargaining. In the process of such role bargaining, often individuals are faced with role stress when one role needs more commitment at the expense of the other roles. In such situations, individuals experience “role strain”. Goode stated that “the individual may face different types of role demands and conflicts, which he feels as "role strains" when he wishes to carry out specific obligations.” See William J Goode, 1960, p. 484. Kandel and Merrick (2007) have adopted this concept of role strain to explain how parents of children with disabilities bargain their roles as parents with the other social roles that they are expected to perform as social beings, ornamentally termed “norm commitment”. Shtenger (1998) lists parental traits that lead to parental role strain, which include perception of maternal image, competency, and parental attachment.

[14] Goffman introduced the concept of “primal scenes of sociology” (Goffman, 1967, p. 13). ‘Primal scene’ is elaborated as traumatic encounters through which an individual point out and recognizes his/her differences from others and develops a sense of self out of an understanding of such differences.

[15] 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, 1963a).

[16] 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.

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[17] The Parents Association for Persons with Intellectual Disabilities (PAPID) was founded in 1992 as an official organization in different parts of Taiwan. The aim of the organization is to engage in public policy, advocate for the rights of people with intellectual disabilities, and work with the League of Welfare Organization for the Disabled (Chang Heng Hao, 2009, pp. 34–59). The Disability Rights Movement began to develop in Taiwan in the 1980s. The activities of the foreign missionaries and the professionals created awareness about disability issues and initiated many grassroots advocacy activities. In the absence of non-governmental awareness campaigns and non-existent appropriate recognition of disability rights, parents of children with intellectual disabilities pushed the agendas into public policies, which resulted in the formation of the League of Enabling Associations in the 1990s and the Parents' Association for Intellectual Disabilities in 1992. Also see Chang, 2007, pp. 1-17.

[18] At the Vienna World Conference on Human Rights held in 1993, the protection of people with mental and physical disabilities by international human rights law was reemphasized. The resolution adopted at this conference led to the framing of the "Standard Rules on Equalization of Opportunities for Persons with Disabilities" ("Standard Rules") by the UN General Assembly. The standard rules established citizen participation by people with disabilities as an internationally recognized human right (Dhir, 2005). The Standard Rules highlighted the areas in which equalization of opportunities was necessary to adopt and implement. These include provisions for access to affordable services, including education, employment, medical care, and support services (Lang, 2009). The provision also states that to include disabled people in the planning, management, and evaluation of disability programmes, as well as the need for international cooperation. See Lang, 2009, p. 266-285.

[19] The National Policy for Persons with Disabilities in India, 2006 recognizes the persons with disabilities as valuable human resources and hence they are entitled to get access to social environments with equal opportunities, protection of their rights, and full participation within society. The policy had put stress on prevention and building awareness relating to disability. The policy had recommended that children with disabilities will be provided with learning materials and books and schools will be equipped with trained and sensitized teachers, and a barrier-free environment, both in schools and public places. The policy suggested re-modifications of the course curriculum and the evaluation system keeping in mind the needs and capacities of the children with disability. The policy had ensured the right of the people with disability to recognition of their equality and dignity. The policy highlighted the creation of an environment that would enable the children to exercise their rights and opportunities (Kumar, 2006). The National Policy had recognized the role of NGOs to be very significant in providing affordable services complementary to the state endeavors. See

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Kumar, (2006). National Policy for Persons with Disabilities. Ministry of Social Justice and Empowerment.

## CHAPTER- 3

[1] A naturalistic account of the disability perspective has been presented by Elizabeth Barnes in her work 'The Minority Body' (2016) on the basis of three beliefs (or misbeliefs): firstly, that disability is a deviance from the idea of the normal functioning of the human body; secondly, that disability indicates a lack of ability which most human beings should possess (that is evaluated against standards of the normative); and thirdly, that disability results from maladaptation and maladjustments of impairment (when impairment is equated as a departure from the standards of the normal functioning of body and mind) with the social environment (2016, p. 13-21).

[2] According to Rolland (1987), a diagnosis is a "framing event" that transforms a set of behaviours into symptoms and behaviours with the meanings surrounding the illness, as well as its experience and course.

[3] Presently, the International Classification of Diseases (ICD-10), produced and published by the World Health Organization, and the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) by the American Psychiatric Association (APA), are considered to be the reference manuals for classifying different intellectual, cognitive, psycho-motor, neuro-motor, and developmental differences both among children and adults. However, there are contradictions between these two standard classification indexes in defining each of the differences based on their symptomatic and behavioural traits.

[4] In the book "Disabled Children: Challenging Social Exclusion", Laura Middleton (2000) attempts to present a holistic picture of the health, education, and welfare services that young children receive, and argues that because the services are different for children with and without disabilities, as their needs are separate, the children with differences undergo a process of "abnormalization" (Middleton, 2000). She maintained that the needs and requirements of these children with differences are compared with those of the standards possessed and expressed by other children without differences, and hence the differences from the standards are seen as (not) normal, paving the way for the creation of disability.

[5] Adrienne Rich (1995) claimed this in the foreword of the book "Of Women Born: Motherhood as Experience and Institution" to situate the context of how motherhood

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and fatherhood have been conceptualized in history and how social-cultural constructions shape their roles in society as parents.

[6] Sara Ruddick, in her work “Maternal Thinking: Towards a Politics of Peace” (1995, p. 111), explains that mothers’ performance of care and responsibility towards their children is or can be judged and evaluated by anyone in society. Her actions, behaviours, and care are monitored under continuous assessment. This often contradicts and upsets maternal authority and decision-making for their children, and often the mothers are left with no option but to surrender to the authority of others with regard to mothering (O’Reilly, 2004, p. 161). This has been termed the “gaze of others” (1995, p. 111). The mothers in my research have similar experiences every time they encounter the medical and clinical stakeholders who are associated with the difference their children have.

[7] 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”. A person is engaged in deep acting when he/she tries to embody the emotion so that displaying the same emotion to others or in social settings does not appear to be pretentious or showy. In deep acting the actor tries to feel the emotion that he/she thinks appropriate to display in a situation of social interaction. In this deep acting, the person wants to feel what he/she thinks he/she should display in a particular situation of social interaction. By adopting the model of ‘deep-acting’, people try to present their emotional display “authentic to themselves as well as to the other person” (Michelle Addison, 2017, p. 10). 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, p. 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

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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, p. 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.

[8] Differences in body and mind functioning, as manifested in various behavioural patterns and actions, are defined and recognized as “others” by broader social and cultural standards. Every society has its own cultural standards that define certain bodies and minds and their functioning as the norm, and anything or anyone that does not conform to the norm is labelled as “other”, and the extent to which such variations occur is defined as “otherness” (Clapton & Fitzgerald, 1997, p. 1-3). The parents see the differences in the children as per the degree or extent of “otherness” they possess, and the attribution of “otherness” makes the parents perceive their child as “other”.

[9] This study accounts for higher pay (monthly family income between Rs. 50,000 - Rs. 91,000) when compared to the family income bands of all respondents combined.

[10] Kathy Gharmaz and Melinda J. Milligan (2006, p. 521) argued that emotions are socially constructed. The historical and cross-cultural studies on emotions confirm that each society acquires a specific emotional culture, which is inculcated and diffused among the members of that society through the socialization of norms, values, and beliefs. Emotions cannot be understood in universal or biological terms because they are constructed within a specific cultural context, and hence, the felt and expressed emotions of the people in a society are products of the socialization of the emotional culture of that society. For more information, see Stets and Turner's 2006 Handbook of the Sociology of Emotions, pp. 516–539.

[11] Brown (2013) has adopted this concept of ‘double mourning’ to show how mothers' feelings and emotions take different forms in response to the news of the detection of disability in their children. His thesis claimed that mothers’ initial level of grief is

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‘double mourning’ on two grounds - firstly, the loss of dreams for the child and secondly, losing hope for her own future (p. 117). I have adopted this concept to show how the mothers in my research, express their grief and loss after they know that their children were detected with certain differences.

[12] Hochschild (1979, p. 552), in her work “Emotion Work, Feeling Rules, and Social Structure”, maintained that there are social-cultural rules that regulate how a person should feel in any given situation and there are unsaid rules that guide the display of emotions by people. People are socialized in ways to feel in ways that suit the definition of the situation or context. The fathers and mothers in my research have been socialized to internalize the gendered display of emotions or feelings, by which fathers are expected to hide or manage their emotional display in front of others. In contrast, it was easier for the mothers to explain and narrate their feelings and emotions in a vivid manner during the interviews. Hochschild (The Managed Hearts, 1983) claimed that men and women use their emotions in a different manner. This is well reflected in the gendered division of labour in work (both within and outside) the family, where mothers are more involved in the emotional work of care while fathers are more comfortable earning the bread in the household.

[13] Arendell (1993, p. 3) provided a list based upon which a "good mother" is evaluated. The list continues that a good mother should be "heterosexual, married, and monogamous" and that she should not be employed, should not be economically independent, and should be dependent on her husband. Good mothers are expected to follow socially constructed and culturally acceptable norms (Miller, 2005, p. 86). Good mothering discourse continues to shape and supervise mothering practices by defining what a mother should do and how she should act or function (Goodwin & Huppatz, 2010, p. 5–6). Good mothers should follow the norms of "intensive mothering" (Hays, 1996), which asks the mother to place her child at the center of everything, even if it calls for a compromise in wealth and power.

[14] Shubhangi Vaidya (2016a, p. 129) in her work on “Autism and the Family in Urban India” has observed that mothers are often blamed by the paternal grandparents of children who are born with autism, and this causes the parents to isolate themselves socially from the child and strain their relationships with other family members. Vaidya (2016a, p. 129) has called this a “blame game” by which mothers-in-law believed that wrong mothering practices and incapability of handling, training, and socializing children, along with their indulgence in careers and jobs, caused Autism in their grandchildren. In my research, interviews with mothers confirm that they were blamed for the differences in their children, in both instances where the child was born with disabilities or developed the disability gradually during his/her early years of development. In both contexts, the mothers were blamed for the differences in their children.

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[15] Leo Kanner (1943) introduced the term "refrigerator mother" (Joseph, 2018, p. 1) while explaining that autism in children is a result of the interaction between the social-physical environment and wrong mothering practices. According to Douglas (2014b, 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 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.

## CHAPTER - 4

[1] Diversities are often generated by certain intellectual, developmental, and psychomotor functions of the body. These diversities are viewed and labelled as differences when they are compared with the idea of what is understood as the normal functioning of the body and mind. When viewed in this light, diversity creates distinctions between people who have the characteristics of a normal body and those who do not.

[2] Under the Disability Act of 1995, the issuance of a disability certificate by competent medical boards (preferably from government and district hospitals) has been made mandatory to access the concessions and relaxations made under the provisions of this law. Possession of a disability certificate comes with a 3% relaxation in educational institutions and employment in public sector organizations. Financial assistance of Rs. 400 is provided to people with severe and multiple disabilities (should be more than 80%). Concessions are available on express trains and airfares by 50%. Public transportation like buses and local trains can be accessed at no cost. Extracted from the official website of the Office of the Commissioner for Persons with Disabilities, Department of Women and Child Development and Social Welfare. Retrieved from wbcommissionerdisabilities.gov.in/. on October 10, 2021, at 5: 30 p.m.

[3] “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, habitus, and capital taken together generates a rule of the

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game by which the professionals by their practice (habitus, field, and cultural capital) hold power over the parents, who are made to follow the directions and accept the reality as shown by the doctors with regard to disability, which often contradicts what the parents actually experience.

[4] 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; 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.

[5] Jagori is an organization founded by Amrita Mukherjee in 2015. The organization works to facilitate children with intellectual disabilities and acts as a local level parents' support group. Jagori, Gobordanga offers a platform for parents both to avail of disability services for their children and to get scopes for developing their agency. The organization runs a special school to facilitate the children living in and around the area where there is no accessibility to special schools and rehabilitation centres.

[6] Dishaa is a daycare and rehabilitation centre for children with special needs. It is an initiative taken under the BVCT (Barasat Vision Charitable Trust). The organization has been operating successfully and effectively for the last five years.

[7] "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

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to devote all their time, energy, and resources (both material and emotional) toward 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 compels the mothers, though passively, to adopt the motherhood ideology of parenting, where mothers are central to the caregiving role for children.

[8] 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.

[9] 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.

[10] 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), pages 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

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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).

[11] Link and Phelan (2001) mentioned that stigma possesses five inherent components: labelling, stereotyping, separation, status loss, and discrimination, each of which exhibits power differentials to a certain extent. (Yousof, 2016, p. 96 ) This has been discussed in detail in Chapter 2.

[12] 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 “misfitting” 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 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.

## CHAPTER- 5

[1] Stress emanates from different kinds of emotions people undergo and display. Behavioral science defines stress as perceptions of threat. Anxiety, tension, displeasure, discomfort (Fink, 2010, p.13), and other emotions that people experience when confronted with unpleasant and unexpected events or contexts trigger the perception. In this chapter, I have used the word "stress" as an umbrella term to cover all the different kinds of emotions that parents undergo after they encounter disabilities in their children or when they encounter the daily life challenges of dealing with diversity in their lives.

[2] Stress and stressors are frequently used interchangeably in psychology and other behavioural sciences (Pearlin & Schooler, 1978, p. 03). Lazarus and Folkman (1984) referred to stressors as evoking emotional responses within individuals who attempt to cope and adjust to the behavioural demands (Thoits, 1995, p. 54). Stressors cause stress among individuals. Thus, stressors are the social, cultural, economic, and systemic challenges encountered by parents in raising their children with disabilities.

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[3] 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.

[4] Pearlin and Schooler (1978, p. 05) compared and classified resources into social resources, psychological resources, and specific coping responses. To them, resources are the things, capital, or strategies available to them in coping with stressors. Social resources are the interpersonal networks of people that form the source of support for people under stress. Family, friends, colleagues, neighbors, and associations are important social resources. Psychological resources are the personal attributes of people with which people cope with situations, objects, and events that pose threats or from which chances of potential threats in the future are perceived. Research findings showed that parents' positive and negative perceptions of difference and their consequent coping relied upon their psychological resources. Specific coping responses are the reactions people give or things people do in response to life strains and stressors. We have observed that parents resort to diverse coping mechanisms ranging from denial to advocacy. For details see, Pearlin and Schooler, 1978.

[5] Affiliate stigma is the kind of stigma that people develop because of their affiliation or association with people possessing stigmatizing attributes. People develop affiliate stigma when they internalize the public stigma meant for people who have attributes that are socially stigmatizing. Parents have been found to develop affiliate stigma when they have internalized the stigma that is socially and publicly extended to their children with disabilities. See, Mak and Cheung, 2008, pp. 531–533.

[6] Folkman and Moskowitz (2000) classify coping strategies as: positive reappraisal, problem-focused coping, and the creation of positive events (p. 115-116). Positive reappraisal is defined by them as a cognitive process by which people develop positive emotions towards events or situations. Positive reappraisal includes developing and finding opportunities for personal growth and also looking for avenues to channel personal growth for the better cause of improving others' living conditions. Problem-focused coping helps in solving or limiting issues that cause stress and strain. It tries to reduce or nullify the cause that causes emotional negativity among individuals. The creation of positive events points to the spaces or events people create for themselves to appreciate the things that they love. Parents' agency and advocacy constitute all three forms of the coping mechanism when they orient their perceptions towards difference through positive emotions.

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[7] Chenoweth and Stehilk (2004) mentioned the “cycle of rejection” (p. 67) to show how care and management work related to disability restrict the parents' ability to reciprocate effectively in social networks. They argue that limited or reduced exposure to social networks and relationships leads to social isolation. The longer parents are socially isolated, the more they distance themselves from external support and network groups, forcing them to rely on internal sources of support from their family in times of need. Hence, restricted or limited (if not no) access to social networks places the parents in a cycle of rejection where limited access causes isolation, and isolation furthers the access to networks, leading to the further social isolation of the parents. See Chenoweth and Stehilk (2004) for details.

[8] Emirbayer and Mische (1998, p. 962-963) in their work, “What Is an Agency?”, have provided an agency on the basis of three elements. The main thrust behind developing such a theory was the incompleteness they observed in earlier theories that talked about the agency. Theories of agency given by Bourdieu and Giddens have focused only on habitual and routinized practices. Rational choice has seen agency from the angle of purpose, means, and ends, and so forth. In such a context, Emirbayer and Mische (1988) attempted to put forward a theory of agency that centers on the question of how actors critically evaluate and reconstruct conditions in their lives. In seeking the answer, they have theorized agency as interconnections of three components: iteration, projection, and evaluation (p. 961–965).

[9] Trainor (1988), in his study among parents of children with differences, classifies parents’ advocacy into four groups based on the resources they possessed and the capital they acquired to reflect back on their life situations. The four groups of parents were: intuitive advocates, disability experts, strategists, and agents for systemic change (p. 40). See Trainor (1988, p. 40–44) for details. In this study, parents were observed to reflect all of the categories at some point in their interactions, with the difference occurring at both the macro and macro societal levels of interaction.

[10] Barasat Vision Charitable Trust (BVCT) is an organization that has been developed by parents of children with disabilities. They have formed a trust and have residential setups for parents and children with disabilities. They also run a daycare and rehabilitation unit for children with disabilities called Dishaa. The organization has been working successfully and effectively for the last five years.

[11] Nowotny (1981) coined the term “Emotional Capital” and defined it as “knowledge, contacts, and relations as well as access to emotionally valued skills and assets” (p. 148). Thoits (2004) referred to emotional capital as the "capacity to experience social emotions predicated on role-taking" (Cottingham, 2016, p. 454). Emotional capital is composed of knowledge based on emotions, management of emotional skills learned or acquired, and the capacity to link personal feelings to

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resources one has. Emotional capital makes a person link “self-processes and resources to group membership and social locations" and hence "posits a direct relationship between macro-structures and micro-resources” (Cottingham, 2016, p. 452). Parents have been observed to use their emotional capital as a coping resource. Parental advocacy and agency require a good investment of emotional capital along with economic, cultural, and social capital to bargain and access services deemed best for their children.

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# APPENDIX-I

# INTERVIEW SCHEDULE

This interview schedule was administered to sixty parents of children with intellectual, developmental and cognitive diversities. Besides interviewing the parents, three teachers, three special educators and three doctors were also surveyed to get insights from the other side; to gain a holistic view of the parents' experiences.

## I. INTERVIEW SCHEDULE FOR THE PARENTS

1. Name:
2. Age:
3. Residence:
4. Religion:
5. Marital status:
6. Education:
7. Profession/occupation:
8. Income (individual/household):
9. No. of children:
10. No. of children with disabilities:
11. Household structure:

12. So, based on our previous phone conversation, how would you describe your child's journey to date?
13. What kind of disability does your child have?
14. When did you come to know about your child's disability condition?
15. Who disclosed you the information about the detection of your child's disability?

16. Do you think that the way it was disclosed to you was not correct? Do you think that the information could have been presented to you in a better way?
17. So, what was your response to the information? How did you feel?
18. What was the first thing that came to your mind after learning that your child was detected with some form of disability?
19. Why do you think you have reacted in that manner?
20. What were your expectations as a mother/father before this child was born?

21. What was your understanding of childhood disability before your child was born?
22. What specifically did you know about your child's disability condition, which had been detected?

23. What was the response of other family members when they had learned about the child’s condition or disability?
24. When was the disability detected? At the time of birth or later?

25. Do you think that the detection of disability in your child has altered the way you had been seeing and expecting your life to be? Especially in relation to your role as a mother or father. If so, how?
26. (In the case where the disability was detected during the formative years of development, what made you feel that you should see your doctor?
27. Did you yourself feel the need to see a doctor, or was it advised to you by others, like your spouse, other family members, neighbors, or friends?
28. What do you think might have caused the disability in your child?
29. Did you feel that you were responsible for causing your child's disability?
30. Who do you believe was to blame for your child's disability?
31. Were you held accountable by others for your child's disability?
32. Who blamed you for causing the disability?
33. How much do you believe parents are to blame for their children's disabilities?

34. Do you think that something was wrong during pregnancy, or something was not done right over the whole conception period that might have caused disability in the child?
35. Do you think the wrong parental practice during the early months and years might have caused the disability?
36. What did the doctor advise you for your child?
37. Did you seek the help of any professional rehabilitation facilitator or special educator?
38. What were the recommendations that you received from the clinical practitioners or doctors?
39. How would you explain your interaction with the doctors?
40. How would you explain your experience with special educators or rehabilitative facilitators with whom you have been interacting regarding your child?
41. Were there any instances or stories of conflict with your doctors or facilitator?
42. Do you think that your understanding of the disability of your child was informed by the way doctors explained it to you?
43. Did you find the explanation provided by the doctors about the disability, when the disability was detected, sufficient for your understanding? If no, then did you do anything next to get a clearer understanding of the same? How?
44. Did your conversations with doctors and medical practitioners make you feel better or worse?
45. Did you access or avail yourself of all the recommendations prescribed to you by the doctors and practitioners?
46. Which early intervention centre in Kolkata did you visit first?
47. Do you know what early intervention and early detection centres are?
48. Did the doctors inform you about such centres in Kolkata?
49. Were you able to access all the rehabilitation facilities that were prescribed to you by the medical and professional practitioners?
50. What were the major hindrances that you had to face while accessing the rehabilitative services recommended to you for your child?
51. Do you have a disability card for your child?

52. When the parents had a disability card,
    a) How did you receive your disability card?
    b) From whom did you know about the disability card?
    c) What was the process of making a disability card for children?
    d) How long did it take to get the disability card?
    e) What was your experience in relation to making a disability card for your child?
53. When parents did not have a disability card,
    a) Why don’t you have a disability card?
    b) Did you try it ever? If no, then can you please explain, what made you not applying for a disability card?
    c) Was the matter of making a disability card unknown to you?
    d) If yes, then why don’t you have the card? Is it due to some other reason? Please elaborate.
54. What are the benefits of having a disability card?
55. Do the benefits of having a disability card help you, or your child, in any productive manner?
56. Do you think it is necessary for your child to get his disability card issued by the competent authority?
57. Who manages all the caregiving activities for your child?
58. Does anyone other than you and your spouse help in managing the care work?
59. How do you strike a balance between child care and household responsibilities?
60. Do you think both parents (fathers and mothers) should take responsibility for handling both the care of the child and the chores of the household?
61. In your household, how does the work of care and chores in taken care of?
62. Did you seek any external help for managing the care and household responsibilities? If yes, then explain the manner in which you got help from him/her. If no, then how do you manage to balance both care and chores?
63. How does your spouse assume responsibility for the child's care?
64. How does your spouse help in the management of both care and chores?
65. Do you and your spouse both work in paid job sectors?

66. How does the management of care and chores occur (if any one of the parents is in paid employment)? How does the management of care and chores occur?
67. Were you working before your child with disability was born?
68. Did you leave your job, after your child was born?
    a) If no, then how do you manage caring for your child, attending to his/her surplus needs due to disability, and dealing with the everyday household chores needed for survival?
    b) If so, what made you leave your job?
    c) Was leaving the job your own decision? Or were you asked by someone to leave the job?
    d) Or was it the context of life you were moving through that compelled you to leave your job? Please elaborate.
69. Do you feel that managing a child with disabilities and fulfilling job commitments clashes with your capacity to work (as in care, chores and job role)?
70. Do you feel overburdened by your caregiving responsibilities?
71. What do you think makes you feel overburdened? Is it just the care work, or managing both of them, or not getting any assistance to conduct all your commitments?
72. What do you do when you feel overburdened?
73. As a mother or father, how do you feel about the disability of your child?
74. Do you feel that the disability of your child is affecting the quality of your life? How?
75. As a parent of a child with disability, what surplus care activities do you think make you more engaged when compared to parents of children without disability?
76. Do you think that getting overburdened with care work is making your life stressful?
77. What are the sources of stress that you feel are making your role as a parent more challenging?
78. What do you do to cope with the stress?
79. Do you have friends? How often do you meet with them?

80. Do you have good contact with your extended family networks? How often do you visit them or do they come to visit you?
81. How often do you get chance of physically attending get-togethers, parties or just outing with family and friends?
82. How was your social life before and after the birth of your disabled child? Do you think this also happens with parents who had children born without any disabilities?
83. Do you spend quality time with your husband?
84. What are the challenges that you have had to encounter as a parent in raising your child with disabilities?
85. Did you admit your child to a school? If so, which type of school-regular or special?
86. Why did you choose to admit your child to a regular school? Why did you choose to admit your child to a special school?
87. What are the challenges your child has had to face in a regular school? What are the challenges your child has had to face in a special school?
88. Why do you think regular schools or special schools are best for your child?
89. Do you think that the interventional needs of your child can be taken care of fully in a regular or special school?
90. Why did you not admit your child to a special or regular school?
91. How do you take your child to school? Do you avail of public transport or private conveyance?
92. Do you think it will be an easy task to carry your child to and from school via public transport?
93. What are the difficulties you face when transporting your child by public transportation?
94. What are the requirements that you believe most public transportation should meet?
95. Why don’t you make contracts with private transport agencies to move your child to school or other places where you need to carry him?
96. Do you encounter similar difficulties when taking your child to public places?Please elaborate.
97. How do you think these challenges could have been resolved?

98. Do you think the resolution of such challenges was an individual problem or required systems level inference of the state and local administration relating to health, education, and infrastructure?
99. Do you know about the rights of children and people with disabilities under the Disability Acts in India? If yes, then do you find them properly implemented in all realms of life for these children?
100. In such a context, what was your reaction as a parent towards the resolution of the challenges that your child had been facing?
101. What did you do to ease his/her challenges in accessing schools and other public places?
102. Did you believe that your child had access to all of the facilities and services that a disabled child should have in a society? Please elaborate.
103. Did you do anything, as a parent, to improve your child's access to the rights he or she deserves in society? If so, then please explain.
104. What were the steps that you took to improve the understanding of your child as a parent of a child with disabilities?
105. Did your existing social relationships and networks help you adjust to the challenges? Or had they gone on to become sources of social repulsion? Please explain.
106. Are you a member of any professional or parents’ groups?
107. How did you know about the existence of such a group?
108. What made you get connected with such groups?
109. Did these groups help you in any productive way? Please elaborate on your experience with such groups?
110. Did these groups help you overcome the stress of managing your child’s disability?
111. Did you contribute in any way to these groups as a parent of a child with disabilities?
112. Do you think that being associated with these groups has helped you improve your understanding of disability?
113. Did you feel that getting associated with such groups has enhanced your quality of life? If so, then in what way? Please put some light on.

114. Do you feel that parents have the capacity to fight for their children in circumstances where their children’s rights to live a quality life remain mistreated? If so, then how? Please elaborate.

## II. INTERVIEW SCHEDULE FOR DOCTORS

1. From the perspective of a medical professional and practitioner, how would you explain the parents' response when they learn that their children had been detected with some conditions of disability?

2. How do you think you should disclose the results of a diagnosis of disability?

3. To whom do you prefer to disclose the information? Associating the parents with mothers, fathers, or other family members?

4. Does the manner or way of disclosure vary as per the type or extent of disability? If so, then how? Please put some light on this.

5. Do you think that the way disclosure of a disability is made has a long-term impact on the parents?

6. Do you think that the evaluation and measurement of disability are backed up only by a medical understanding of disability?

7. As a medical professional, do you have knowledge about the laws relating to disability where the ideas of social barriers and disabling environments have been highlighted? What is your opinion on this?

8. It is known by parents that, in cases of disabilities that are expressed during the formative years of the development of a child, they initially take their children to a general paediatrician when something odd in their behaviour is noticed. But the doctors could not find any issues with their child and the early intervention got delayed. What is your opinion on this?

9. Do you think Kolkata has sufficient infrastructure to support early intervention and early detection services for parents whose children have been detected with disabilities?
10. Do you, as a medical practitioner, listen or give importance to the observations of the parents relating to their children’s behaviour?
11. How do you think parents’ understanding of disability and their children cut across the way medical recommendations should have been followed by them?
12. Do you think that the medical infrastructure is sufficient in Kolkata to facilitate the rehabilitative needs of children with disabilities?
13. Do you know about the recent laws related to disabilities?
14. What is your opinion on the disability card?
15. Do you think the evaluation and measurement of 40% of disabilities was possible for conditions like Down's syndrome, autism, ADHD, and other conditions creating limitations in the intellectual and cognitive capacities of children under clinical setup only?
16. Do you believe that for conditions such as Down's syndrome, autism, ADHD, and other conditions that limit children's intellectual and cognitive capacities, reaching or failing to reach the yardstick of 40% is related to the extent of parenting challenges that parents face when raising their disabled children?

## III. INTERVIEW SCHEDULE FOR THE SPECIAL EDUCATORS

1. How long have you been working in the field of special education?

2. Do you specialize in providing special educational facilities for children with intellectual and developmental disabilities?

3. What do you think about the challenges parents of children with disabilities might have encountered in accessing special educational services for their children?

4. Many parents have reported the high expenses involved in accessing special educational services. What is your opinion and experience regarding this?

5. Do you think Kolkata has a sufficient number of special schools and special educational services that can cater to the needs of these children and their parents?

6. Do you think that the locations of such schools or centres are well distributed throughout Kolkata? Or are they concentrated mainly in the core urban centres of the metropolitan area?

7. How do you think parents residing in the distant parts of the city would access such facilities for their children with disabilities?

8. Do you find the state policies relating to disability compatible with the real life needs of these children?

9. Which one do you think is a better option for children with intellectual disabilities—regular schools or special schools? Why? Please elaborate.

10. Do you think that accessing the services of special education is feasible for parents belonging to lower income groups?
11. How do you think early detection and intervention of disabilities influences parents and their children with disabilities? And how can the non-availability of such facilities affect children? Please explain in detail.
12. Do you agree that the only way to understand disability is through medical understanding and subsequent rehabilitative recommendations? Or, do you think that society and the functioning of its different systems and institutions play a larger role in the creation of disability?

## IV. INTERVIEW SCHEDULE FOR THE TEACHERS OF REGULAR SCHOOL

1. How long have you been associated with the field of education? How long have you been teaching in school?

2. Does your school have a special educator?

3. Does your school have ramps to ease the movements of children (if any) with disabilities or make provision for the movement of wheelchairs?

4. Is there/were there any children in your school who have/had intellectual and cognitive diversity conditions?

5. How does your school respond to the cases of admission of children having issues with intellectual and cognitive development?

6. Is there any instance when your school has denied or rejected admission of any such children in the recent past? Please explain your answer.

7. How many children do you teach at a time in a class?

8. Is there any child in your class who has intellectual, developmental, or cognitive disabilities?

9. If there had been any child in your class who had intellectual, developmental or cognitive disabilities, how would they have managed to learn?

10. What kind of difficulty do you think a teacher might have faced in a class where children with and without intellectual disabilities would have attended the class at the same time?
11. Did you take any teacher training courses?
12. Did your curriculum include any special education modules?
13. Do you think it would be possible for a teacher trained in a regular B.Ed. course to manage to teach children with intellectual and cognitive diversities?

14. Do you think that teaching children with intellectual, developmental, or cognitive disabilities would never be possible without a teacher trained in special education?
15. Does the academic curriculum followed in your school accommodate the teaching and learning needs of children with intellectual and cognitive disabilities?
16. What do you think about the admission of children with intellectual, developmental, and cognitive disabilities to regular schools?

# Parenting Children with Disabilities: A Sociological Exploration in Kolkata

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