

## Research Article

# Too Much or Too Little? Paradoxes of Disability and Care Work in India

Nandini Ghosh, PhD & Supurna Banerjee, PhD

Institute of Development Studies Kolkata

**Abstract:** The notion of care often normalizes within it violence that can have devastating effects on the lives of disabled people. Crippling care critiques the normalization of such notions of care. This paper articulates this paradox of care within the lived experiences of disabled girls and their mothers as primary carers. Through extensive case studies of young, disabled girls and their carers in villages of West Bengal, Jharkhand, and Odisha in India—where abject poverty, lack of resources, and a dearth of sensitized social relationships remain entrenched—this paper problematizes care relationships, moving beyond social model approaches to include understandings from the Global South of what it might mean to cripp care. The paper explores care relationships within the family, which valorize the emotional and physical labor of women in the garb of motherhood while negating the personhood of disabled daughters. While the care relationship between mother and daughter is enhanced by the affective bonds of empathy, emotional responsiveness, and perceptual attentiveness that transform intimate tasks into relationships of trust and demonstrations of trustworthiness, in the unforgiving realities of rural poverty in India the collective act of survival of such families needs to be contextualized within the debates about crippling care.

**Keywords:** care, disability, feminization

“She cannot do most of the things by herself. Tending to her and caring for her therefore is a big part of my work” (Gautami’s mother).

## Introduction

Care-giving and receiving raise complex questions and evoke much debate within feminist and disability studies literature. While Tronto (1993) and Sevenhuijsen (1998) have emphasized that care, vulnerability, and mutual dependence are central concerns of human life shared by all, disability studies has problematized care research as objectifying disabled people, who are positioned as dependent and unable to exert choice and/or control and therefore in need of care. Disability studies largely focuses on promoting the empowerment of disabled people and emphasizes the “disabling barriers” of society, including disabling environments and cultures that result in society’s failure to provide appropriate services and adequately ensure the needs of disabled people are fully taken into account in its social organization (Oliver, 1990, 2004). Societal barriers are both physical and ideological, and are enshrined within discriminatory and disempowering practices and structures that inhibit the full social participation and citizenship of disabled people (Kroger, 2009). Within disability studies, the understanding of independence focuses on self-sufficiency or the capability of

disabled people in terms of choice and control over how necessary help is provided (Morris, 1993). Thus disability studies scholars are critical of care service systems that, through the discourse of medicalization, empower medical professionals to sideline concerns around the right to independent living and availability of services. This reinforces traditional assumptions about people with impairments as needing to be cared for.

On the other hand, feminist ethics of care prioritizes interdependence, relationships, and responsibilities, and understands care as a socially just way of providing personal support for disabled people, one with transformative potential. Kittay (2011) questions the emphasis on independence and choice for disabled people who may find themselves dependent on others for self-care, economic security, and safety. Fine and Glendinning (2005) argue that “to recognize ‘interdependence’ is not to deny but to acknowledge relations of dependence” (p. 612). While the concept of care values interdependence, it also points to power dynamics within the carer-cared for relationship. Morris (2001) argues that some people’s experience of their bodies (their impairments) places them at much greater risk of losing their human (and civil) rights and makes them vulnerable to being denied a good quality of life. Yet the denigration of care and dependency often renders the work and value of the carers invisible, thus creating one oppression in the effort to alleviate another. Kittay (2002) argues that in a care relationship, it is not only the care receiver who is in a vulnerable position; caregivers are vulnerable as well, and at risk of devaluation and domination (Kittay, 1999). The devaluation of care within capitalist and patriarchal social structures increasingly places premium on autonomy, productivity, and individuality over relationality, thereby denying the emotional bond between two people that is closely associated with care work. Thomas (1999, 2004) highlights the fact that social behaviors and power relations that are enacted between “impaired” and “non-impaired” persons, for example in familial relationships, determines the meaning of relationships with others and has an effect on disabled individuals’ sense of self, self-esteem, and existential security. The concept of “impairment effects” recognizes that “impairments do have direct and restricting impacts on people’s social lives – restricting as judged against socially defined age-norms” (Thomas 2004). Such restrictions are distinguished from the restrictions, exclusions and disadvantages that people with impairments experience as a result of disability (Thomas, 2004). While the primarily western Disability Studies classifies social relationships between those designated impaired and those designated nondisabled, as exclusionary towards the former and privileging the latter, in Asian and other communitarian societies, such notions of individuality, exclusion and accommodation within relationships of care operate through distinctly different norms guided by cultural context, as we will see below.

Recognizing such tensions between the primarily individualist western societies and communitarian global south, we argue that disability studies needs to engage more fully with informal family care because the majority of care is provided informally in families and communities and has invisible costs attached to it, even in societies in which the state provides many services (Daly & Rake, 2003). Going further, we align with both Ghai (2001) and Grech (2009), who argue that the dominance of the British social model in disability

studies is unhelpful for the analysis of disability in the Global South. Western individualistic frameworks of care are often inadequate in explaining the ways in which notions of care are subsumed within familial and communitarian ethics in countries like India. Unlike in western contexts, early intervention and rehabilitation are inaccessible to most people. For Grech (2009), who sees impairment as the key issue for disabled people in environments where survival depends on physical labor, the political rhetoric of the social model risks rendering invisible the basic survival needs of disabled people in the Global South. In developing economies of the rural villages in our study, the total absence of care for persons with disabilities within a range of medical, rehabilitation and other institutions means that the responsibility for providing care falls on society, delivered largely within the institution of the family and specifically the mother. Communitarian societies that do not have formal care systems manage dependency collectively in a social context in which the public–private dichotomy is blurred (Chakravarti, 2008).

Alongside Sherry (2007), we call for culturally-specific examinations of disability and impairment. The meaning of disability in the Indian cultural context is embedded in multiple cultural discourses (Ghai, 2001), where notions of dependence and independence, and caring and being cared for are further complicated by impairment. Grech (2013) argues for a move beyond the individual and toward a recognition of different family and community structures while examining the lives of disabled children in the Global South. That is, everyday practices of care need to be contextualized within localized social codes and norms, including shared understandings of caste norms, religious, and cultural practices that shape the everydayness of care practices. The family emerges as the primary site for care, which here includes the management of impairment. In such a context, caring and receiving care becomes a paradoxical experience of enabling/constraint, love/duty, agency/dependence; a situation which is often further complicated by poverty and lack of access to resources.

Further, this paper approaches the care-giving and receiving relationship involving disabled people within families in rural villages in three Indian states with the understanding that care is composed of two indispensable elements: work and emotion (Graham, 1983). Using the framework offered by Thomas (1993, p. 665), which understands care as the unpaid provision of support involving work activities and feeling states, provided mainly, but not exclusively by women to dependent adults and children in domestic spheres, this paper explores the paradoxes of deeply emotional care relationships—dependence/independence, love/duty, paid/voluntary work. Erickson (2005) and Papanek (1979) point out how the twin processes of the valorization and devaluation of care and its association with “natural” feminine tendencies results in what is a curious paradox. This paper situates the care as sets of paradoxes within lived experiences of disabled girls and their mothers as primary carers in a context of abject poverty, a lack of resources and a society insensitive to the social needs of persons with disabilities. Care in such situations implies contradictions, where intimate interdependence signals culturally specific power relationships and constraints alongside prospects and opportunities. Moreover, the overdetermined construction of the mother in

India as the repository of unquestioning devotion and unfathomable care becomes a generative site to interrogate in the case of children with disabilities.

Within disability studies, the role of mothers of children with disabilities has often been pushed into a liminal space because they are often not disabled and yet they can experience forms of disablism (Ryan & Runswick-Cole, 2008). This indicates the need to explore the ways in which mothers of disabled children negotiate, manage and approach their daily lives, operating within culturally-specific mothering ideologies and disabling environments prevalent in the Global South in general, and rural India in particular. This paper examines the paradoxes of care and caring within families and communities with varying levels of training, knowledge and access to rehabilitation services, and therapeutic management of impairments. The dichotomy between the social constructs of care and neglect, for example, must be contextualized as a western creation. Within the complexities of the Indian social context, which involves intersecting strands of poverty, disability, and restrictive gender norms, such straightforward differentiations often do not work. Turning to the lived experiences of those who need help and those who do the work of care shows that caring is complex, and crips normative western assumptions about disability and care in a number of different ways, as we will see.

Crippling care offers a critique of perspectives which normalize violent and/or dehumanizing care regimes. Crip theory is seen to function as a resistance to the norm, and advocates the choice of an impaired individual to call oneself crip and experience pride, instead of hiding or feeling shame. Kafer (2013) argues that studies of disability frequently tone down the individual difficulties of disability, while addressing the very important large-scale issues, such as structural disablism and the built environment; this can mean that pain, loss, and internalised disablism are more often swept under the carpet (Wendell 1996; Hughes & Paterson 1997; Shakespeare 1998). A crip approach, however, may provide a way to include individual issues and bodily problems in a context that addresses both social and personal structures affecting the lives of disabled people.

McRuer (2006) believes that crip is a consciously adopted position, a critical questioning of the norm and how our society privileges the idea of a normative body. Crip theory therefore criticizes the standards that maintain the boundaries of the “normate”, which represents the idea of the able-bodied individual. The centrality of the able-bodied individual or what is in fact meant by one, however, is culturally specific. We argue that the idea of crippling needs to be contextualized within the specific settings within which it is applied. In the remote poor villages in which our respondents are located, caring is perceived as oppressive not just for those who receive care but also for the carer. In this context, crippling cannot exist as a binary to oppression, rather, it needs to be understood within and through it, in the limited possibilities in which care becomes a crip relationship. The article seeks to demonstrate that while the conditions of care are often disabling for the young girls as well as their mothers, both are able to crip care within the frame of their relationships and according to their circumstances.

The other point to consider here are the crippling possibilities and their relation to types of disabilities. Sandahl (2003) and McRuer (2006) suggest that the term “crip” includes those with physical, mental and sensory impairments. The questioning of categories in crip theory means that there is no conceptual difference between people with different types of disabilities. Yet McRuer (2006) has focused his work mainly on people with physical disabilities, who are able to express their voice, opinions and dissent clearly, and who dominate the international disability rights movement. On the other hand, there are other groups such as people with intellectual disabilities who do not have the same opportunity to understand what it means to embrace the stigma and to charge the word crip with positive meaning. In the cultural context that this article is located in, such a homogenizing approach to disabilities might be problematic. The specific understandings of ability and disability often provide different possibilities for crippling care.

Therefore Kafer’s (2013:4) “political/relation model” is more useful as it is flexible enough to fit the lives of disabled people, critiquing the power of medicine while acknowledging the need for medical care, and highlighting independent living without denying those who need assistance a voice. This model therefore accommodates the wide variety of needs of persons with intellectual impairments and multiple disabilities and their need for care, especially in terms of how disability is globally located as well as situated differently in particular places and spaces (Wendell 1996; Grech 2012). It is a task of this article therefore to situate the experiences of crippling outside a homogenous understanding emanating from Western experiences and to locate it in a very different cultural context. If crippling is the adoption of a positive disabled identity and representing the voices of the disabled, we ask how do these voices get represented—if the representation is not through oneself as such then does it not count? Also in the culturally specific context of rural poor households of eastern India where our study is located, can we understand crippling as relational made possible through agency shown by the interdependence of people caught within two oppressive structures?

## The Context

Our paper is based on fifty-eight qualitative case-studies of young girls with disabilities in poor rural households in eastern India. While it is important to recognize that India is a large and diverse country with significant cultural diversities, some of the observations made in this article will hold true for remote poverty-stricken areas in other parts of the country as well. Participants were identified through organizations working in rural areas within these three states based on criteria laid out for inclusion in the study, which included the economic status of the family, severity of impairment and access to rehabilitation and other support. In order to maintain confidentiality and abide by the standards of ethical research all names mentioned here are pseudonyms. Also the names of the organizations have not been revealed here on similar considerations. Data was collected through intensive fieldwork conducted between October 2015 and March 2016. Fieldwork involved a series of sustained interactions with families, children with disabilities, and primary caregivers using qualitative research techniques like in-depth interviews and participant observation. Research

participants include young girls (ages 4-17 years) across a range of physical, mental, and sensory impairments and their families in West Bengal, Jharkhand, and Odisha. Families that participated in this study live primarily in remote rural areas and are poor—they live in one room tenements, sometimes pucca, and with little or no access to toilets. Most of the families have limited access to education and little awareness of their rights or rehabilitation facilities available for their children. The interplay between a child's impairment and the socio-economic conditions of the families and communities in which they live constrains the type and quality of care received by disabled girls in the study. Further, many girls who participated in this study are non-speaking and do not write, and thus rely on their primary caregivers to interpret their communications with others for them. Thus, while centrally recognizing the personhood of disabled girls, this paper focuses on the experience of care primarily from the perspective of and interpretation by mothers. This enables us to understand the dehumanizing nature of care for mothers and their daughters while at the same time locating possibilities for crippling it. The emotions of love, tenderness, and mutual emotional dependence often rescue the process of care from becoming a mechanical set of duties making care relational and multi-layered. We also explore the ethics of care and intersections of gender and class which lie at the core of the lived experiences of disabled girls and their primary carers.

### **Dividing Care?**

In developing countries, the experience of disability and hence the need for care is significantly influenced by access to early interventions for development and rehabilitation. While in the western countries, disability studies has sought to critique and question discourses and institutions of early intervention, we assert that privilege of access to such services enabled the critics to find their voices. The tensions in western framing of binaries of autonomy/ dependence and medical/ social are experienced differently in remote rural contexts of countries like India. While, on the one hand, the cultural connotations of autonomy and dependence are experienced in specific ways in such communities, on the other hand, access to early interventions and rehabilitation is structured not only by provision of services but also by one's social location. Access to early identification and early intervention was limited for most of the girls in our study due to financial and knowledge constraints and lack of access to support services within their local contexts. Everyday material realities also precluded awareness about these possibilities. Kafer (2013) warns against invisibilized the personal experiences of disability through the overemphasis of structural constraints. However, the structural constraints in this case have affected the everyday lives of the girls, with implications for type of care required on a daily basis which in turn determines the crippling of care.

Girls with visual impairments or deafness experienced less functional restrictions, and hence were better able to manage their personal care than more profoundly affected girls with locomotor impairments such as cerebral palsy, as well as those with intellectual impairments and multiple disabilities. These girls required support in almost all physical aspects of everyday life, which means a lot of time and attention needs to be devoted to these care

activities. Crippling care has at its core a critique of normative understandings of development, function, severity and of disability itself. While the differences of impairment and the access that the girls could therefore have to life had some variations, in the course of the paper we hope to show that the life experiences of the girls and their carers offered a similar critique, though tentative and often invisible to such homogenizing notions of ability. Disability was one of the many constraints of poverty for these families and thus families focused on adopting strategies that would minimize the need for care as a necessary condition of their socio-economic setup. In such remote locations, mobility or lack of it is not just about the nature of impairment but also its connection with the family's survival. In poor families, this intense level of care is considered a constraint not only in terms of time, but also in terms of the lost labor of those doing care-work, labor that could be used to provide a better quality of life for entire families.

Care is most noticed when it is absent and most appreciated when it can be least reciprocated (Kittay, 2005). Girls with both severe locomotor and mental impairments require full time care and support by their family members for fulfilling their basic daily needs of hygiene, feeding, clothing, and shelter. Tara (age 10) lives with her family in a remote rural village in Jharkhand. As she cannot move about by herself, she sits in one place while her parents, the primary caregivers, feed her, bathe her, and clean her after she uses the toilet). Usha (age 9) has cerebral palsy—she needs assistance in all personal care activities like eating, dressing, using the toilet, and bathing.

In these families, given the need of girls with significant impairments for continuous care, one member of the family is constantly engaged in providing the care required for the disabled child. It is usually the mother who assumes the responsibility for this role. This is almost normalized in rural India where tending to the child forms the core of mothering, a function which increases in significance with a disabled child. In economically poor families, however, this means that there is one less earner, which has consequences for the survival of the entire family (Ghosh & Banerjee, 2016). Arya's mother regrets that her care-giving responsibility severely obstructs her chances to earn money, which in turn could have been used to provide her daughter with better care and support. In contrast, within the task of caring for their disabled daughters, fathers, and siblings seem to play a peripheral role. In many cases the fathers distance themselves from the entire process of tending to their daughters' care needs, thus reinforcing gender stereotypes and cultural taboos. Often, this is connected not only to the father's role as provider within the family but also to status within community. Shrimati's father works in the army and is away from the family for a considerable part of the year from their village in Odisha. He takes no responsibility for her care needs, and shies away when asked. "I am not home all the time, her mother looks after her." However, longer conversations with family members reveal that because he is concerned about his status in the tribal community, he does not want attention drawn to his disabled daughter. In fact, Shrimati's mother has had to discontinue the medicines for Shrimati's (age 16) epilepsy as her father is not interested in procuring them for her from the city where he is posted. Without him providing the medicines it is not possible for the mother

both economically and in terms of access (these medicines were not available in the village where they lived) to procure them. This specific instance also illustrates that caring functions are often divided along public-private lines which then map onto gender stereotypes. The public stature of the father and his concealment of his daughter's disability, prevents him from procuring necessary medicine and compromises the well-being of his daughter.

Among our participants such cases of abject neglect are, however, less common. What is more commonly seen are fathers playing a secondary role in the care of their disabled children. Some of our respondents, such as Shila's (age 10) mother, said that their husbands do not extend any help in terms of "care". "Yes, he is very attached to her, he loves her a lot, he buys her whatever she wants and contributes financially, but taking care of Shila is only my responsibility." In her description of her husband's role, Shila's mother makes a separation between "love" and "care", challenging the dominant Indian cultural norm that care is based only on feelings of love. She specifies that the child is not neglected by the father, who shows an emotional attachment to her, while the physical tending of her daughter remains her responsibility. Thus, the mother classifies care as responsibility and probably even work which is normalized in its gendering.

The supplementary support given by fathers in helping their disabled children further entrench gendered notions of care. In the remote rural setting in which most of our participants live, division of responsibilities meant that fathers usually provided primary economic support which enabled whatever little access to institutionalized form of care, while mothers looked after the physical and emotional well-being of the child. This division of work mapped onto gendered understandings of what care denotes. The role of fathers was seen more as providers of support in terms of seeking rehabilitation and access to assistive devices. Munni's father fashioned a walker from bamboo for her. Munni (age 16), who has cerebral palsy, can stand upright holding it and also walk a few steps if she so wishes. Lata's father made a wooden draw-cart suitable for the rural terrain in which they live. Lata (age 15) can sit on it and hold onto the side bar while somebody pulls it by ropes to take her around. Sometimes her friends take her out in this cart to the playground.

The only family in the study where both parents take equal responsibility for the care of their disabled daughter is in urban Kolkata. Mum's (age 18) father helps her mother provide physical care and mental support to their daughter with cerebral palsy. As Mum's mother says, "It is imperative that both the parents are able to take care of the child." Both parents have university degrees and have access to information which facilitated their sharing of caring functions. Even in this case, however, the mother retains the major responsibility for planning and delivering care. This gendered nature of care is aggravated by the local context of poverty, with underdeveloped resources and a lack of physical and financial access to a basic minimum standard of living. The next section demonstrates how care is constrained by these factors in the everyday lives of the families.



## Constraints of Care

In poor families especially of rural India where manual labor provides the primary source of livelihood, one of the reasons being born with or acquiring disabilities in childhood is seen as catastrophic is because of the economic implications of caring for the child and managing the impairment. This is exacerbated by a general lack of awareness about possibilities for rehabilitation. One significant barrier for poor families in rural areas is the lack of basic amenities within the home. Many rural areas, such as Jharkhand and Odisha have no toilets. This means additional care responsibilities for the mothers as they have to either carry the child to distant fields used by the village as a toilet or attend to their toilet needs at home. A further complication is the fact that many of the disabled children in the study with severe mental challenges often do not have control nor can they vocalize their toileting needs. Hemanti's mother cries, "In winter my hands get swollen as I have so much washing to do throughout the day. Now I am getting older I need more time to complete the tasks."

The onset of puberty adds to mothers' roles in the physical care of their daughters. The cultural context of rural India comes with a series of taboos and proscriptions around menstruation relating to notions of purity, pollution, and shame (e.g., Bean, 1981). Mothers who have to provide considerable support to their disabled daughters pray for the delayed onset of puberty. In a culture of silence around sex and sexuality within India generally, all girls, including disabled girls and especially those living in rural areas, have minimal knowledge of the reasons behind menstruation. When Munni (age 12), a visually impaired girl started her period for the first time, she thought she had lost urinary control and complained to her mother, who then showed her how to use the sanitary napkins and clean herself during that time. In rural India most women still use cloth as sanitary pads and for disabled girls this is often a necessity not only for financial reasons but also for their particular physical embodiments. For many girls, who can afford only basic quality drawstring panties, thick cotton pads offer better protection during periods, implying less work for the mother. For disabled girls who are able to manage some part of their personal care, mothers teach them like their other daughters, to take care of their menstrual cycles and associated issues. In case of disabled girls who require significant support however, mothers have to provide complete care. Cultural taboos around menstruation in India, which involves avoidance, proscription from certain familial spaces and activities along with a culture of silence, also affect the ability of mothers to seek medical help for disabled daughters when there are problems with the monthly cycle.

Lack of medical facilities and access to treatment creates further pressures on familial care situations. Rukmini (age 18) lives with her family in a remote rural area, so her parents could not access treatment facilities both due to poverty and lack of awareness. As Rukmini has no toilet control, she regularly soiled her clothes and her parents used to come back from work to find her legs full of insect bites. One day when they noticed that ants had gathered on the stool that Rukmini had excreted in the compound, they took her to a doctor who diagnosed that Rukmini has severe juvenile diabetes. This illustrates how seeking professional care is a

matter of accident in such contexts. Despite the diagnosis, they have not been able to provide proper treatment for her due to a lack of financial resources. The circumstances of their lives have therefore limited them to prevent harm to her by ensuring that she is not bitten by insects, which will lead to further medical consequences.

Care-giving becomes even more intensive and complex if there are multiple disabled people within a family. Both Khushi (age 9) and her brother have intellectual impairments and have been having epileptic seizures since infancy. While Khushi cannot move about at all, her brother is more mobile, and can perform some of his own self-care. As their mother has to cope with caring for two disabled children along with other household chores, she often asks her impaired son to protect Khushi from the flies and mosquitoes that keep biting her. Rather than infantilizing the disabled child, parents often give them the responsibility to look after the well-being of their profoundly disabled siblings. Similarly, three of Mumtaz's children have different forms of locomotor disabilities. Since her husband works in another city, she is left with the care and responsibility of all her children. As her teenage daughters are now able to manage their own personal care, Mumtaz can focus all her attention on her son, who is more profoundly disabled. In Mumtaz's case, the remittance that her husband sends home enables her to access better health care for her children in terms of surgeries, medicines and mobility aids like callipers. In the limited situation of these families, these acts of caring for their siblings undertaken by the disabled children has to be seen as a joint act of crippling by the primary carer—i.e., the mother, the secondary carer and the cared for. The understanding of constraints highlighted in this section is central to understanding crippling care in this cultural context. As argued before, crippling care here is not outside the constraints but is very much shaped by and in turn shapes these constraints.

### Labors of Love

As an attitude, caring often denotes a positive, affective bond and investment in another's well-being. Care, as a virtue, is a disposition manifested in caring behavior (the labor and attitude) in which "a shift takes place from the interest in our life situation to the situation of the other, the one in need of care" (Gastmans, Schotsmans, & Dierckx de Casterle, 1998, p. 53). Relations of affection facilitate care, especially within families. As mothers are assigned the responsibility of caring for their disabled children, the emotional bonds between them become intensified and they develop mutual understanding which may often be invisible to outsiders. Communicating with their non-speaking children with disabilities is one dimension of such intensified relationships and provides illustrations of understanding crippling through a relational lens. Through this communication, daughters are able to exercise some degree of opinion/choice in the process of caring. Arya's (age 15) mother can differentiate between the sounds of her daughter's cries. "She makes a particular sound if there is less salt in her food—she does not like it. She also cries if left alone at home." Rukmini's mother says while no one else can understand, she can make out when her daughter is smiling as she feels comfortable. This expression of inter-relationship shows that caring is not just a passive process but a relational one which is often fundamentally shaped by the personhood of the daughter. The terms of care in many cases sets the terms for the

mother-daughter relationship.

But the responsibilities of care and caring for can, at times, become a constraint for those doing the carework. As girls grow up and become heavier, mothers find it difficult to provide physical care, which often involves lifting grown-up daughters to help with all activities of daily living. Arya (age 15) has to be fed lying down on her mother's lap. Her mother now finds it difficult to fit her on her lap as she has grown both tall and heavy, and it is often a strain to hold her in the lying position. Mothers often carry their children whenever possible even when they move in the neighborhood. Many mothers have stopped going out of the home because their children have become too big to carry around, thereby becoming confined to their own homes and caring roles. Similarly, Aparna (age 16) and her mother, face social isolation as she has become too heavy to be carried around by her elderly father and mother. They are unable to negotiate the two flights of stairs in their home to get out of the house. The care work undertaken by mothers is made more tedious by the lack of supports for both mother and child, and results in mothers forgoing pleasures in their own lives to compensate for other essential structures of support that are missing.

Questions around constraints of care are, however, not straightforward. Notions of sacrifice constructed as a core of good mothering in the gendered cultural framework of India are internalised by many of the women in the study. The patriarchal construction of motherhood as embodying sacrifice and selflessness is valorised. Erickson (2005) illustrates how caring as emotional labor, since it is classified under natural feminine tendencies, is erased under patriarchy. The internalization of gendered performances of mothering, and the privileging of these motherhood ideologies and values, forms the core of the care work of mothers towards their disabled daughters in this study. The "sacrifice", because of its valorization in the shared understanding of the community, cannot be resented within such a framing.

Emotional bonds between those who care and those who need support in this study ensure that the uniqueness of children with intellectual impairments is accepted by their families without protest, even when it affects them adversely. Gauri doesn't sleep until late at night and wakes up very late. Her parents, after tiring daily labor in addition to her care, prefer to go to bed early, but Gauri stays awake. Her mother says, "Once we close our eyes, Gauri starts to pull my hair, poke her father in the eyes and forces us to stay awake till one or two o'clock at night." Yet there are few regrets and a complete acceptance of their child who is unable to mentally comprehend the demands she makes on her parents. While this can be a manifestation of the internalisation of a "natural mothering role", it also needs to be placed in the context of the multiple difficulties that most of these families face. Within harsh conditions of existence, looking after a disabled child is one of the many impediments of daily life. However, the task of caring for a disabled child is one that is taken up with few complaints by the parents and other family members based on ideas of love, duty and familial bonds. What this obscures, often, is that the care provided and received can, through the infantilization and assumed dependency of disabled people, lead to a limiting of possibilities for some disabled children. In the next section we explore this process of over-care and

protection.

### Care that Constrains

Across the globe, disability is usually equated with infantilism. However in the cultural context of India, this becomes further complicated as notions of dependence and independence are understood and interpreted through identity markers of different status positions that an individual occupies at different stages of their lives. In a communitarian society, where individualist understandings of personhood and independence are subsumed under communal ways of life and determined existence, a crip perspective critiques disabled children as being denied their personhood. Cosseting and overprotection by families, especially mothers, often becomes a barrier to self-growth and progress for these children. Rather than being discriminated against negatively vis-à-vis other children in the household, what is evident in most cases within our study is that disabled children are given special treatment, at times in excess of what is required. This overprotection emerges from viewing caring as mostly a passive, one-way relationship between the giver and receiver of care. Munni is not allowed to do any of her personal care work—her mother brings water and bathes her, takes her to the toilet in the fields and cleans her afterwards, helps her change her clothes and is there for any other demand she may make. Rama's (age 16) mother does not allow her to do any work by herself, fearing that she might hurt herself in the process. This has affected Rama's wish to be involved in her own and her family's work.

The protectiveness of Lata's (age 15) family is evident in the way her family members always insist that she is not able to do things because she cannot walk, "She cries in pain when she tries to stand straight." They acquired a wheelchair for her but emphasize, "It is too high for her to sit so we could not use it at all." The family refused special shoes and callipers for her as they were worried that she would experience pain. Her father says, "How can she walk? How will she hold the crutches?" This kind of over-protectiveness on the part of families, although offered with the best of intentions, often prevents girls with disabilities from achieving different degrees of independence and thus from making the most of opportunities in life. For those who push their children, the results are obvious. Lipika's (age 17) mother revealed that a tricycle was offered to her daughter who has moderate cerebral palsy but she refused it. Lipika's mother felt that, "If she got the tricycle then she would never walk." She ensured her daughter's comfort when she was walking with callipers and crutches. "I tied a cloth at her waist which I held at the back, so that she would not fall."

Over-protectiveness and constant negation of a child's capabilities means that many disabled people remain in need of care and protection throughout their lives in the socio-cultural context of India. When asked, eighteen year-old visually impaired Kokila felt that, if trained, she could make ropes from sabai grass, which is the most common activity in their area. She complains that nobody in her family teaches her to do any kind of work. Her mother immediately responds, "How can she understand only by touching whether the ropes are made properly or not? Can she ever work like any of us?" This denigration of abilities has made Kokila reluctant to assert herself or confidently select her own life-course. The

comparative “like us” is a manifestation of the embeddedness of an ableist society’s normative evaluations and reinforces a clear binary between able-bodied and persons with disabilities, of us/them, ability/disability. Similarly, Saloni (age 9) has become so used to her mother and sister catering to her every need that she gets angry if her mother asks her to do any work. Her mother said, “I know it is difficult for her to do the work. One day, in anger over her uncooperative body she asked me to kill her. Since then I never ask her to do anything.” While disability studies has challenged the notion that impaired bodies are helpless bodies, it is evident that the notion of helplessness and dysfunctionality here are the products of the experiences of impairment as equated with infantilization and the negation of possibilities for self-sufficiency and personhood within some familial care situations.

The cultural infantilization of disabled people rendering them unable or unwilling to attend to basic needs accentuates the experiences of disability in their everyday lives, affecting their confidence. As is evident from Kokila’s comments, more than her visual impairment, it is the excessiveness of care that stands in the way of her chances for self-sufficiency. In a curious contradiction, the sense of helplessness around disability is foregrounded through an excess of caregiving.

### **Crucial Parental Concerns**

For girls with profound impairments, parents are concerned not only with providing constant tedious care but also with preventing abuse. More crucial is their concern to ensure that they are able to prevent self-harm. Anupama (age 14) was found missing one evening from her home and after much searching her father found her roaming near a dam one kilometre away. Similar incidents had happened twice before. Her mother explained that Anupama does not do this intentionally; she keeps moving and then cannot remember the way back home. Once, during a monsoon, she fell into the clogged well and was saved only because a local boy heard the sound of her splashing arms in the water and called her father for help. Such life and death situations highlight the limited infrastructure within rural communities.

Security concerns dominate the minds of the families of girls with moderate intellectual impairments because they are vulnerable to sexual abuse both in childhood and adolescence. Karima’s mother found her talking to a stranger who tried to entice her with the promise of food. Out of fear for her child, she started escorting Karima (age 10) to and from school after alerting the school authorities that such a man was preying on female students. Thus, mothers of children with intellectual impairments have to be constantly alert for their children, especially if they are girls, as the threats to their security are great.

Parents worry about the future of their severely disabled daughters. Arya’s mother asks if there is a disability grant available to Arya so that her siblings can be “bribed” into taking care of her. The need to “bribe” her other siblings to take care of their disabled sister contradicts the communitarian understanding of care that has dominated mainstream discourses of care in India. It illustrates how the task of caring is not always naturalised and

emotional but requires structures and incentives. Gauri's (age 14) parents hope to find a state sponsored residential facility where she can avail care and protection after their death. Vani's (age 16) story highlights how care is complex, and how structures of care can turn into those of abuse:

Vani's mother ran away after her father's death, leaving the small girl with severe mental and visual impairment with her aging grandmother. The elderly grandmother works irregularly and spends most of her income on alcohol, as a result of which, they live in destitution. The grandmother loves Vani very much and takes care of her as best as she can, even if it means going hungry herself. Somewhere between her grandmother's absence due to work and her alcoholism, Vani was sexually assaulted twice by an influential man of the village. Villagers say that he gives Vani's grandmother money to buy food for Vani when she is ill, and so no one is ready to protest against him.

Vani's life story as narrated by neighbors and her caseworker, illustrates the complexity of care alongside support, and the many paradoxes that lie at its core, where the family which is projected as a "natural" center of love and care, becomes the space for inadequate care and neglect. Orphaned, and having profound mental disabilities and restricted mobility means that Vani is completely dependent on her elderly grandmother. As the primary caregiver, the grandmother is curtailed by poverty, old age, and drinking habits. The abysmal economic conditions faced by Vani's family force them into a curious relation of dependence with the perpetrator of abuse, thus making him a stakeholder in Vani's care. The complex nature of the structures through which care is delivered becomes entangled in the relationship with the perpetrator of sexual abuse. The carer therefore cannot always be clearly distinguished from the abuser. It is often the very structure of abuse that functions as the structure of care, complicating the binary between carer and abuser. While Vani's case is a particularly stark example of this, the ways in which care is provided within other families also hides a patronizing, dehumanizing, and humiliating notion of disability. It also raises the question of how girls like Vani can crip care? As McRuer (2006) argues, the possibilities for crippling care are immense for persons with disabilities but raise the crucial question whether girls like Vani can understand how to charge the word "crip" with positive aspects. In such cases can we consider the work that her case-worker and destitute grandmother does with her to be efforts of crippling? The more obvious illustrations of crippling care in the next section makes this contrast an important concern for advocates of crip theory.

### **Crippling Care**

Within these limiting notions of care there are, too, narratives of hope. After two of their children were born blind, and one died at the age of three years, Munni's parents decided to stop having children and concentrate on Munni's upbringing. This was not about physical tending, but instead about acknowledging Munni as a human being with life chances. As Munni's mother said, "I want her to study and learn so that she can help herself. Some of our relatives said, 'She cannot do anything, she doesn't have a future.' My husband and I decided

we will put in all our efforts to raise Munni so that she can take care of us.” She further elaborates, “I want her to be self-dependent and lead a respectful life, that’s why I constantly push her to be more self-reliant. Yes, she has a disability but she has to be a strong person.”

In a context where the entire core of society is premised on ableist terms, disability—especially in poorer households—spells insurmountable difficulties for children as well as their parents. Advice of willful neglect of such children is commonplace. In such settings, the very act of living and strategizing by children and their primary carers constitutes resistance. In this scenario, Munni and her parents challenge a dehumanizing notion of care. Munni and her parents—even if in limited ways through their decisions—critique the normate in a society where everything is premised on ableist terms. The focus on self-reliance, respect and strength as a person, cripps the notion of care. By foregrounding transgressive possibilities and a collective agency, the family views care as relational.

Mum’s mother recounts that she gets into arguments with her daughter regarding everyday choices of clothes, food, etc., not just for Mum but for herself as well. Once again, this mother-daughter relationship illustrates a crippling of care practices. In this case, care is relational as there is recognition of the individuality of the disabled daughter, who may be dependent for all her individual needs on her parents, but is still able to voice her choices, which are respected. These few instances illustrate how care becomes more than a one-way exchange structured by poverty and cultural constraints, and instead is conceptualized as exchanges in which those who perform the care work and those who receive support are mutually constituted through learning and exchange. This establishes the care relationship as symbiotic and reciprocal (though not necessarily symmetrical).

## Conclusion

Disability studies has powerfully illustrated how the notion of caring for people with disabilities has justified abuse in various forms. Our research, which draws from feminist political economy and ethics of care, however illustrates that there is no unilinear trajectory for understanding care relationships. The responsibility of caring for disabled children within disabling contexts can be limiting for both the receiver and the giver of care, and can work to reify care roles in ways that elide how disability might also cripp care, as the previous section illustrates. Within disabling contexts of care, care work is feminized labor that increases the workload of the primary carer, and can also signify a deficit of agency on the part of the disabled recipients.

Care as a form of feminized, naturalized labor operating through patriarchal logics masks the exploitation inherent within it. It is further constrained by equating care of disabled children as a passive relationship. The notion of crippling care allows us to explore the two-sided exploitation within a patriarchal, neo-liberal (state withdrawal from services automatically limits the marginalizeds’ access to service) notion of care. While the illustrations of care in this paper might suggest the existence of a power hierarchy between the primary carer and cared for (i.e. the mother and the disabled daughter), the reality is far more

complex. Studies in the West have shown that those thrust into the unexpected “career of caregiver” for a child with a disability (Boaz & Muller, 1992; Hoyert & Seltzer, 1992; Keith, 1995; Pruchno, Patrick, & Burant, 1997) experience stressful life situations that can have negative consequences if health care and social service systems are inadequate. Becoming an informal caregiver is not typically chosen or planned; people do not envision being in a caregiver role when they project themselves into the future. The role is taken up by them through the naturalization of familial ethics of care without any additional training or resources available to them. In the context of the remote rural areas of the study, becoming an informal caregiver manifests itself in conceiving of care in terms of physical tending to the disabled girls rather than in focusing on their autonomy to make care choices. To conceive and perform care as a process in which the autonomy and personhood of the disabled girl is developed through a reciprocal process is a more time-consuming process.

This process also requires a sophisticated understanding of individuality and disability which is neither available nor applicable in the cultural context of poor households of rural India. In the situation of rural poor India—constraints with limited resources and limited understanding of possibilities in the lives of the disabled children—it becomes easier for mothers to limit care-giving to a performance of physical tending akin to other household tasks. This severely curtails possibilities available to their disabled daughters.

Moreover, an informal caregiver lacks rights, privileges and prerogatives that come with a formal career status. Caregiving duties, in most cases, are subsumed under natural mothering responsibilities and rendered invisible as housework. The role also differs from occupational careers as it is driven not by personal ambition, but rather by the progression of the impairment and the functional dependencies it creates. Finally, a caregiving career cannot be entered into and left at will, especially by women, who shoulder the major burden of caregiving responsibilities in the home. It is therefore our contention that this patriarchal notion of care actually marginalizes both the actors while further embedding this dominant care ethic.

Our stories demonstrate the urgency with which such families require not just financial and medical support from the state but also psychological support services. This is all the more acute in a context where the neoliberal state is rapidly withdrawing from care and the erstwhile familial structure disintegrating due to increasing nuclearisation and urbanisation. The vulnerabilities of these families become even more pronounced with their marginal social position and harsh realities of their impairments.

At the same time, the constraints of these experiences do not disqualify the possibility of agency. Herein lies the crippling of care. In a context where life-chances are conceived in ableist terms, disabilities spell dual marginalities for the girl and her family. In the unforgiving realities of rural poverty in India, the collective act of survival of such families becomes a tale of resistance against all odds, a pushing back against stereotypes of disability. The lack of facilities, sensitization and access to resources probably preclude a more radical take towards the lived realities of these disabled girls, but in the absence of such grand acts of



resistance, the everyday survival of these girls and their mothers show us that resistance can take such invisible forms too. Proponents of crippling care have spoken of the transformative potential of the notion of crippling. In the context of the constraints that we were researching in, it is not useful to map crippling through transformations, big social changes or qualitative improvements. This, however, did not necessarily mean that there was no transformative potential in these acts. Crippling care in these contexts was made possible through everyday acts of survival.

Further, these largely passive notions of care are complicated by relations of affect. While an unpracticed eye might not be able to map the agency of the girls in this “cared for” relationship, the ties of intimacy between the mother and daughter often enables the latter to communicate her needs, wants, likes, and dislikes to the mother, and assert their importance. By seeking to frame her care within these preferences, she no longer remains a passive recipient of the care process. While talking of this as autonomy might be an exaggeration, she is able to exert her opinion in many cases. This can be seen as being akin to forming alliance which has agential values. Williams (2001) notes that often care is rejected in favor of alternative concepts such as empowerment (particularly where it emphasises choice and control) and support. She feels that while the ethics of care emphasises interdependence and the relational, disability activists using the social model of disability have argued for the strategic centrality of independence, autonomy, and control over one’s life. But in this case, there is an important distinction between conceptualizations of autonomy as self-sufficiency, and autonomy/independence as the capacity to have choice and control over one’s life (Williams, 2001). This alludes to feminist care ethics (Pettersen, 2011) which perceives care as a relation of intimacy. While we are aware of the oppressive equations of disability and dependence which can be masked within this ethics, we contend that a true feminist care ethic has at its core mutual dependence and reciprocity.

An examination of the questions of care and caring within the lived experiences of the families and communities in this study illustrates how the process of care is multilayered and paradoxical and cannot be understood by situating it within binaries. Both the carer and receiver express agency through strategies that they use singularly and/or together to manage their impairments and disabling circumstances. The care relationship between two people is enhanced by the affective bonds of empathy, emotional responsiveness, and perceptual attentiveness that transform unpleasant intimate tasks into times of trust and demonstrations of trustworthiness, gratifying and dignifying to both those who provide care and those who receive care.

**Dr. Nandini Ghosh** is an Assistant Professor of Sociology at Institute of Development Studies Kolkata. She has a Bachelor’s degree in Sociology from Presidency College Kolkata and a Master’s degree from Calcutta University. She completed her PhD in Social Sciences from the Tata Institute of Social Sciences Mumbai in 2008. Her areas of interest are qualitative research methodology, sociology of gender, marginalization and social exclusion, and social movements.

**Dr. Supurna Banerjee** is an Assistant Professor in the Institute of Development Studies (IDSK) since 2014. She completed her PhD from University of Edinburgh on gendered labor and resistance in tea plantations of Dooars. Her research interests are primarily gender, labor, violence, migration, and urban spaces.

## References

- Bean, S. S. (1981). Towards a semiotics of 'purity' and 'pollution' in India. *American Ethnologist*, 8(3), 575-595.
- Boaz, R. F., & Muler, C. F. (1992). Paid work and unpaid help by caregivers of the disabled and frail elderly. *Medical Care*, 30(2), 149-58.
- Chakravarti, U. (2008). Burden of caring: Families of the disabled in urban India. *Indian Journal of Gender Studies*, 15(2), 341-63.
- Daly, M., & Rake, K. (2003). Gender and the welfare state: Care, work and welfare in Europe and the USA. Cambridge: Polity Press.
- Erickson, R. J. (2005). Why emotion work matters: Sex, gender, and the division of household labor. *Journal of Marriage and Family*, 67(2), 337-351.
- Fine, M., & Glendinning, C. (2005). Dependence, independence or interdependence? Revisiting the concepts of 'care' and 'dependency'. *Ageing and Society*, 25(4), 601-21.
- Gastmans, C., Schotsmans, P., & Dierckx de Casterle, B. (1998). Nursing considered as moral practice: A philosophical-ethical interpretation of nursing. *Kennedy Institute of Ethics Journal*, 8(1), 43-69.
- Ghai, A. (2001). Marginalisation and disability: Experiences from the third world. In Mark Priestley (Ed.), *Disability and the life course: Global perspectives* (pp. 26-37). Cambridge: Cambridge University Press.
- Ghosh, N., & Banerjee, S. (2016). Girls with disabilities in India: Living contradictions of care and negation. In K. Kannabiran and A. Ghai (Eds.), *India Social Development Report: Disability Rights Perspective* (pp. 60-75). New Delhi: Oxford University Press.
- Graham, H. (1983). Caring: A labour of love. In J. Finch and D. Groves (Eds.), *A Labour of Love: Women, Work and Caring* (pp.13-30). London: Routledge & Kegan Paul.
- Grech, S. (2009). Disability, poverty and development: critical reflections on the majority world debate. *Disability & Society*, 24(6), 771-784.
- Grech, S. (2013). Disability and childhood in spaces of poverty: critical perspectives on Guatemala. In T. Curran and K. Runswick-Cole (Eds.), *Disabled Children's Childhood Studies: Critical Approaches in a Global Context* (pp.89-104). London: Palgrave Macmillan

- Hoyert, D. L., & Seltzer, M. M. (1992). Factors related to the well-being and life activities of family caregivers. *Family Relations*, 41(1), 74–81.
- Kafer, A. (2013). *Feminist queer crip*. Indiana: Indiana University Press.
- Keith, C. (1995). Family caregiving systems: Models, resources, and values. *Journal of Marriage and the Family*, 57(1), 179–89.
- Kittay, E. F. (1999). *Love's labor: Essays on women, equality, and dependency*. New York: Routledge.
- Kittay, E. F. (2002). When caring is just and justice is caring: Justice and mental retardation. In E. F. Kittay and E. K. Feder (Eds.) *The Subject of Care: Feminist Perspectives on Dependency* (pp. 257–76). Lanham: Rowman & Littlefield.
- Kittay, E. F. (2005). Equality, dignity and disability. In M.A. Lyons & F. Waldron (Eds.), *Perspectives on Equality The Second Seamus Heaney Lectures* (pp. 93-119). Dublin: The Liffey Press.
- Kittay, E. F. (2011). The ethics of care, dependence, and disability. *Ratio Juris*, 24(1), 49–58.
- Kroger, T. (2009). Care research and disability studies: Nothing in common? *Critical Social Policy*, 29(3), 398-420.
- McRuer, R. (2006). *Crip theory: Cultural signs of queerness and disability*. New York: New York University Press.
- Morris, J. (1993). *Independent lives? Community care and disabled people*. Basingstoke: Macmillan.
- Morris, J. (2001). Impairment and disability: Constructing an ethics of care that promotes human rights. *Hypatia*, 16(4), 1–16.
- Oliver, M. (1990). *The politics of disablement*. Basingstoke: Macmillan.
- Oliver, M. (2004). If I had a hammer: the social model in action. In: J. Swain, S. French, C. Barnes and C. Thomas, (Eds.) *Disabling Barriers – Enabling Environments* (pp. 7-12). London: Sage.
- Petterson, T. (2011). The ethics of care: Normative structures and empirical implications. *Health Care Analysis*, 19(1), 51-64.
- Papanek, H. (1979). Family status production: The 'work and 'non-work' of women. *Signs: The Labour of Women, Work and Family*, 4(4), 775-81.
- Pruchno, R., Patrick, J. H., & Burant, C. J. (1997). African american and white mothers of adults with chronic disabilities: Caregiving burden and satisfaction. *Family Relations*, 46(4), 335–46.

- Ryan, S. & Runswick-Cole, K. (2008). Repositioning mothers: mothers, disabled children and disability studies. *Disability & Society*, 23(3), 199-210.
- Sandahl, C. (2003). Queering the crip or crippling the queer? Intersections of queer and crip identities in solo autobiographical performance. *GLQ: A Journal of Lesbian and Gay Studies*, 9, (1-2), 25-56.
- Sevenhuijsen, S. (1998). *Citizenship and the ethics of care: Feminist consideration on justice, morality and politics*. London: Routledge.
- Sherry, M. (2007). (Post) Colonizing disability. *Wagadu*, 4, 10-22.
- Thomas, C. (1993). De-constructing concepts of care. *Sociology*, 27(4), 649-69.
- Thomas, C. (1999). *Female forms: Experiencing and understanding disability*. Buckingham: Open University Press.
- Thomas, C. (2004). Developing the social relational in the social model of disability: A theoretical agenda. In Colin Barnes and Geof Mercer (Eds) *Implementing the Social Model of Disability: Theory and Research* (pp. 32-47). Leeds: The Disability Press,
- Tronto, J. (1993). *Moral boundaries: A political argument for an ethic of care*. London: Routledge.
- Williams, F. (2001). In and beyond new labour: Towards a new political ethics of care. *Critical Social Policy*, 21(4), 467-93.