

Disability and Mothering: Embodied Knowledge

Rachana Johri

Abstract

The relationship between feminism and motherhood has not been without its complexities. These acquire additional layers when disability is introduced as a third aspect of this relationship. While feminists, from Adrienne Rich onwards, have critiqued the social construction of motherhood in a world that valorizes mothers without granting them any subjectivity, women with disabilities are rarely imagined as capable of care. This is an exploratory article on the disabled woman's right to be a mother. It is based on secondary literature to suggest that rather than be seen as abject and incapable of mothering, women with disabilities may be thought of as potentially feminist in their maternal practice. As such, mothering with a disability interrogates the normative discourse of motherhood and care.

Author Profile

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Jacqueline Rose (2018) looking critically at the relationship of mothers with Western culture writes, 'mothers are almost invariably the object, either of too much attention or not enough'. While mothers are often absent from narratives, they may also emerge as blameworthy and often suffering. Although Rose writes from the context of public debates in the United Kingdom, she enables the framing of the problem at the heart of this article. In the Indian context, womanhood has till very recently been equated with motherhood (Nandy, 2017). Women who voluntarily opt out of motherhood are frowned upon. At the same time, giving birth does not automatically confer the status of a 'mother'. Writing in the context of patriarchal North India, I have wondered whether the fact of becoming a biological mother of daughters confers the social status of a mother on the birthing woman. In foregrounding the maternal, I have asked whether sex selection, most often constructed as the denial of life to unborn daughters, is better understood as the subjugation of the maternal to patriarchal demands. In this paper, I extend this thinking to the question of disabled women. I draw upon existing research to argue in favor of the rights of women with disabilities to be mothers.

I look at the intersections of feminism, mothering and disability. To do so, I briefly return to my own research on the question of the selective abortion of a fetus that is projected to be disabled. In the major part of the article, I discuss the other side of the question, the right of a woman with disability to be a mother. I argue that focusing attention on mothers with disability might be a productive space from which to negotiate a relationship between disability theory, feminism, and mothering that is less antagonistic than appears to be the case through the prism of debates on selective feticide of the disabled. I begin with a short discussion of the problematic place of the mother in feminist theory.

Mothers in Feminist Theory

Mothers have been the subject of some difficulty for feminist theory. Much of the difficulty can be traced to the fact that the association of women with pregnancy and birthing placed them squarely in the domain of nature. This was precisely the equation that feminists were attempting to undo. Although women across history and culture had access to some forms of contraception and abortion, the likelihood of a sexually active woman becoming pregnant was always very high. The first modern birth control pill was developed in the 1950s in the USA. By the 1960s, it was approved for use as contraception establishing a freedom, of sorts, for women. The emergence of new reproductive technologies transformed the relationship between being a woman and becoming a mother. Although what seemed like a feminist panacea is now viewed with greater suspicion, the early writing of second-wave feminism in the West certainly coincided with this development. In some ways, these writers were celebrating the newly found freedom for women from compulsory pregnancies, and the ensuing fear around sexuality.

In such a context, it was not surprising that early second-wave feminists, many of whom were White, saw motherhood as the primary obstacle in women's search for freedom. The most stringent critique of biological motherhood appeared in *The Dialectics of Sex* (1970) by

Shulamith Firestone. Patriarchy, Firestone argued is rooted in the biological differences between the sexes. Sex, the fundamental class distinction did not directly result in oppression. However, the difference in reproductive roles that ensue from it, did. Firestone was certain that the choice of motherhood would lose its attractiveness once other alternatives were available. The idealization of motherhood was a patriarchal ploy to keep women in a position of subordination. She believed that the answer to this biological trap would come from technological innovation.

The reproduction of the species by one sex for the benefit of both would be replaced by (at least the option of) artificial reproduction: children would be born to both sexes equally, or independently of either, however one chooses to look at it; the dependence of the child on the mother (and vice versa) would give way to a greatly shortened dependence on a small group of others in general, and any remaining inferiority to adults in physical strength would be compensated for culturally. The division of labour would be ended by the elimination of labour altogether (through cybernetics). The tyranny of the biological family would be broken.

Most women, including some feminists, found this vision somewhat unintelligible. O'Brien (1981) agreed that reproduction and motherhood had become sources of oppression for women. The task for women and feminists was, however, to recognize that these also contained the possibilities for her liberation. Essentially, O'Brien suggested that patriarchy results from male alienation from reproduction. Presaging later developments, O'Brien suggested that control over reproduction may be interpreted as an attempt at establishing control over the products of reproduction and technological interventions, which may play no role except to enhance the alienation of woman from her own body. In keeping with feminist writing of that period, women were treated as a homogenous category.

As Cynthia Lewiecki-Wilson (Lewiecki-Wilson & Cellio, 2011) points out reproductive control has played an important part in women's control over their bodies. Until the advent of contraceptives, both women and the disabled occupied a position of subjectivity trapped within its embodied reality. The possibility of freedom from reproduction has given women some distance from this. Such a disembodied relation is not possible for people with disabilities. Contraception, in large measure though not exclusively provided with a new technology of the self that enabled the possibility of individuation and individual rights. This guaranteed some distance from the disabled position which remained caught in the 'particular embodiment' of special needs' (p. 69). In the context of becoming mothers, disabled women were caught in the position of an embodied existence whose neediness precluded her capacity to care and hence to be a mother.

Mothers within patriarchy

Perhaps the most significant contribution to feminist rethinking of the experience of mothers came from Adrienne Rich (1976). Rich distinguished between mothering as 'the potential relationship of any woman to her powers of reproduction and to children' (p. xv) and to motherhood as the institution which aims at ensuring that that potential remain under male control. In an interesting reversal of conventional understanding Rich (1976, p. 116) wrote,

...the mother child relationship is the essential human relationship. In the creation of the patriarchal family, violence is done to this fundamental human unit. It is not simply that women in her full meaning and capacity is domesticated ... safely caged in a single aspect of her being-the maternal-she remains an object of mistrust, suspicion, misogyny in both overt and insidious forms. (Rich, 1976, p. 116)

In establishing the distinction between motherhood as institution and mothering as experience, Rich rendered the twin phenomenon of desire for and oppression within motherhood intelligible. While many women want to have children they find themselves enraged and fatigued in the daily work of bringing them up. Rich believed that much of the oppression associated with being mothers came from the patriarchal conditions within which women are expected to relate to their offspring. Critically, from the perspective of the question of disability, Rich foregrounded the question of care.

Firestone was preoccupied with the vision of reworking the sex class system. The underlying assumption was to see the dependency-care dyad as inherently limiting to the formation of a woman's identity. By contrast, Rich (1976) opens her work with a reference to dependency. Rich (1976, Foreword) writes,

All human life on the planet is born of woman. The one unifying, incontrovertible experience shared by all women and men is that months long period we spent inside a woman's body. Because young humans remain dependent upon nurture for a much longer period than other mammals, and because of the division of labor long established in human groups, where women not only bear and suckle but are assigned almost total responsibility for children, most of us first know both love and disappointment, power and tenderness, in the person of a woman.

Meanwhile, care has come to occupy a central place in feminist theory. The significant strands of the work on care reflect some of the following: problematizing care as the natural domain of women, recognizing care as work and rethinking ethics from the perspective of care (Hollway, 2006). The question of care is also central to the construction of motherhood. As Sara Ruddick (O'Reilly & Ruddick, 2009, p.17) put it, 'the aim of maternal practices is to meet the demands of vulnerable "children" for safety and wellbeing'. The inherent vulnerability of children requires the practice of mothering, one that includes care.

The foregrounding of dependency and care has considerable significance for any reflection on the relationship between the question of maternal subjectivity and disability. There seem to be two movements that stem from the acknowledgement of this dependency. At one end, the issue pertains to giving birth to a child with disability. The decision to bear a child who may not achieve normative independence and autonomy has often been constructed as a selfish or immoral choice. The push to screen pregnancies for fetal abnormalities and to discourage the continuation of a pregnancy that might result in a child with disabilities emerges from these grounds. The right to give birth to a child with disability may be thought to be grounded in an ethics that stands in opposition to the ideal of individuation and autonomy and paves the way for alternative epistemologies.

Eva Feder Kittay (2011), feminist and disability scholar, philosopher and mother of a disabled daughter, worries about the valuing of autonomy and independence as the route to a dignified life. Kittay (2011, p. 51) writes,

I want to suggest that an ethics that puts the autonomous individual at the forefront, that eclipses the importance of our dependence on one another, and that makes reciprocal exchanges between equals, rather than the attention to other's needs, the model of ethical interaction is not one to be preferred in the construction of an ethics of inclusion—at least not without the correction of an ethic of care. (Kittay, 2011, p. 51)

The question of care also emerges as significant in discussions of the right of a woman with disability to become a mother. As Lewiecki-Wilson (2011) has argued, because the woman with disability might require care, it is often imagined that she is incapable of mothering. In the ensuing arguments of this article, I hope to unravel the assumptions underlying the relationship between the capacity to mothering by engaging with the narratives of disabled mothers. I will argue that it is in fact the disabled woman's capacity for care that is subjugated when she is prevented from becoming a mother.

In the Indian context, feminist engagement with motherhood has been particularly sensitive to its simultaneously private and public aspects. As with other aspects of feminist interrogation, reflection on motherhood emerged in the colonial context. Indian feminists have grappled with the paradox between the presences of Mother Goddess in the form of Shakti and the material reality of the lives of mothers. Clearly, motherhood has been used to domesticate women, relegating their power to the domestic realm (Bagchi, 2017). While many feminists writing in India speak of the joys of mothering (Aneja & Vaidya, 2017; Bagchi, 2017), the word 'banjh' stigmatizes the woman without children as barren. Nevertheless, there is now a growing recognition of both the rejection of conventional motherhood by women in India and the rethinking of mothering amongst those who chose non-traditional practices. Yet, care giving in families remains feminized while it remains politically and economically devalued (Nandy, 2017).

Becoming a Researcher of Mothers

My interest in maternal subjectivity goes back to my doctoral work conducted in the latter half of the 1990s. As a feminist psychologist, I was curious about mothers' desire to eliminate the fetus of their own sex. The preference for male children has a long legacy in large parts of North India. Until the 1970s, when ultrasound technology first became available, female infanticide, both passive and active were practiced for eliminating daughters. Once ultrasounds were available to detect the sex of unborn fetuses, the practice of sex-selective abortion became rampant. A purely discursive or social constructionist argument seemed incompatible with my understanding of maternal subjectivity. I believe that I found a partial answer to my dilemma when I began to read Adrienne Rich (1976). Somewhere along the way I decided to reverse the question to ask what made mother's love for daughters possible in a culture of son preference.

For most of the women I met, motherhood was not a matter of personal agency as much as a familial responsibility. Families, including the mothers themselves, did want to have a

minimum of one son in the family. This desire for one son led to the birth of many daughters. Speaking to mothers with many daughters, I understood that mothers loved daughters but desired sons. This split was central to the contradictory narratives I heard. As these mothers of daughters spoke, they swayed from their state of non-recognition as mothers to their fiercely protective love for their daughters, negotiating their liminal status as mothers. They spoke of both the sympathy they evoked and the ostracism they faced as ‘barren women’ (*banjh*). At the time, narratives in mothers’ voices were rarely captured. While paying attention to the mothers of daughters I tried to capture the contradictions and difficulties inherent in loving daughters in a culture of son preference.

It is well known that the patriarchy’s preference for a son, accompanied by a rapidly changing economy and the entry of new technologies has made it increasingly easy to determine the sex of the unborn child. The sex ratio in the first five years of life has been remarkably skewed for several decades and there is an increasing tendency to plan a small (even one-child family) preferably with the only child being a son (John, Kaur, Palriwala, Raju, & Sagar, 2008). Although there is plenty of data to suggest that female infanticide was practiced across many parts of Northern India (Bhatnagar, Dube & Dube, 2005) even during the colonial period, the availability of relatively inexpensive ultrasound technology after the 1970s has, in all probability, rendered what was once destiny as choice. The Pre-Conception and Pre-Natal Diagnostic Techniques Act (PNDT) was passed in 1994, almost two decades after the entry of ultrasound technology. It is an accidental fact that the stories I heard were from women who gave birth in a period when sex-selective abortion was legally possible. I began to unravel the way the experience of mothers shifted with sociopolitical and technological changes. New technologies that allowed for sex detection also resulted in the shift in the mother from a victim of destiny to a self-choosing agent who could design the ideal family using technology.

From Sex Selection to Disability Selection

The story of the feminist response to sex selection has been narrated in several accounts (Menon, 2004; Ghai & Johri, 2008). While the intent of the PNDT Bill that followed was to prevent the medical profession from revealing the sex of the unborn fetus but it clearly failed. In 2008, disability scholar and activist Anita Ghai and I foregrounded a different problematic that emerged from the PNDT, or PCPNDT Act (Ghai & Johri, 2008). Our argument was that the very process by which the PCPNDT had delegitimized sex selection had also constructed the fetus with a disability as the appropriate object for selective abortion. The difficulty, as feminists elsewhere have also noted (Rapp, 1999), is that the development of new technologies of fetal monitoring have radically altered the relationship between medical professionals and the pregnant woman such that the doctor now has direct access to the fetus. Images of fetuses are now visually available and have changed the discourse of maternal rights vis-a-vis the unborn child. In some ways, the processes of reproductive technology have, as Rose (2018) would put it rendered the maternal body as both redundant and responsible.

Lorna Weir (2006, p. 1) writes eloquently about this: ‘the threshold of the living subject constitutes the zone of transition into and out of the human bodily substance. Women in pregnancy bear the between, the entrance across which the unborn must pass in order to be distinguished from those that carry them.... When and where that between begins and ends,

what status the bodily substance at that threshold might have, is an entirely social and cultural matter.’ In the last century, concerns about reducing infant mortality gradually gave way to a new conceptualization, that of the prenatal period. In doing so, the mother and the unborn fetus she was carrying became distinct entities. The life of the fetus became the subject of risk assessment with the maternal figure emerging in both law and medicine as the subject of governance. Cases of maternal fetal conflict became possible within this form of bio politics. Mothers, particularly from marginalized locations, could now be held increasingly responsible for the life of the child within the womb; sometimes even subject to legal disciplining. A careful look at the literature suggests that the disabled fetus is only one category of children considered to be at risk of harm from errant mothers.

In the context of disability, it implies that mothers ‘at risk’ will be expected to go for prenatal screening and are likely to come under systems of surveillance and governance that will restrict their autonomy in determining the fate of this fetus considerably. However, it also implies that those mothers who do not abort the fetus will be subject to blame for their choice. In India, poor women are likely to be subjected to disciplining while those more privileged may find themselves exercising the choice of selective feticide of the disabled. Given such a scenario, it seems to me that there is little space for mothers to exercise a voice, thus the debate between feminists and disability rights advocates might indeed be wasted.

This also provides us with the juncture to rethink the similarities between daughters and disabled daughters. While both are imagined as vulnerable, the daughter who survives is expected to become a future mother, while the disabled daughter is deemed unfit for motherhood. She is undesirable both at birth and as birth giver.

This is a concern highlighted by a section of disability activists. Ghai (2003) writes, ‘Constituted as being profoundly ‘Other’ disability symbolically represents lack, tragic loss, dependency and abnormality. It is true that all of us begin life in a completely dependent state, often undergoing experiences of shame and loss. This... is moderated by the recognition that human minds and bodies are always in transition, moving from an incomplete, imperfect and vulnerable existence to a relatively autonomous existence. The possibility of this movement... is not accorded to the disabled’.

In such a context, the disabled woman who wishes to take upon herself the subject position of a mother finds herself faced with multiple barriers. Following from the logic articulated by Ghai (2003), it seems that because she has at one time been the recipient of more care than would perhaps have been required by another woman, she cannot be assumed to have attained the state of maturity required to take care of another. Nandini Ghosh (2013) similarly shows that the disabled daughter is not considered to have the characteristics of the ‘bhalomeye’ or good women that would deem her fit for marriage and the responsibilities of adulthood. Clearly, motherhood is unlikely in such a context. The few women with disabilities who do have children have internalized the dominant ideology of motherhood that sees them as unfit for care. As N. Ghosh (personal communication, August 23, 2018) puts it, the women who had children saw themselves in need of support from mothers and mothers-in-law. While this support was not significantly different from that provided to able-bodied mothers, it was constructed within the model of deficit.

Mothering with Disability

In the following sections, I bring together the questions raised by feminists and disability activists while retaining a concern for mothers. To this extent, I hope to mediate both discourses of disability theory and feminist theory. Although the argument I make may be critiqued as being applicable largely to the Western world, I will share some voices from women with disabilities in India to support my claim.

It is also important to state at the outset that feminist discourse has been appropriately concerned with uncoupling the relationship between pregnancy and becoming a mother. Given these, it is no longer possible to essentialize the mother as an older woman who gives birth and is involved in the care and socialization of a younger person. Mothering as an activity can go on well past the adulthood of the child, it may be reversed, may be carried out with non-biological children and without the presence of a woman as with a gay couple. Nevertheless, for the purposes of this article, the disabled pregnant woman or the non-pregnant disabled woman who desires to be a mother produce new problematics for thinking about each of the three terms central to this article – disability, mothering, and feminism.

The normative construction of ‘woman’ incorporates the ideals of pregnancy and motherhood within them. And although there are outliers (Nandy, 2017), the woman with disability is most often deemed to be incapable of both the biological processes of childbirth and the psychological capacity to take care of her children. In this section, I draw upon some literature on disabled women as mothers to interrogate this construction. I attempt, based on this, to suggest that rather than seeing disabled women as incapable of being mothers, they may be visualized as involved in the practice of feminist mothering. My writing is based largely on a review of secondary research, news reports and some accounts on the web. The reality of Indian women with disability is poorly represented in this literature.

Cynthia Lewicki-Wilson (Lewiecki-Wilson & Cellio, 2011) brings mothering and disability together through the metaphor of liminality: *Disability is not a thing, an essence or a fixed identity or a single kin of experience.... It is an embodied, situated and social experience in culture, constituted out of an ever-changing flow of relations among bodies, practices, institutions, experienced personally and socially constructed* (p.3).

In a similar fashion, mothering is independent of the process of child birth but ‘a relation to another and an experience in flux’ (Lewiecki-Wilson & Cellio, 2011, p. 3). My question in this article concerns the right of the disabled woman to become a mother. Numerous scholars, both within and outside the Indian context, have commented on the construction of a woman with disability as lacking femininity. They are regarded either as asexual or sexually available and unfit to be wives. Further, since disabled women are thought to be unfit to care for their own selves, they fall outside the description of potential caretakers. The ideals of motherhood, already inscribed within the ableist discourse, resituate the woman with disability within the master status. In India, women with disabilities are likely to experience significantly low levels of choice and agency. Married women with disability may be expected to give birth as a normal part of being women, regardless of its consequences for her own health or well-being. Nevertheless, the discourse surrounding the

disabled woman's body deems her to be 'defective, undesirable and thus devalued' (Aneja & Vaidya, 2016).

However, the marginalization of women with disability from the experience of mothering does not come only from patriarchal society. Instead, both disability and women's movements have, perhaps without conscious awareness, kept out disabled women's desires to mother. It has taken feminist disability scholars to point out that while women's bodies are normatively the object of a gaze, the disabled woman's body receives the stare, 'framing her body as an icon of deviance' (Thomson, 1997 in Prilletensky, 2004, p. 31). While a woman's body is theorized as too easily sexualized, a disabled woman may find herself deemed asexual and incapable of reproduction and parenting. Unfortunately, the masculinist nature of the disability movement has de-emphasized these concerns. The woman's movement too failed to see a capacity in motherhood, as caught up as it is with the compulsory nature of this for many able-bodied women. For disabled women, stories of oppression include those of forced hysterectomies, abortions, sterilizations as well as subtle messages from professionals and a general silence in literature that rests on an assumption that women with disabilities cannot mother. A horrendous manifestation of this was the forced hysterectomies of 11 intellectually disabled women in a state-run home near Pune in 1994.

In an early work, Thomas (1997) critically examined the lived experience of disabled women as they considered the possibility of becoming pregnant, were already pregnant or engaged with child rearing. Thomas sees the work as looking at reproduction through the lens of disablism. In consonance with later research, the question of risk emerges as a major determinant of the preliminary response to the idea of a pregnancy in a disabled woman. Sterilizations and abortions are recommended and the question of risk frames interventions, decisions and emotional experiences of mothers. Disabled mothers also encountered doubts about their capacities resulting sometimes in battles over custody of the children. Finally, the research considered the question of 'help' to mothers with disability. Although women with disabilities may require more professional help throughout their pregnancies, they find appropriate help absent while they are coerced into forms of help that they do not require.

The situation for women with disabilities is considerably worse in India. India has a legislation, Person With Disabilities (PWD) Act since 2016 to ensure equity, opportunity and access. Nevertheless, the dominant ideological construction of Indian women as mothers notwithstanding, several researchers have found pregnancy to be less frequent amongst disabled women (Gudlavalleti et. al, 2014). Some recent research studies in India (Mitra, Long-Bellil, Smeltzer & Lezzoni, 2015; Chitnis and Samant, 2017) reiterate that there is a severe lack of accessibility of health services for disabled women in India despite the promise of the PWD 2016 to support women with disability for livelihood and the upbringing of their children (p.11)

The Act also makes a provision to respect the decision-making capacities of persons with disabilities on all concerns pertaining to 'family life, relationships, bearing and raising children; and reproductive healthcare especially for women with disability' (p. 15). Within the medical profession, it is assumed that the process of birth will be particularly difficult for women with disabilities despite the fact that there is no apparent relationship between

the nature of the disability and processes such as pushing the baby during labor (N. Ghosh, personal communication, August 23, 2018).

Writing from the position of a mother with a muscular dystrophy, Ora Prilleltensky (2004) notes that women with disabilities grow up with the message that marriage and motherhood are not feasible choices for them. They are not fit for either sexual-intimate relationship or the difficult work of caring for another that motherhood entails. Gupta (2013) quotes one of her participants, Priyanka, *“If the impaired woman fails even once or twice in her role as a mother it is not only she who is blamed and accused, but also her partner is blamed for getting married to such a woman.”* (Gupta, p.40)

Prilleltensky also documents the rather varied experiences of women with disabilities, the normative responses from both families and medical practitioners is of anxiety, horror or dismay. The participants of her research also spoke eloquently about their fears and excitement about pregnancy and childbirth. However, regardless of whether they went on to become mothers or not, all the participants emphasized the importance of choice.

The freedom of this choice was circumscribed by the twin medical discourses of pregnancy and disability. Despite feminist writing from the early 70s, medical practitioners tend to view both disability and pregnancy as illnesses. The pregnant disabled woman is an even greater contradiction. It is not surprising that she is seen as an ill woman in need of cure rather than a woman with ordinary desires that may require facilitation. She receives ‘a double dose of dependency creation’ (Thomas, 1997, p. 639).

On the other hand, there is very little specialized training to look after the disabled pregnant body even in prosperous Western countries. Doctors also construct the unborn child as carrier of the defective genes of the disabled mother even though there is often no genetic basis for the mothers’ disability. These attitudes reflect the infantilization of the disabled pregnant woman, seeing her as egocentrically pursuing her own desire without any concern for the unborn child. Research shows on the contrary that women take decisions about their pregnancy after a conscious reflection on the possibility that the child may inherit their disability (Thomas, 1997; Mason with Long-Bellil, 2012). Boardman (2011) discusses her research with 21 women with Spinal Muscular Atrophy in this context. Interestingly, women who had experienced disability did not define it as a necessarily negative experience. The experience provided them with a bounded form of knowledge and a privileged perspective on life. Others preferred to refrain from giving birth to a child with a similar disability, doubting that they could provide the quality of care to the child that they had themselves received.

The construction of the disabled woman as essentially outside the realm of motherhood goes beyond the medical profession. Walsh (2011), a woman with visible physical disability narrates a chance conversation about motherhood with her beautician for whom disability and becoming a mother seemed to be mutually incompatible. As Walsh puts it, ‘there is something disturbing about the inference that I cannot mother. I feel it is an inference that shakes the foundation of my personhood...’ Citing Nancy Pedrick Mairs, Walsh wonders if in excluding women with disability from the possibility of being mothers they are not also excluded from the status of women. The phenomenological position of the disabled woman is thus diametrically

opposed to that of the able-bodied woman, whose desire not to be a mother may push her to the boundaries of womanhood. Walsh poignantly notes her own tense location within these contradictions. While she does not experience a pressing need to become a mother, there is a demand to counter the dominant narrative and ‘confront the commonsense narrative’ (Walsh, 2011, 83).

While Walsh had not experienced the desire for a child, many disabled women want to have children and the embodied experiences that accompany pregnancy. In a moving account, Heather Kuttai (Kuttai, 2011) writes about the birth of her second child during an episode of severe disabling pain. The narrative is woven around her passion to breast feed her baby despite the experience of a body that was ‘so crooked that I cannot see my face in the bathroom mirror anymore’ (p. 157). As she realizes she must re-enter hospital for surgery, she writes, “I have spent the better part of the day crying. I live in a body that is devalued in so many ways. My body takes on a new value, importance and even status when it is pregnant, nurturing and breastfeeding. The threat of having that importance taken away is devastating.” (p. 158)

Unfortunately, their desire to mother does not always protect women with disabilities from the trauma of losing their children. As Lorna Weir (Weir, 2006) indicates prenatal screening for disability is only one of the many ways that bio politics configures the mother as harmful to the child. As a consequence, the children of disabled mothers are often taken away from them without any consideration for the resultant disenfranchisement and grief.

Feminist Mothering

Motherhood researcher, O’Reilly (2008), notes that although there has been considerable feminist writing on mothers, the practice of feminist mothering has rarely been defined. Feminist mothering may be conceived of as an oppositional practice that operates as resistance to the institution of motherhood. It provides a counter narrative to the patriarchal understanding of motherhood and may be imagined as a way of interrupting the dominant or master narrative. Further, the practice of feminist mothering may be thought of as one that challenges any aspect that limits the potential of mothering.

Although O’Reilly (2008) is concerned about the lack of theorizing on feminist mothering, she draws upon a few sources that have foregrounded this. Tuula Gordon (1989 cited in O’Reilly research with feminist mothers) depicts several features that determine their practice. These include retaining their right to work, bringing up children in deliberately non-sexist and non-racist ways, expecting greater participation from fathers, and taking active political positions.

Feminist mothering includes the experience of mothering of non-dominant identities including single mothers, lesbians and others. It values mothering experiences outside the normative structure of families. Further, feminist mothers emphasize the political nature of mothering as an activity, thus critiquing the construction of mothering as located singularly in the private domain. Most significantly, they are frequently involved in forms of maternal activism, using their positions as mothers to critique and transform their world.

In thinking about mothering with a disability, I find myself asking if the disabled woman who mothers may be thought of as involved in the practice of feminist mothering. To state the question somewhat differently, is there a possibility, even if it is not universal, for a mother with a disability to provide a model for feminist mothering. Falling back on the criteria suggested by O'Reilly (2008), mothers with disabilities may have a life beyond parenting. As is evident from the authors cited here, writing as well as a generic commitment to the field of disability studies is a major inspiration for these authors. In India too there are several women with disabilities who combine activism and scholarship along with a commitment to their children.

The greater contribution of mothers with disability lies in the reinterpretation of the very practice of mothering that emerges from their lives. Nandy (2017) describes the outlier mother whom she calls Kanak (p. 308) in defiance of norms of heterosexuality and the accompanying ideology of family, Kanak decided to adopt a daughter with a female partner that she refuses to describe as a lesbian relationship. Mothering with disability provides an alternative ethics of the parent child relationship. Mary Grimley Mason (with Linda Long-Bellil) (2012) point to the requirement for rethinking the dyad of mothering and care that plays such a significant part in feminist discourse. Despite the passionate desire to mother, the experiences of women with disabilities do not fit within the ideal of the caregiver described by feminist scholars such as Sara Ruddick. For disabled mothers, self-care and the care for the child become competing priorities. The usual hierarchies are often reversed with children emerging as co-workers, friends and even caretakers of their disabled mothers. These pose a serious challenge to the stereotype of the devoted mother.

Feminist and disability activist Nandini Ghosh (2018) also describes her experience of adopting a daughter. The dominant ideology of motherhood that acts as a barrier against biological motherhood for disabled children, also works to prevent women with disabilities from adopting children, often citing the disability as ground for refusal. Once again, there is an assumption that only certain forms of caring can constitute appropriate mothering. As Ghosh (2018) puts it in a personal conversation, it is assumed that a woman with a physical disability cannot soothe her child because soothing involves walking with the child. However, other practices may also be used to soothe the child. Her own daughter aged 6 is now almost as tall as her and it is impossible for the mother to pick her up. However, she can walk along with her daughter and does, thus subtly rendering an alternative understanding of maternal practices possible.

Another form of resistance expressed by disabled mothers and fathers serves as a critique of ableism. There is a common assumption that disabilities will cause unremitting suffering to the family, society and the child. Parents with disabilities have very different experiences in this regard. Rather than being stigmatized completely by their disabilities, they enable their children to acquire some aspects of their identities. Learning sign language is one such marker that deaf parents might want to teach their children even when they are not disabled. There is greater need to research the experiences of mothers with disabilities, particularly in India. It is also important to start the process of listening to children who have lived with disabled mothers.

As I was struggling to complete the article, I came across a heartening facebook post from disabled mother Meenu Bhambani (Facebook, 28.07.2018). In the post, the mother finds her daughter wanting to identify with her by wearing toy version of her braces.

Something very funny happened today. Everyday my daughter, who is 4 years old, asks me if she could wear my brace and I keep telling her it is not for her, her legs are too small for my size of brace and so on. This morning she said, “Mumma, can you get me a toy brace which I can wear on my leg. It needs to be exactly like yours”. While I found it funny, but it made me think how assistive devices and disability are normalised when children are exposed to them from a very young age and also how our toys are always so exclusive of disability prosthetics. While I understand that there will be little market for it, but wouldnt it be nice if some toymakers also thought of different kinds of dolls which were inclusive of disability and which went beyond a special edition doll in a wheelchair?

Older children of disabled mothers have also begun to come out in the open about their experiences of childhood.

Children of disabled mothers have begun to share narratives that are somewhat reminiscent of the writings of feminist daughters. Emily Beitiks (2016) writes that growing up with a disabled mother made her a better person. She cites four grounds for her reasoning. At times, her mother needed assistance. This taught Emily interdependence and made her more confident than other children. She also became less sensitive to the stare that her mother and she received, learning to protest and acquiring some degree of activism early in her life. She is less afraid of disability and more comfortable using rights and entitlements that benefit her. Finally, she was conceived after her mother was diagnosed with multiple sclerosis at age 40. Emily was born as a part of her mother’s resistance to the medical predictions about her disablement.

While accounts such as Emily’s can be interpreted in a variety of ways, they also constitute a process that engages with new versions of mothering. Just as there is no way a 4-year old can find a toy prosthetic to wear to identify with her mother, there are also no photographs in hospitals of mothers with their disabled babies. Both mothers with disability and disabled children are rendered as radical Others, to be kept outside the realm of imagination. ‘Mothers with disabilities need to be heard not only to enhance mothering with a disability may be thought of as providing a challenge to the ‘maternormativity’” (Nandy, 2017) that characterizes the hetronormative ideology of motherhood in the service of a feminist practice of mothering. I have foregrounded the question of the pregnant woman, while recognizing that the issues at stake are likely to be significant for disabled women wishing to adopt children. To give the right to mother to women with disability is to rethink the construction of femininity and the capacity to care.

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