

# Constructions of motherhood in feminist and disability studies

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**Abstract:** *This theoretical essay analyzes proximities and distances between feminist and disability studies concerning care and motherhood constructions. It discusses the elaboration of a norm for human experiences; disability studies; feminist disability studies and the ethics of care; the social construction of a normative motherhood and its implications for women living with disabilities. Within feminist disability studies, women with disabilities or mothers of people with disabilities indicate that the patriarchal institution of motherhood challenges them differently, for they are not compelled, but discouraged from reproducing and providing care, being unfavorably positioned in the reproductive hierarchy. Based on their experiences, they reveal various possible motherhoods, beyond normative maternity.*

**Keywords:** *Disability; Motherhood; Feminism; Care*

*Análise das construções possíveis de maternidades nos estudos feministas e da deficiência*

**Resumo:** *Neste ensaio teórico analiso aproximações e distanciamentos entre os estudos feministas e os da deficiência nas produções do cuidado e de maternidades, por meio da discussão da elaboração de uma norma para as experiências humanas; dos estudos da deficiência; dos estudos feministas da deficiência e da ética do cuidado; da construção de uma normativa materna e suas implicações para mulheres vivendo com deficiências. Nos estudos feministas da deficiência, mães com deficiência ou mães de crianças com deficiências apontam que a instituição da maternidade patriarcal as interpela de maneira distinta, pois não são compelidas, mas desestimuladas a se reproduzirem e cuidarem, desfavoravelmente posicionadas na hierarquia reprodutiva. A partir de suas experiências, evidenciam diversas possibilidades maternas, para além da maternidade normativa.*

**Palavras-chave:** *deficiência; maternidade; feminismo; cuidado.*

## Introduction

"Ain't I a Woman?" (Sojourner TRUTH, 1851)

The dialogue between feminist and disability theories involves tensions and possibilities that particularly concern the (im)possible motherhoods of women<sup>1</sup> with disabilities or women whose children have disabilities or chronic illnesses. This dialogue and tension can deconstruct a maternal normativity that is anchored in binary patterns of normality and abnormality, opening spaces that echo other voices. In this study, I consider disability to be a term that is missing in the intersectionality of gender, race, class and sexuality. Understanding intersectionality as an intertwining of different experiences of inequality (or privilege) that when combined result in more than the sum of separate oppressions, we cannot consider race, class and gender as static categories that overlap in a linear and hierarchal way (Kimberlé CRENSHAW, 1991; 2002; Carlos Eduardo HENNING, 2015; Patricia

<sup>1</sup> This provocation with possibilities and impossibilities refers to the interdictions imposed on women living with disabilities, while simultaneously emphasizing their resistance to and breaks from a maternal hetero-cis-normativity.

Hill COLLINS, 2015; Helena HIRATA, 2014). We also cannot consider these themes without inserting disability, which is another product of the colonial/modernity<sup>2</sup> binarism between a central, Eurocentric and standard pole, and another subordinated one. In this case, between a normal and an abnormal.

Anthropologist Rita Segato (2016) affirms that the binarisms inaugurated by the European invasion of the Americas were significantly different than previous dualisms, especially that of gender. Dualisms concern universes that have different meanings, but which are complete and specific in their own existence: they are not hierarchically opposed and antagonistic binaries, with one supplanting the other and negating its own existence as an interlocutor. Binarisms reduce alterity to a purging and expulsion of the other, if not physically, ethically.

It is crucial to insert disability into this intersectionality because there is a larger number of people with disabilities among blacks and women and in developing countries (Lennard DAVIS, 1995; Jenny MORRIS, 1996; Helen MEEKOSHA, 2011); and the colonial process has produced disability internationally and locally. Wars, arms trading, land mines, forced displacement, the feminization of the labor force, international migration, and lack of epidemiological control are among the extreme international and colonial situations that produce disability. However, the production of disability can be more subtle within a country: strenuous work on textile production lines; precarious job security in civil construction; mutilations in sugarcane fields; unequal access to drinking water, public health services, vaccinations, condoms, disposable needles and pre-natal care; poor access to good, safe and public transportation in urban centres; and traffic-accidents, are all factors that increase the number of people with disabilities among those who are most at risk. Not to mention the countless possibilities for comorbidity that affect more people with disabilities because of their reduced access to quality health services. According to Meekosha (2011, p. 671), people with disabilities or chronic illnesses compose 20% of the poorest population:

The processes of colonisation, colonialism, and neo-colonial power have resulted in vast numbers of impaired people in the global South. Much of this relates to the global economy; it concerns control of resources. Impaired people are 'produced' in the violence and war that is constantly provoked by the North, either directly or indirectly, in the struggle over the control of minerals, oil and other economic resources – ultimately control of the land and sea themselves. (MEEKOSHA, 2011, p. 668).

The Convention on the Rights of Persons with Disabilities promulgated by the UN in 2007 and ratified by Brazil in 2008, by then President Luis Inácio Lula da Silva, brought important advances in theoretical and practical considerations about disability (BRASIL, 2008). The document strives to introduce disabilities to intersectionalities, by emphasizing that people with disabilities are subject to multiple forms of discrimination, especially women and girls, and recognizes that the majority of people with disabilities live in poverty.

Brazil's recent Zika virus epidemic is an example, for it resulted in a large number of babies born with the congenital Zika syndrome, especially among the most vulnerable populations: women, the poor, blacks and people from the country's Northeast, making it a geographically, politically and socially localized epidemic (Rozeli Maria PORTO; Patricia Rosalba Salvador MOURA, 2017). Thus, women who work as caregivers are positioned in intersectional dynamics in which they either can have access to healthcare plan and home care or be users of Brazil's Unified Public Health System (SUS); have a car to take their children to therapies or have to use urban public transportation with a child in a wheelchair; have to leave their paid jobs to care for children or be able to hire care aids.

The study of disabilities from outside the rehabilitation perspective from a social perspective as a construct forged in the colonial and exclusionary binarisms, is still a field in expansion, especially in Brazil. This is troublesome because of the large number of people who compose this group, as well as those who may enter it one day due to accidents, urban violence, technological and medical advances – or their scarcity –, diseases or, simply due to aging. However, there have been important advances in disability studies - from the social model - and this production is fundamental to the dialogue that I propose (Debora DINIZ, 2003a; 2003b; 2007; DINIZ, Marcelo MEDEIROS; Flavia SQUINCA, 2007; Anahi Guedes de MELLO, 2010; 2016; Marivete GESSER; Adriano NUERNBERG, 2014b; GESSER, NUERNBERG; Maria Juracy Filgueiras TONELI, 2012; 2013; 2014; MELLO; NUERNBERG, 2012; NUERNBERG, 2015; Marco GAVÉRIO, 2015; 2016; 2017, in addition to work by the NGO ANIS<sup>3</sup> and the Brazilian Collective of Disability Studies Researchers - Mangata).

The understanding of disability as a term missing from the intersectionality of race, gender, sexuality and class locates it as a social and historical construction, guided by a norm that is also social and historical. The idea is prevalent that what we understand by normality and its products

<sup>2</sup> The concept of colonial/modernity was developed by Anibal Quijano and Immanuel Wallerstein to designate the colonial/modern world-system, which considers that the invasion of the Americas not only reordered the world-system, but created modernity and ethnic, racial and gender hierarchies, amongst other binary and dichotomic divisions that justify the exploitation of this new territory. They argue that the independence of the former colonies cannot undo coloniality, which is still an intrinsic part of the hierarchical functioning of the states.

<sup>3</sup> Anis. Instituto de Bioética. To learn more, access <http://www.anis.org.br/>.

(a normal woman, a normal man, a normal body...) have always been present, similarly to how we consider patriarchy to be timeless:

Among the truths thus instituted, the universalization of patriarchy, as an a-historical agency, that is, universal, since the origin of the human, becomes an indisputable fact for all times and places, an essential part of its tactics for domination [...] In fact, the patriarchal dispositive is, like any human agency, historical, that is, manifestly dynamic and plastic (Tania NAVARRO-SWAIN, 2014, p. 37 [author's translation]).

Just as patriarchy is historical, so is normality, and it has operated in a way that separates people between normal and abnormal. Michel Foucault (2002) demonstrated this in his course on the Abnormal (1975-1976), which addressed the dispositif of power, truth and knowledge responsible for the creation and subsequent separation of individuals guided by a norm. This norm materializes with the innovation of disciplinary power, replacing a discourse of law and sovereignty with a discourse of normative rules. Two complementary formulations of the norm compose this concept: the norm as a rule for conduct, as a model and repetition; and the norm as adjusted regulation of functioning.

These two formulations enabled the appearance of a desirable normality with its own attributes and qualities based on regularities: one in opposition to disorder and the other in opposition to the pathological. They therefore elaborate a sense of rejection and qualification – rejection of irregularities and deviations and the qualification of the normalities that are possible, which separate normality from abnormality. This rejection defines a dichotomous separation between an abnormal and a normal that mediates people's interpretations of themselves and their bodies with which they produce their narratives of desired humanity (Simi LINTON, 2006; Terri MILLER, 2011; Cynthia LEWIECKI-WILSON, 2011).

A sense of universal and natural normality was consolidated along with what is at its margin, but which is necessary to define the center. Thus, the relationships we establish with the markers of difference position ourselves in this supposedly universal dichotomy. To historicize normality and question the naturalization of the marking of disability and difference of bodies, rationalities and sensorial experiences is central to the development of disability studies: disability is not a tragedy and personal deviation, but produces an abnormal other through a discourse designed to sustain normality. Common notions of tragedy, failure, error and even those of overcoming and heroism are suspended.

According to the disability studies feminist Rosemarie Garland-Thomson (2006), the term disability has four aspects: it is a construct for interpreting and disciplining the corporal variations in the human spectrum; it also involves the relationship between the environment and these bodies through the imposition of an environment that is restrictive to differences. In addition, the term disability refers to a social practice that produces both disabled and non-disabled bodies, in which the very construct of disability destabilizes the concept of the normal body. For Garland-Thomson, disability – like gender – constructs our shared bodily experience.

Therefore, the task of inserting disability into this intersectionality involves understanding that disability does not concern only people with disabilities, but a corporeality and functionality guided by a historical construction of normality. Disability is not just a nuance added to other oppressions, it is constitutive of the subjectivity of people with disabilities and temporarily able-bodied people. An alternative way of thinking about disability is to try to escape the natural representations of disability and look for the historical productions related to its meaning making. Looking for these productions enables us to question the definition of disability as it is elaborated by standards of normality.

Thus, the challenges raised by disability studies concern not only those bodies marked as deviations, but how we interpret the world through our bodies that we want to be controllable and fit. In this way, disability studies offer an important contribution to feminist theories, from which disability studies also gain, because feminist theories dispute a supposed universal normality of bodily experiences, which can deconstruct sedimented games of power. The questioning of the very concept of normality raises an anti-essentialism that can teach us about the social construction of human differences, not only those considered, in this time and space, as disabilities (Linda WARE, 2001).

In addition to this contribution and sharing of motifs such as “biology is not destiny” and “the personal is political”, there are several possible approximations between disability and feminist studies: “1) the presumption of the denaturalization of the body; 2) the identity dimension of the body; and 3) the feminist ethic of disability and care” (MELLO; NUERNBERG, 2012, p. 638). However, there is still a lack of approximation between them in terms of theory and political activism.

## Similarities between feminisms, disability studies and care

Feminist theorists of disability studies (Susan WENDELL, 1996; 2006; MORRIS, 1996; GARLAND-THOMSON, 2006) have emphasized a dual silence imposed on the specificities of women living with disabilities – whether they are women with disabilities or provide care to people with disabilities – because there is little insertion of disability studies in feminist theories. For this reason they have not found space to reconsider disability in the light of gender. However, these theories reinforce and

complement each other, as the experience of women and people with disabilities, and, especially, women with disabilities are similar in several aspects<sup>4</sup>. The same division between public and private that reserved for women private space and care for the production and reproduction of life also restricted the lives of people with disabilities, the elderly and sick to the private world, almost always under female care. Contrasted with what is expected of young, efficient, strong and productive bodies, weak, sick or dysfunctional bodies find resistance to their circulation in the public world.

The colonial/modernity inaugurated societies of status, societies of the “self”, which defined a universal male, white, Christian, European referent. In these societies, the others in relation to this referent are castoffs, leftovers who only serve to endorse the central term that establishes dichotomous binarism in opposition to dualities. This binarism opposes whites and blacks, men and women, normal and abnormal, and sets these possibilities into two antagonistic worlds, one with all the value and the other devoid of it. In a supposed duality found among Amerindian peoples before the European invasion (SEGATO, 2012; 2013), public and private worlds could coexist with their own complete meanings, which related, interconnected and interchanged with each other.

The binarism that supplants dualities creates a unique, universal and political public sphere, where state dialogue takes place and the sphere of private life: which is marginal, particular and broken in its importance and completeness, and only useful in status societies to serve, endorse and reproduce the public sphere (SEGATO, 2012; 2013). Private life, devoid of its potential, encloses the “others”: women, children, the elderly and people with disabilities or illnesses, establishing binary oppositions. The dichotomy between a public and male sphere, and a private and female sphere also altered the relations of caring for those with disabilities: many relations of community, social or family care were individualized. The individualization of disability and its care, as well as care for the ill, is essential to understanding the medical definition of tragedy and burden (LEWIECKI-WILSON, 2011).

About this division, Rachel Soihet (1989, p. 113) recovers what Hannah Arendt wrote in her study *The Human Condition* about the division of the public and private worlds, in which the private world is a place of deprivation instead of intimacies, with its own knowledge and meaning. The limitation of women’s circulation in the public sphere and their confinement to the private one removes them from the place of speech and debate and thus from the possibility for political existence. As in the Greek polis, it is men, who through the circulation of discourses, make decisions about the common world. They are, therefore, deprived of the opportunity to elaborate narratives about their own experiences. Emily Martin (2006) states that in this division, work in the public world, the productive and paid one, was (and still is) linked to the domination of nature, while the private world was the domain of nature. Consequently, women were seen as part of nature and thus dominated. Therefore, when women, people with disabilities, or people in need of care are relegated or even confined to the private space, there is an interdiction to political participation and, as a result, their representation in this world is conducted by people who do not necessarily live their experiences. It is important to note that many women – black, rural, and working-class women – have always participated in the world of work and, often, in the work of care, whether paid or not.

In these considerations regarding the separation between the private and public world, feminists engaged in disability studies, many of whom were women with disabilities in need of care and many caregiving mothers of people with disabilities, began to emphasize the importance of talking about the care experienced in the private world as part of the experience of disability and illness (Eva KITTAY, 1999; WENDELL, 2006; GARLAND-THOMSON, 2006; Melanie PANITCH, 2008). In addition, they questioned this separation between the public and private worlds: mothers of people with disabilities act in the public world, often as their interpreters, translators, advocates and activists. They considered that the work of care, which is fundamental to the daily life of many people with (and without) disabilities and chronic diseases, was hidden by discussions about the independent action of these people in the public world. Thus, they began to highlight a dimension that had been silenced in the disability movement: the logic of independence and an ethics of care.

This questioned the first theorists of the social model (Mike OLIVER, 1986; Paul ABBERLEY, 1987; Vic FINKELSTEIN, 1990; Len BARTON; OLIVER, 1997), who claimed that once all barriers (whether social or architectural) were removed, people with disabilities could live independent lives with no need of help, assistance or care. What is prevalent, in this perspective, is an idea of liberal citizenship, which seeks equal rights, access and the possibility for participation in social and political life, which means that the right and opportunity to be a worker would only be fully accomplished in disconnection from others (Bill HUGHES; Linda McKIE; Debra HOPKINS; Nick WATSON, 2005; MILLER, 2011; Joan TRONTO, 2013).

<sup>4</sup> Some black American women, in the 1970s and ‘80s, reported something similar: they did not see themselves in the feminist movement or in the black movement: the feminist movement was dominated by white women and the black movement by black men. The Combahee River Collective manifesto was an important expression of the questioning of both movements at the time. Women with disabilities have a similar experience: women in the feminist movement are able-bodied and the disabled movement is dominated by men (who are white).

For these first theorists (who were mostly white, adult, males with spinal cord injuries), to need and be cared for by someone, to be dependent on this care, was a position of subordination and oppression. To have a body that required care trapped them in biomedical categories from which they sought to free themselves. The emphasis on the care needed in the private space put them in a place of dependence and inability: in the domestic space, seen as feminized and infantilizing. The focus is, therefore, on who receives the care, and not on the care work, silencing the caregivers, who were mostly women - paid or not - making them invisible (WATSON; McKIE; HUGHES; HOPKINS; Sue GREGORY, 2004). Feminist theorists, on the other hand, emphasize the stories, needs and expectations of people involved in the work of care, which is central to the understanding of women living with disabilities. In Westernized cultures in general, domestic chores and care work are the responsibility of women, as a supposedly biological function of a natural motherhood. Thus, the work of care, even when not maternal, would be a women's natural and biological function due to her predisposition to care, love and be tender.

This difference between prioritizing who receives and who provides care has generated a theoretical and practical discord. Feminist theorists question precisely the idea that needing care or providing care are conditions of subordination. For these theorists, care is an intrinsic part of experience, not only of disability, but of life in general, and to limit this need to specific stages or conditions of life (such as childhood, old age, illness and disability) presupposes that, according to a male standard, people could live their productive lives without any kind of external help. This understanding is fallacious for people with disabilities, chronic or serious illnesses, but also for people who are temporarily non-disabled. The way we organize and provide care says a lot about our constitution as a society (Pascale MOLINIER; Patricia PAPERMAN, 2015). An obvious example is that no one produces everything needed to live, we thus need other people to conduct our most basic daily activities – such as eating and dressing (Annemarie MOL, 2008, p. 4). The concept of male independence presupposes invisible people and work that make it possible for them to act in the public world as dressed, fed citizens whose children are cared for. Paid care is also intersectional and part of colonial/modernity, for it is often performed by women, who have little education, in conditions of social vulnerability, often from less favored regions (from the rural regions, in Brazil, and from the global south, in northern countries) (Delia DUTRA, 2015; Marcela CERRUTI; Alicia MAGUID, 2010). Regarding the unpaid care provided by family members, it is also women that perform it and mothers are the ones who are expected to quit their jobs with the birth of a child that requires intensive care (Julie MAYBEE, 2011).

The logic of care seeks, therefore, to talk about this work and these invisible people, incorporating the ethics of caring for others, both bodily and emotionally, recognizing that the social fabric is sustained by this feminized work of caring, which is often erased and discredited (Nalu FARIA; Renata MORENO, 2010). This makes it possible to break the dichotomy between dependence and autonomy and recognize their interdependence. The need for care is no longer seen as an individual characteristic of some dependent people but is affirmed as a social relationship, which connects us with people we don't even know and who are distant in space and time, reminding us of our own weaknesses.

The feminist ethics of care proposes, therefore, that beyond the burden and invisibility of caregivers and the infantilization and disempowerment of people cared for, that the interdependence necessary for life can weave support networks. Feminist ethics of care affirm that we are not atomized individuals who occasionally come together, but that we are born out of relationships and are intertwined in them throughout our existence. In these relations, there is reciprocity in caring relationships, in which the people involved are neither simply caregivers or receivers, but occupy these places interchangeably, with agency, in a network of mutual dependency (Michael FINE; Caroline GLENDINNING, 2005; MOL, 2008; Whitney JONES-GARCIA, 2011; MOLINIER; PAPERMAN, 2015).

Thus, feminists have found opportunities for encounters, since they have brought to the center of the debate the interrelationship between care, disability and the body's material experience. To question and theorize about this is an important step for both caregivers and people with disabilities (WATSON *et al.*, 2004).

Regarding childcare, feminist disability studies thinkers – many of them caregivers – question some feminist discourses, which consider care as exploitation of women's unpaid work (Helena HIRATA; Guita Grin DEBERT, 2016). They also question other discourses of disability studies that consider that being in need of care and being dependent is a situation that colonizes the bodies and lives of people with disabilities. They thus question the discourse of independence that presupposes an individual autonomy in which mothers are expected to care for their children alone, raising them to become also independent and autonomous. This discussion is permeated by a devaluation of persons receiving care and of the lives of people around them, as it is culturally an intrinsically feminine activity, often exercised in the private sphere – peripheral and also feminine – in which lives are consumed: both of those who care as well as those who need other people to live. To think from a feminist ethics of care is to embody the experience of otherness, of the relationship, of feeling, of touching, of being open to other people's need. Caring relationships seem to highlight how

limited the male dimension of a supposedly non-relational world is and how it conceals people and relationships in favor of an imagined neutral autonomy and independence: “Caring is one of those repressed and excluded aspects of Western culture that is about flows, fluids, multiplicity, difference, rhythm, embodiment, transient boundaries, contingency and the maternal” (HUGHES *et al.*, 2005, p. 268).

Furthermore, the feminist ethics of care aims to highlight the false dichotomy between the person cared for and the caregiver, antagonizing people who exist mutually: it is only one of the multiple interdependent relationships that constitute us as subjects in alterity, but it is precisely this experience that best highlights the fallacy of independence, because it reveals the fragility of our bodies, our possible failures and pains. In relation to the embodied experience of the world, feminist theorists of disability studies have been crucial in the inclusion of the narratives of people who spoke from the experience of bodies in pain, that became tired, and needed rest (GARLAND-THOMSON, 2006; WENDELL, 2006; Bruna SILVEIRA, 2016; Fabiene GAMA, 2017). To affirm that someone is dependent on daily care does not require reducing the experience to individual medical issues or reducing the political struggle, because it reveals the ableism experienced through personal narratives (WATSON *et al.*, 2004). This perspective understands that we are all involved in mutual tasks of caring, dissolving the confinement of care to the private space.

The challenge is thus to think about the specificity of care in each relationship, so that it is neither subordinate nor universal. This can create opportunities to constitute oneself through paths based on interdependence, empathy, reciprocity and mutual help and not on the liberal concept of citizenship carved along the lines of colonial/modernity and its ideals of individual and productive independence (MOL, 2008; VALDÉS, 2008; Helena FIETZ, 2016).

With these cracks opened by women from disability studies, feminism begins to gain ground in this field and the silencing of women with disabilities or who care for people with disabilities begins to be overcome. But the challenge still requires using feminist theories to question how disability is seen through a fictional narrative of the body based on corporal marking and differentiation (GARLAND-THOMSON, 2006). Therefore, it not only concerns people with disabilities, but discourses about the body and its functionalities.

## Women and possible motherhoods

Based on the request by feminist theorists that disability studies incorporate the dimension of care in these discussions, there was also a demand that feminists consider the complex constructions of motherhood of women with disabilities or of mothers of people with disabilities in their analyses. There is a recognition that the category of motherhood (or non-motherhood) cannot be automatically transposed from non-disabled women – who are seen to be compelled to reproduction and caring – to people with disabilities, who are often discouraged or prevented from reproducing, even if this is a symbolic interdiction, as it is for transgender people (Mônica ANGONESE, 2016). For Margaret Lloyd (2001), this issue, along with those of sexuality and selective abortion, is crucial to differences and similarities between women with disabilities and those who are temporarily non-disabled.

This divergence gained prominence in Brazil, also because of the Zika epidemic. A lawsuit was presented in federal court regarding the possibility for abortion in cases of pregnancies of fetuses with microcephaly, while some people and groups, especially of women who are mothers of children with the congenital Zika syndrome who argued that this is not necessarily what they wanted or a priority, given the state’s disregard for the realities they experience with their children (PORTO; MOURA, 2017; Russell Parry SCOTT; Marion Teodósio QUADROS; Ana Cláudia RODRIGUES; Luciana Campelo LIRA; Silvana Sobreira MATOS; Fernanda MEIRA; Jeiza SARAIVA, 2017).

To understand the dissonance in productions of motherhood, it is essential to understand how it became a fundamental characteristic of the subjectivation of women, both those who are mothers and those who are not (Elisabeth BADINTER, 1985; Mary DEL PRIORE, 1993; Zeide Araújo TRINDADE; Sônia Regina Fiorim ENUMO, 2002; MARTIN, 2006; Andrea O’REILLY, 2004; 2006; 2008; 2012; 2016; Valeska ZANELLO, 2016). Motherhood can be read as a special form of women’s subjectivation, a path that has a quite recent history that cannot be reduced to instincts, hormones or the natural attribution of a genetic-morphological sex (ZANELLO, 2016). As a maternal dispositif, it is constituted from a supposed sexual difference and the ability to procreate that would justify linking the destiny of women to children and domestic work, that is, to the private world because of their femininity, for being docile, loving, submissive and, of course, caring.

To fit women into this place of producers and reproducers of life, which has served patriarchy and capitalism so well, it was necessary to combine several types of knowledge: religion, economics, medicine, philosophy, literature, law, criminology and psy knowledge – psychiatry, psychoanalysis and psychology and pedagogy. The feminist scholar Badinter (1985), in her work *Mother love: myth and reality: motherhood in modern history*, shows how conceptions of maternal love and instinct, a mother’s preferential or exclusive care, that is, the concept of motherhood as we conceive it today, to a lesser or greater degree, have been developed in European countries for some 300 years.

Badinter affirms that women were at first encouraged to breastfeed their children and care for them in the postpartum period to reduce the risk of death, which was very high in France in the seventeenth and eighteenth centuries. Mothers were then encouraged to accumulate functions related to this child: caring for it in its early years, feeding, educating it, including morally, accompanying it throughout life, etc., in such a way that a woman's life was tied to that of her child. A discourse was created about love, happiness, power within the home, sacrifice, devotion and guilt that trapped women in these bonds. By sacrificing herself and her time for the sake of her children, a mother acquires an importance within the family that is not comparable to others: the role of women as integral caregivers for their children became fundamental to the maintenance of the bourgeois family. This slow historical production resulted in women's responsibility for reproduction and the life cycle itself: contraception, pregnancy, childbirth, breastfeeding, care for children, youth, and good family health. (Lucila SCAVONE, 2003; Patty DOUGLAS, 2014). This dispositif silences the ambivalence of various experiences of motherhood, the necessary regulations and negotiations of it and its multiple interpretations for the lives of the women who live it (Mariléia SELL, 2012).

In Brazil, women were submitted (through domestication and training, in the words of Del Priore (1993)) to a Christian motherhood. With the ideals of marriage and reproduction, the ideal was forged (not without resistance) of the holy-mother – wife-mother who would find her biological and moral fulfillment in motherhood, devoting herself to the procreation and care of her children. This route relied on medical, scientific and religious knowledge and was inspired by the prevailing colonial and slavocratic logic.

Following the proposals of these researchers, I question the nature of the work of care for women. As previously discussed, care is an intrinsic part of human relationships and should not be limited to mothers with their offspring and family. Maternal love, the naturalization of maternal instincts of protection and care were historical constructions, which took centuries to be established, but today form a powerful dispositif for controlling women.

This dispositif includes definitions of what it means to be a mother, good and bad, when to be a mother (neither too young nor too old), how many children one should have (neither too few, too many or none), the financial situation needed to have them, how to breastfeed them, how to feel in the postpartum period, what to expect from the product of motherhood, among other norms about being a devoted mother (Lisandra E. MOREIRA; Henrique C. NARDI, 2009). These definitions vary with time, socioeconomic conditions, location and culture, as each woman's experience is produced by her age, race, education, gender identity, and marital status, in a reproductive hierarchy that creates a maternal normative that values some motherhoods and subordinates others. In an allusion to the sexual hierarchy, the reproductive hierarchy proposes an ideal of how to exercise maternity and care within the norm of motherhood: this ideal would be the motherhoods of white women, with privileged socioeconomic conditions, young, adult, healthy, with bodies without disabilities, exercised within heterosexual, monogamous marriages, invested in the intensive creation of their offspring. Each experience that deviates from the ideal, which can intersect women in different ways, positions them unfavorably in an hierarchical pyramid (Laura MATTAR; Carmem DINIZ, 2012).

The author Adrienne Rich (1995) called this normative the patriarchal institution of motherhood, which she affirmed works as a hegemonic discourse that produces this ideal, even if unattainable, of the good caring mother who, at the top of the reproductive hierarchy, would be: white, heterosexual, married to the father of their offspring, devout, altruistic and, above all, invested in the needs of their children (Angela WIGNALL, 2012). Thus, this institution positions women as either potential or actual mothers, or those in debt to motherhood (TRINDADE; ENUMO, 2002; Luci Helena MANSUR, 2003) and is a call to women to be mothers and to find fulfillment and satisfaction as such. And if a woman does not find satisfaction in motherhood, she should question her relation to the norm.

It is also important to position motherhood as both a product and producer of culture, as a socio-historical reality that implies hierarchy and inequality between the sexes (Eliane CADONÁ; Marlene Neves STREY, 2014). This inequality naturalizes women and their sex as caregivers, as unpaid workers in the production of life, as loving and tender, that is, as being biologically destined to be mothers and to mother.

This maternal dispositif that subjectivates women to the position of mother - even those who are not - produces them as natural caregivers. This is critical to understanding the dissonance between feminist and disability scholars. For some feminisms - especially those of the second wave, which focuses on the woman-subject - who are anchored in individualistic and universalizing concepts about the normative motherhood, maternity is at the center of women's oppression and, therefore, it is necessary to subvert the woman's place (in the singular) as a mother, as a womb (SCAVONE, 2003).

Meanwhile, some women with disabilities or women who care for children with disabilities or chronic illnesses, have experienced a denial of the possibility for motherhood and caring. They seek an opportunity to occupy the role of caregiver, since many are prevented by the same maternal norm from exercising this role. For many women with disabilities, the issue of motherhood and reproductive

rights is not a compulsory motherhood, but a denied one, with involuntary or encouraged sterilizations, selective abortions, and embryonic selection (Marsha SAXTON, 2006; Hebe RÉGIS, 2013), although such practices contradict the Convention on the Rights of Persons with Disabilities, article 23.

This denial intertwines the maternal dispositif, the norms regarding a normal body and motherhood, and what is expected from the product of a “normal woman”, which considers women with disabilities or chronic illnesses to be unable to provide care, unstable and asexual. They are also considered to be responsible for the transmission of their disability, whatever its etiology (Samantha WALSH, 2011). For those women whose motherhood is discouraged or even prevented by a supposed failure of what is expected of their bodies, the desire for motherhood can be an attempt to live another experience that does not reduce them, or their children, to their disabilities or diseases.

Thus, women with disabilities complain that they primarily want to be recognized as capable of performing motherhood or care. They want to be recognized as sexual beings, who are able to make decisions about their body, even if it is to exercise a hegemonic gender performance (LLOYD, 2001; LEWIECKI-WILSON; Jen CELLIO, 2011; GESSER; NUERNBERG; TONELI, 2014a, GESSER; NUERNBERG, 2014b). The first step for them, regarding motherhood, is not to separate themselves from the role of natural caregiver, but perhaps to be able to perform the traditional construction of women as mothers. On one hand, they want to perform the stereotyped role of motherhood while, on the other, they can suffer the same oppressions that non-disabled women suffer in this role, intersecting gender and disability:

... the experiences of disabled women in terms of both reproductive rights and family relationships, where it becomes clear that the primary discrimination experienced by disabled women arises not from society's expectations of them as wives and mothers, but from society's denial of both their right and their capacity to fulfil those roles. Inherent in this denial is a complex intertwining of prejudice about the body, discriminatory judgments about dependence and caring capacity, and prejudicial assumptions about expectations in intimate relationships. (LLOYD, 2001, p. 717-718).

They want, therefore, the right that temporarily non-disabled women claim: motherhood as a practice and a choice; which, for them, is the right not to have an abortion. Often, to be recognized in this role as mothers, they are required to have exclusive responsibility for their children's care: if they need other people for the basic care of their children and their homes, they are seen as poor mothers or as irresponsible, because if they need care, they cannot be caregivers. This care seems to be reduced to the performance of daily tasks, almost only manual ones. Thus, the idea is promoted that healthy children of mothers with disabilities would become young caregivers responsible for domestic chores. For Morris (1996, p. 94), these questions are posed only to mothers with disabilities, since they are the ones expected to perform household chores and the need for other people to participate in these tasks would indicate failure in their natural role as caregivers. Emotional, relational care is not usually addressed, only physical care, removing from these mothers the fundamental aspect of caring for their children lovingly and subjectively. By recognizing that we begin, live and, most likely, will end our lives interdependently, care can be seen as a community appeal to solidary reciprocity.

Another point of tension between women with disabilities and those who are temporarily non-disabled is related to having children with chronic or genetic diseases: women who care for these sons and daughters have some particular qualities. Their ability to produce a child is questioned, as well as their decision (when it was, in fact, a decision) to maintain the pregnancy of a fetus marked as unfit, and they are subject to moral judgments that consider them irresponsible and selfish (Felicity BOARDMAN, 2011).

When they have children with disabilities or illnesses, they are treated as caregivers before being recognized as women transformed in mothers. Their children are reduced to a burden they must handle, to a disease, to a disability, nevertheless, they recognize themselves as mothers taking care of their children's needs. Their children are seen, firstly, as medical cases, treated as diagnoses and problems to be solved by their fathers and mothers who must even make decisions regarding life support. They complain that the disability does not describe their relationships with their children and that there are affections, desires, joys and sorrows and they want to be the ones to tell their stories, which do not fit into medical records or special schools. In addition, they complain that many of the difficulties in mothering and caring for their children come from the relationship with the ableist society, especially the health and education services and markets, so they demand public policies that recognize their needs from their own experiences (Michael BÉRUBÉ, 1998; LLOYD, 2001; PANITCH, 2008; MAYBEE, 2011; Rachel ROBERTSON, 2011; Rayna RAPP, 2011).

If a woman's body was constructed, for centuries and by various forms of knowledge, as naturally destined for procreation, women who have this ability questioned may suffer from this alleged failure. For this reason, I turn to what Mary Del Priore (1993) found in the records of Colonial Brazil about women who had children considered monsters, whose ability to generate “good fruits” was questioned, as well as their moral conduct and construction as women:

The propagated feminine imagination served medicine to guarantee the principle that the mother was the seedbed where good or bad fruits thrived according to the quality of the land.



The perspective of a physical and simultaneously moral system that governed the female body is thus conquering mental structures, to meet the need to keep women prolific and orderly around the demands of the Church and the State (DEL PRIORE, 1993, p. 292 [author's translation]).

To this day, the burden for a child with a disability or genetic disease is placed on the woman and a possible failure of hers: in prenatal care for her health, her body, or even a genetic defect. With the advent of genetic mapping in the second half of the twentieth century and the possibility to use it during pregnancy with genetic counseling, the choice to have a child with a disability or illness is judged morally. It is important to note that this possibility is locally situated, since these tests are not accessible equally to all people around the globe, for financial, political and religious reasons, which is one of the ways in which the colonial/modern system continues to produce disabilities and perpetuate diseases for which there are already cures or prophylaxis.

For scholars from the disability movements (SAXTON, 2006; Ruth HUBBARD, 2006; MILLER, 2011), the race to use genetics can be seen as a new eugenic push, involving an attempt to draw a dividing line between lives worth living and lives that can be discarded. And this takes place without involving women in the process, since what is under discussion is the viability of the fetus and not a woman's desire to end a pregnancy or not. Central to this point is the struggle for control over a body, especially the female body and its reproduction.

Selective abortions, genetic tests and other types of gene therapy advocated in the event of a possible disability can be interpreted as a new attempt to control female reproduction, with quality controls and market ideas about women's bodies.<sup>5</sup> These quality controls can limit women's reproductive autonomy and bring them closer to the health market (SAXTON, 2006; Jen CELLIO, 2011; MILLER, 2011). Of course, there is a crucial difference between the realities found in countries where abortion is a women's choice and those found in Brazil, where abortion is only decriminalized in three situations: pregnancy resulting from rape, that is life-threatening to the mother or with an anencephalic fetus (DINIZ, 2003a; Alessandra BARROS, 2003). Although this discussion is still incipient in Brazil, it is relevant for cases of pre-implantation genetic testing. Furthermore, it is conceptually relevant, since these discourses are shared and are also producers of the maternal dispositif:

In circumstances in which the foetus is abnormal, the right to have the pregnancy terminated is *absolute and unquestionable*. It is not the fact that many women may feel unable to contemplate the everyday reality and long-term commitment of parenting a disabled child to which most disabled women object. It is, rather, the cavalier assumption that there is no place in a sophisticated society for people who are physically and/or intellectually 'abnormal', little recognition of the devaluing of disabled sisters as 'less than whole' women and therefore never full partners in the feminist struggle, and the lack of commitment to opening up the layers of ethical, philosophical and socio-legal debate demanded by the complex relationship between disability rights and abortion rights. (LLOYD, 2001, p. 719).

The limits of these tests are also questioned, because they seek to draw a line between those who are good enough to inhabit the world and those who are not, considering economic and random parameters much more than those agreed upon with the mothers and fathers. (HUBBARD, 2006). Tests are made available as they are discovered: it is the development of a test that determines whether testing will be conducted and not the need for a previously discussed condition or disease to be detected early. Feminist disability thinkers argue that it is not possible to consider equivalent syndromes or conditions that are easily diagnosed in tests such as those used for Down's syndrome, cleft palate or dwarfism with other rare diseases that culminate in short lives and that, precisely because they are rare, are not available in the standard tests. What do these technological tests and procedures tell us about the suffering that is likely to be involved or about our myth of healthy and perfect bodies? Even when tests exist and are made available, will the decision to undergo them be automatic and should they be mandatory (Susan COX, 2003; Alison PIEPMEIER, 2015; Catherine MILLS, 2015)? Furthermore, do tests and a possible fetal diagnosis reveal everything there is to know about a future child? This is not to say that these technologies should not be offered to women, the ones that should be responsible for making decisions about their own bodies and their lives, but that these technologies must be offered in combination with providing access to all kinds of information. And women who choose to carry on with the pregnancy should be provided with conditions to do so. Thus, it is crucial to hear about experiences with disabilities from women who are mothers and caregivers – who are made invisible in the care work and in the activism to understand their needs, which may be genetic testing, but may also be palliative care, better professional training of medical staff to deal with child suffering, and access to social assistance, quality public healthcare and education (PANITCH, 2008; Corinne MANNING, 2011). This may lead to better financial investment in studies endorsed by the public for which they are intended, as called for by the Convention on the Rights of Persons with Disabilities.

<sup>5</sup> An example of this is the profiles of egg and sperm donors, which emphasize youthfulness, beauty, health and professional success.

## Final Considerations

Finally, I understand that people are neither essential nor permanent, but “speakers and spoken of” (Rosa Maria B. FISCHER, 2001, p. 207), in constant transformation and reflection, about themselves and others that cross their path and that, therefore, we construct ourselves in constant relationships of alterity mediated by the available narratives and discourses. Thus, having space for other narratives, other grammars of care, many of them colonized and subordinate, allows us to recognize ourselves from other places and with new words:

... to speak of subordinate knowledge is not, therefore, just giving voice to those who have had their voices denied. More than that, it is participating in the effort to provide another grammar, another epistemology, other references than those that we have learned to see as the “true” and even the only ones worthy of being learned and respected. (Larissa PELÚCIO, 2012, p. 399 [author’s translation]).

This is perhaps the great disruptive potential that women living with disabilities can bring to hegemonic motherhood: to understand the historical construction of women as mothers. It can also create space for other possible or impossible experiences of motherhood: there is room for love, dedication, care, responsibility, suffering, dissatisfaction, ambivalence, frustration, happiness and regret. These are some of the ambiguities raised by mothers with disabilities or mothers of children with disabilities: different maternal (and non-maternal) experiences are possible. Cisgender mothers; transgender mothers; lesbian mothers; mothers with children with disabilities or chronic and rare diseases; mothers themselves who are ill or have disabilities; reciprocal, outsourced and shared care; and creative uses of bodies and technologies; the possibilities are as diverse as are women.

It is essential that feminist theories incorporate to their analyses women who are on the margins of compulsory motherhood, even if constructed by it, in order to expand the embodied understanding of possible motherhoods (LEWIECKI-WILSON; CELLIO, 2011; Mary MASON; Linda LONG-BELLIL, 2012; Harold BRASWELL, 2015). Considering intersectionality not as layers that add up, but as productions that emerge from specifically positioned places and people, the experiences of millions of women with disabilities and women with children with disabilities or chronic diseases are fundamental to transform feminist theories themselves. As for women with disabilities, approaching feminism and questioning the naturalization of motherhood can be a useful tool for them to deconstruct, based on their own narratives, motherhood as biological destiny. Thus, possible and impossible motherhoods can be more a verb and a practice than a monolithic noun. To be a mother is a situated practice, in constant negotiation with the norm, but can resist and destabilize the hetero-cis-abled-bodied-patriarchal normative maternal norm. Listening to the stories of caregivers’ who report dedication, love, interdependence, difficulties and state abandonment, and the exhaustion and loneliness of mostly female and maternal care, allows us to apprehend new meanings about their articulations, struggles, joint journeys and coexistences with children with diseases and disabilities (Diego PINHEIRO; Marcia LONGHI, 2017; Soraya FLEISCHER, 2017). Still with Pelúcio (2012): “These insurgent feminist voices speak from marginal, frontier locations, where there are no possible reductionisms, but tensions posed by the discomfort and challenges of being identified as inadequate” (p. 404, author’s translation).

Finally, as long as we hear other voices (or gestures), a wide range of experiences of motherhood and non-motherhood is possible (SCAVONE, 2003). These voices reveal that the truths with which we construct ourselves and with which we make meaning of the world are not natural sources and can always be different. In the words of a mother of a child diagnosed to be on the autistic spectrum: “perhaps we are contributing in a small and very personal way to cultural change and social inclusion. This is my hope. This is why we share our stories.” (ROBERTSON, 2011, p. 155).

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