

To care, to preserve, to love: debates on activism in gender and disability in Brazil, from the feminist ethics for care

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Introduction

More and more, the field of Feminist Studies has linked gender with other social categories, such as class, race/ethnic group, sexual orientation, generation, region and religion. This comes from the emergency of new demands in the core of feminism, in which the challenge of considering the diversity of its/their political subjects leads to evaluating differences and plurality of political context. On the other hand, the policies of inclusion for persons with disabilities, impelled by social movements, ended up providing greater visibility to this social group, thus causing this meaningful difference — the disability — to demand reflection and analysis.

Before beginning my presentation, I would like to point out that this paper is based on the Anglo-Saxon references of Disability Studies due to the fact that this field has emerged firstly in England and the United States of America in the eighties. With respect to the French debate in the area, since I do not command French language fluently, I will not make any reference to it, except mentioning that in both France and Brazil the field of Disability Studies is just emerging.

The social model of disability², initially proposed by the British sociologist Michael Oliver (1983), identified two major forms of oppression against persons with disabilities: the first form is the socioeconomic discrimination; the second, the medicalization of disability, thus of subjectivity too. However, Margaret Lloyd has argued that these oppressions are pertinent to disability, but not to gender, since they do not consider, by no means, the specific reality based on the double approach, the gender and the disability: the discrimination experienced by men with disabilities is augmented

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² There are two "classic models" of disability, the medical model and the social model, although Pfeifer (2002) differentiate 10 models or paradigms of disability. In general terms, in the medical model the focus is on the disability of the person, aiming at the cure or the medicalization of disabled body. In the social model, disability does not confine itself in the body, but it must be understood as a result of interaction between a body with impairments of physical, intellectual, psychosocial or sensorial nature and an environment that is unable to meet the architectural, informative, programatics, communicational and attitudinal demands, which would guarantee equalitarian conditions of insertion and social participation for persons with disabilities.

in the case of women with disabilities. As a matter of fact, women with disabilities experience, with greater intensity, the situations of social exclusion than men with disabilities and women without disabilities, due in part to patriarchal values predominant in capitalistic societies. Therein, women with disabilities are in double disadvantage due to a complex discrimination based on gender and disability and, consequently, they face a peculiar situation of vulnerability, whose complexity can become evident incisively through the incorporation of categories such as race/ethnic group, class, sexual orientation, generation, region and religion, among others.

For Michelle Fine and Adrienne Asch (1988), in conjunction with the categories of race/ethnic group, class and sexual orientation, the feminism should examine how disability interacts with gender and the heterogeneous forms of oppression that may emerge from these double approaches. These authors still suggest that a good way of unifying the concerns between feminists and women with disabilities would be to fight for sexual and reproductive rights.

To care, to preserve, to love: the emergency of the category of *care* in the feminist theory of disability

The feminist perspective of disability is ruled on the same theoretical-epistemological bases of gender studies and feminism, that is, following the example of dichotomy sex(nature)/gender(culture) present in this field of studies, the social model of disability did the same when it separated lesion from disability, producing the dichotomy lesion(nature)/disability(culture). As Debora Diniz defined: "lesion, for the social model of disability, is the equivalent, in the gender studies, to sex. And just as the role of gender that fits in each sex is a result of socialization, the meaning of lesion as disability is a strictly social process" (2003, p. 2). This verification implies, therefore, in the relevance of reflection of disability as a fundamental analytic category for the feminist and gender studies.

Mello & Nuernberg (2012) accentuated three axes in which it is possible to identify central points in common between Feminist and Gender Studies and Disability Studies: the presupposition of the body denaturalization, the identitarian dimension of the body, and **the feminist ethics of disability and care**, this last axis being the focus of this paper. As Diniz (2003, 2007) has observed, a large majority of the first generation of theorists of Disability Studies was composed by men with spinal cord lesion, identified by feminist theorists as members of the élite of disabled persons and,

therefore, multipliers of dominant discourses of gender and class in society. Thus, in the years 1990 and 2000, the social model of disability went through a new revision, with the definitive entry of feminist perspective, composed by the second generation of theorists:

Feminist theorists were the ones who, for the first time, mentioned the importance of care, spoke about the experience of sick body, demanded a debate about pain and brought the severely disabled to the center of discussions – those who will never be independent, productive or enabled to social life, regardless of which architectural or transportation accommodations are done. Feminist theorists were the ones who presented the issue of children with disabilities, of intellectual limitations, and the most revolutionary and strategically forgotten by the theorists of social model, the role of caretakers. **It was the feminism that led the cause of subjectivity in the experience of injured body, the meaning of the transcendence of the body to the experience of pain** [boldface mine], forcing a discussion not only about disability, but also about what it means to live in a sick or injured body. (DINIZ, 2007, p. 3-4)

Thus, the second generation of theorists of Disability Studies was pioneer in the criticism to the notion of independence of the first generation, who denied the dimension of care, proposing in its place the notion of interdependence as a human value applicable to persons with and without disabilities. One of most distinguished advocates of this idea is Eva Kittay (1999), philosopher and caretaker of her daughter with disabilities, for whom the *feminist ethics of care*, beyond the issue of gender, must transcend the issue of disability because of its being an ethical and moral principle of the human condition, since birth to death. In other terms, the dependence on others is a part of human condition, but also the guarantee of care is, for many people with and without disability, a fundamental right to the maintenance of life and the conquest of human dignity, which forces us to think about care as a responsibility of State and society, denaturalizing this activity as *naturally* feminine and proposing an *ethics of care* based on the human rights and recognizing disability, including the dependence as inherent to human diversity.

My master's course research on violence against women with disabilities has revealed to me the possibility of thinking about the violence against this specific segment from the standpoint of dimension of care, also considering the problem of the effects caused by the double stigma: gender and disability.

The great "revelation" happened when I verified that, oppositely to what is written in feminist publications about the issue of violence at home against women in

the conjugal sphere — in which the financial and emotional dependence is the main reason why women in situation of violence give up denouncing their aggressors — , the issue of financial independence is secondary in the violence committed against women with disabilities, because the first big question that arises about denouncing or not the aggressor is: "Who is going to take care of me?". These *caretakers* of the person with a disability include persons of her kinship, such as mothers, fathers, sisters, brothers, daughters and sons, who, to some extent, will take care of their daughter/son, sister/brother and mother/father with disabilities. The forms of violence against women with disabilities happen in the spheres of kinship, but not necessarily in the conjugal sphere as is the case of this research. In my viewpoint, this research has shown that the violence against women with disabilities is closer to the theoretic debates involving the violence at home against the elderly than to the violence at home against women, just because in the first case the dimension of care is more significant, whereas in the second case we have the conjugal dimension of the analysis. This does not mean that there is no aspect of feminization of violence against the elderly, as already mentioned in papers written by researchers such as Guita Debert & Amanda Oliveira (2009) and Alda Britto da Motta (2010), and does not mean that also women with disabilities are not victims of violence in the conjugal sphere, as shown in the research by Marivete Gesser (2010). So, *gender and generation* and *gender and disability* should be considered in the analysis of both phenomena. For example, the study contained in the doctoral thesis in Psychology by Gesser (2010) deserve distinction for addressing the violence against women with a physical disability in the context of conjugal relations. Starting from the relation perspective of violence, initially proposed by Gregory (1993), for whom it is important to give a relative importance to the model of male domination and female victimization in the context of conjugal violence, since "the conjugal relationships are of partnership and that the violence may also be a form of communication, even though perverse, between partners" (*idem, ibidem*, p. 183), Gesser finds out that the violence against women with a physical disability who were interviewed is related to the traditional roles of gender, socially attributed to men and women, accentuating a greater vulnerability of a woman to suffering violence due to her condition of physical disability.

This dimension of double vulnerability, by gender and disability, was also accentuated in my research.

Women with disabilities in the academia and in movements of feminists and persons with disabilities: the Brazilian case

Under the aegis of *social integration*, the Brazilian movement of persons with disabilities, in their majority managed by women with disabilities, was born in late seventies of last century, specifically in 1979, when the principal associations of people with disabilities got together thus beginning a political movement as protagonists, no more being tutored by the State, family members and specialists from the fields of health and rehabilitation. This movement formed a lobby of representatives within the Constituent Assembly of 1987, whose work culminated, in 1988, in the approval of the first chapters of the present Brazilian Constitution to mention the protection of specific and diffuse rights of persons with disabilities. This movement also participated in the campaign "Decade of Rehabilitation (1970-1979), organized by the United Nations Organization (UNO), in favor of the creation of more rehabilitation centers and educational opportunities (BRASIL, 2010).

This was the first generation that emerged simultaneously with the uprising and strengthening of the so called feminist movement of "Second Wave". But, oppositely to the its main demands against the sexist oppression, principally in relation to a greater sexual freedom and freedom of expression, the concerns of the disability movement focused on prevention of disabilities, health care and rehabilitation therapies. That is, at first, in analogy to sexism, here the struggle was against the oppression of disabled body. This concern had a sense, even though at that point the issue of sexuality of persons with disabilities was not discussed. The full exercise of their sexuality depended on discussing the issues of rehabilitation first. This would be perhaps one of the reasons why the movement of women with disabilities did not participate expressively in the feminist movement in Brazil for a long time and, to some extent, until the present days. Another possible reason for not including the demands of disability in the feminism is due to the inexpressive number of persons with disabilities who could enter the academic career and thus bring from inside the disability movement the issues of disability to the academia, so that they also could contribute to the consolidation of the Disability Studies field in Brazil.

Altogether, the issue of gender is not considered a theme having priority in the debates within the social movements of disability. In the same manner, in the feminist agendas and in government policies for women, the issue of disability is still in the

process of construction, sometimes being practically non-existent or usually mentioned just momentarily without the necessary discussion and deepening that this issue requires. In late November 2012, there was a meeting in Brasilia, invited by the Secretary of Women's Policies, with the object of discussing the main gaps in the actions, advances and challenges regarding the implementation of public policies for women with disabilities in Brazil, along with defining a proposition of a "conversation circle" on issues about women with disabilities to be included in the program of the III National Conference on the Rights of the Person with a Disability, in Brasilia, December 3-6, 2012. All this political scenario reflects a panorama that is characteristic of the social movements of disability, in which the "feminist conscience" is very absent and, consequently, it contributes to a timid advance of this debate in the feminist spaces, in the sense of making the feminists to become aware that the dimension of disability is important and it concerns all persons and not exclusively someone who has a disability. Therefore, it is in this context that my intervention as a feminist researcher with a disability has been needed in two ways: the feminist field and the disability field. For example, it was also with the intention of legitimating the agendas and demands of women with disabilities for public policies of gender that this researcher used her condition as a woman with a disability and her activist profile to anticipate the theoretical indicators about the issues of disability by means of written production, together with her co-advisor at master's course, of the article "Gender and disability: intersections and perspectives", whose main originality is in the composition in Portuguese of the revision of national and international literature about feminist debate on disability. This intellectual work is presented as a "form of activism" and it is the first and definitive tentative to fill this gap, not only to the political field of disability segment, but also to the feminist and gender studies, since what is at stake is the absence of a more meaningful dive over the epistemological foundations of the Disability Studies field, especially in its feminist perspective. As I have argued in former times, such foundations address the very central notions of corporality, of interdependence, of transversality, and of intersectionality of disability, not always thought in their tensions and theoretical and methodological implications in the field of feminist studies and gender studies.

Final considerations

In questioning the reasons for the exclusion of the disability dimension on the part of feminists, María López González (2007) shows at least three themes in which the issue of disability, particularly of women with disabilities, gets in confrontation with the feminist epistemology, explaining the absence of studies on women with disabilities in the theoretical analysis, in the feminist actions and agendas: the social image of disability in contrast with the model of woman in the feminist perspective, the disagreement over the issues about reproductive freedom and prevention, and the attention in the community. Continues the author affirming that, in spite of these divergences, in many ways the studies proceed "in confluent orientations on the part of two tendencies of theoretical analysis and political activism involved: feminism and disability movement" (*idem, ibidem*: 142). It is exactly the existence of persons who participate as academicians and activists in both tendencies and movements — and, therefore, they see themselves involved personally, sometimes as women and sometimes as persons with disabilities in these debates — that stimulates the development of new approaches of research and new interpretations about the complex and multifaceted reality of women with disabilities. But, how does the field of Disability Studies present or should present itself different in relation to other countries? One of the challenges is to consider the exclusively Brazilian approaches or, at least, as a back-cloth in the Brazilian reality of dimensions of gender, sexuality, race/ethnic group, and class in the intersection with the disability experience.

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