

## «The Maternal is Political»

### Exploring Mothering among Women with Disability

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#### Abstract

In this paper disabled women's mothering experiences in the Portuguese society are explored, drawing from in-depth interviews with 21 women with a variety of impairments, living in the metropolitan region of Lisbon. The women offer accounts of mothering which in many ways resonate with the findings reported in the mainstream literature on care, motherhood, and mothering. But disability is also a factor of *difference* in their lives that transforms and re-shapes their experiences and practices of mothering. Thus, both commonality *and* difference permeate their stories. Importantly too, women's narratives highlight their self-determination in the face of stigmatizing discourses which historically have operated to exclude many like them from motherhood. Thus for these women, mothering is also a site of struggle and empowerment. For them *the maternal is political*.

**Keywords** disability, motherhood, feminist theory

#### Resumo

«O Maternal é Político». Um olhar sobre a Maternidade entre Mulheres com Deficiência

Neste artigo são exploradas as experiências de maternidade de mães com deficiência na sociedade portuguesa, sustentando esta análise nos dados obtidos em entrevistas semi-directivas realizadas com 21 mães com diversos tipos de deficiência a residir na região metropolitana de Lisboa. As narrativas destas mulheres fazem eco dos resultados reportados na literatura geral sobre maternidade e o trabalho de cuidar. Mas a deficiência emerge também como factor de *diferenciação* na sua vida, que transforma e confere especificidade às suas experiências e práticas de maternidade. Assim, traços de igualdade e de diferença pontuam as suas histórias. No contexto de discursos estigmatizantes, que historicamente têm servido para excluir muitas mulheres com deficiência da maternidade, as narrativas destas mães sublinham também a sua autodeterminação na escolha do percurso de vida. Neste sentido, para estas mulheres a maternidade surge como um lugar de luta e empoderamento. Para elas, *o maternal é político*.

**Palavras-chave** deficiência, maternidade, teoria feminista

#### Résumé

«Le Maternel est Politique». Un Regard sur la Maternité entre Femmes Handicapées

Dans cet article les expériences de maternité de femmes handicapées dans la société portugaise sont explorées, à partir des données obtenues par le biais d'interviews semi-directives, réalisées auprès de 21 mères avec différents types de handicap, résidentes dans la région métropolitaine de Lisbonne. Les narratives de ces femmes font l'écho de résultats rapportés dans la littérature générale sur la maternité et le travail de soins. Mais l'handicap émerge aussi comme un facteur de différenciation dans leur vie, qui transforme et apporte spécificité à leurs expériences et pratiques de maternité. Ainsi, des traits d'égalité

aussi bien que de différence traversent leurs histoires. Dans le contexte de discours stigmatisants, qu'historiquement ont servi à exclure les femmes handicapées de la maternité, les narratives de ces mères soulignent aussi son auto-détermination dans le choix d'un parcours de vie. Dans ce sens, pour ces femmes-là, la maternité se constitue comme un lieu de lutte et pouvoir. Pour elles, le maternel est politique.

**Mots-clés** femmes handicapées, maternité, théories féministes

## Introduction

In her seminal book 'The Impossibility of Motherhood' feminist scholar Patrice DiQuinzio (1999) argues that feminist theorizations of motherhood should always focus on specific instances and specific contexts, rather than aspiring to develop a totalizing account, given that motherhood is itself always differently constituted. Thus, she encourages feminists to embrace a «paradoxical politics of motherhood [and leave behind] univocal, coherent and exhaustive position[s] on mothering» (DiQuinzio, 1999: 248).

In this paper I seek no more than to offer such «partial» and «fragmented» theorization, one which takes into account disability and the difference that it entails. More specifically, I want to explore disabled women's access to rights in Portuguese society by focusing on their mothering experiences.

To accomplish the task, I draw on key concepts of maternal theory and the feminist ethics of care and advance a framework revolving around three interconnected themes – *Maternal Practices and Thinking*; the *Meanings and Experiences of Mothering*; and the *Ethics of Maternal Care*. This framework is further informed by a rights approach to provide for an assessment of women's mothering experiences according to human rights principles and standards.

The women who participated in this study offered accounts of mothering which resonate with the findings reported in the literature on care, motherhood, and mothering. In other words, their intimate experiences of mothering, their practices, as well as the values informing those practices are in many ways similar to those of non-disabled mothers described in the literature. But disability is also a factor of *difference* in these women's lives that in small and big ways transforms and re-shapes their subjectivities, intimacies and lives, including their experiences and practices of mothering. Thus, both commonality *and* difference permeate their stories. Importantly too, across these themes women's narratives highlight their self-determination, resourcefulness and creativity in the face of powerful social, political, and medical discourses, which by stigmatizing disabled women as incapable of being «good mothers», have operated to exclude them from motherhood and to deny them their fundamental human rights. And thus for these women, who have achieved motherhood against all odds, mothering is a site of struggle and empowerment. For them the maternal *is* political.

## Methodology

The data presented in this paper is part of a larger study that used a multi-method approach to investigate the everyday lives of women who are mothering with disabilities in Portugal, and the social and polity contexts which shape and constrain them. A qualitative examination of women with disabilities' mothering experiences, collected through in-depth interviews, was thus combined with analysis of secondary data and statistics on people with disabilities in Portugal, and selected Portuguese law and policy analysis.

Twenty-one women with various kinds of impairments, who were mothering and living in the metropolitan region of Lisbon, were interviewed for this study. Women were recruited through a strategy of purposeful sampling (Maxwell, 1996), involving five organizations of people with disabilities and chronic diseases (two of them with a cross-disability focus), and two service providers in Lisbon. These organizations were specifically selected to create a sample with maximum variation. In fact, given their diverse membership and publics serviced, it was expected that the selected organizations would facilitate access to women with various types of impairments, and from a variety of social and economic backgrounds. After an initial contact, the five organizations proceeded to internal dissemination and recruitment of participants. Three basic requirements were established for sampling: first, that women had experienced the onset of disability prior to motherhood or at most during the first year of life of their children (to enable an exploration of women's experiences through pregnancy, childbirth, and the more demanding stage of childcare); second, that participants lived in the Great Metropolitan Area of Lisbon (where the large majority of resources for people with disabilities is available); and third, that the sample was varied in regards to types of impairments represented (to afford greater breadth to the inquiry).

After obtaining ethical approval from York University, fieldwork took place between 27 December 2007 and 12 January 2008. Interviews took in average one hour and a half and followed an in-depth, semi-structured format. A few questions and probes were prepared in advance to elicit the discussion of particular topics, but women were welcome to introduce new issues in the conversation at any time. There was no rigid order in which to ask the questions, and therefore each interview followed a unique rhythm and path. Questions invited women to share their understandings, experiences, and feelings about motherhood, to describe the kinds of obstacles they have faced in mothering, and the supports they have had available for them, including at the law and policy levels. Based on their knowledge and personal experience, women were also encouraged to identify areas in which they would like further supports or protections. Interviews were transcribed verbatim and analyzed with NVivo 8, software that supports qualitative analysis.

In the analysis developed, I was guided by the main concepts and findings of the mainstream literature on maternal theory and care. Thus, the broad themes

of «maternal practices and thinking», «experiences and meanings of mothering», and «values of maternal care» structured my reading and the coding of mothers' narratives. Subthemes within these large categories emerged from the data as I went through the transcripts, exposing both the similarities and differences between the experiences and accounts collected from mothers in this research, and those reported in the literature reviewed for the study. So a combination of «logico-deductive» and «grounded theory» approaches (Charmaz, 2004) informed my analysis, but with greater predominance of the latter over the former. In other words, if to some extent theory guided my approach to data, the most relevant analytic categories in this research were actually developed from the data itself, and not from pre-conceived hypotheses. Let me now turn to the analysis of these themes.

### Maternal Practices and Thinking

Sara Ruddick (1980/2007) has categorized as «maternal practices» the activities that mothers undertake which involve protecting the life of children («preservative love»), fostering their development («nurturing») and infusing in children norms, values and ideals in order to promote their social development and acceptability («training»). All mothers in this study described their engagement with similar activities. *Fernanda*<sup>1</sup>, a single mother of three, summed up in the following way the challenges involved in the work she, and other mothers, do:

«Being a mother is difficult. We have to know how to do it; it's not just bearing children. I don't know... it's beautiful if one likes it, but it's hard (...) very hard: a mother has to know how to love, how to reprimand ... how to say the right words at the right moment. It's not easy being a mom. (...) Being a mom ... I often say it's like a job, and it's the hardest job in the world. 'Cause one has to do it right!».

While carrying out the tasks that make up maternal work, as Ruddick explained, mothers engage in maternal thinking. Through maternal thought mothers make choices regarding priorities, attitudes, and values in caring for their children. The stories collected through this research reflected the complexity, and also the tension, pervading maternal thought for the large majority of these mothers. Against myths and social attitudes that construe disabled women as helpless and dependent, these mothers struggled to carry out their mothering roles on their own terms. In contexts marked by societal resistance to the notion that disabled women can parent, they strived to be validated as «good enough mothers», who could effectively protect and care for their children. This often created contradictory values for women who had to juggle their children's

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<sup>1</sup> To protect confidentiality and anonymity, all names used are pseudonyms.

requirements for protection, with their own need for agency and empowerment. All women were committed to ensure the safety of their children, but they also talked about their desire for doing things «just like other moms». Given the inadequacies of the physical and social contexts which they had to navigate, reconciling these two goals required from mothers careful thought, at levels that non-disabled mothers perhaps do not experience. *Filipa*, a mother and wheelchair user, recounted:

«We go out for lunch, we go shopping. I take him to the park. But I always make sure that it's a place where I can be in control, a place with accessibility. I don't go somewhere to explore, «let's see how it works» and take [my son] with me. No, I go first by myself, and then I take him with me. (...) When I'm all by myself I may take some risks, but when I'm with him, no! I don't take risks at all!»

Careful planning – an illustration of maternal thought – allows women to «be in control» as *Filipa* puts it, and enables them to negotiate their maternal role and personal goals in the face of the challenges that a physically inaccessible, hostile environment places on mothers whose embodiment differs from the norm.

In a short passage, while discussing the implications for mothers of engaging with practices of preservative, attentive love, Ruddick calls attention to the importance of self-preservation:

«In developing the discipline of attention (...) one must be constantly wary that moments of radical self-denial – which are necessary – do not become the perverted aim of attention rather than its occasional expression. (...) The attentiveness that aids growth, (...) is an attention that respects both self and other» (Ruddick, 1980/2007: 120).

Several mothers in this study highlighted this dimension. Particularly women with chronic conditions such as lupus, rheumatoid arthritis and multiple sclerosis, emphasized the need for a different pace of life, and the necessity of incorporating extended moments of rest in their daily schedules, in order to be able to cope with children's and other demands. Sometimes, though not always, these women expressed feelings of guilt, as these periods of rest were moments away from their children, and as they measured themselves up to – and fell short of – restrictive, traditional standards of 'good' motherhood. But mostly women were confident and proud of their achievements like, *Lúcia* who has multiple sclerosis (MS) and is a single mother of one, working full-time outside the home, disclosed to me:

«My mother never leaves home without making her bed. She always irons her laundry as soon as she takes it from the line. I mean, it's an example of life I can't follow! ... But I had to deal with this situation, and deal with it my own way. Sometimes I think: 'I'm not the best woman, nor the best mother, but I am who I am! And whoever accepts me

has to accept me as I am!" ... And there are other more important things like caring for my little girl, and that I do well. I care for her, I care about her, and I give her love, I try to love her the best way I know. But it's all done my own way!».

*Lúcia* struck me as an incredibly strong woman beneath a very fragile appearance. Beyond this evident love for her child, like others, *Lúcia* was aware of and responded to the need to care for herself, invest in herself, preserve in the best possible way her health and well-being – and that not just to be able to mother her child, but for her own sake. Given that the physical and social implications of impairments and disability require many women to think about, and act upon, their bodies and their lives in critical and unique ways, I argue that «self-preservation» should figure as an additional, distinct category in theorizations of maternal practices and thinking among mothers with disabilities.

### Experiences and Meanings of Mothering

In separating the patriarchal institution of motherhood from mothering, Adrienne Rich (1976) emphasized for feminism the importance of theorizing women's intimate experiences of maternity, and their relationship to their bodies and their children during pregnancy, childbirth, and childrearing. These, she argued, are distinct from the norms and models that rule motherhood in a patriarchal society. In this study, I also sought to explore the intimate dimensions of mothering and specifically inquired women about what it meant for them to be mothers. This question prompted long narratives, through which women disclosed their intimate experiences and revealed how maternity had contributed to reshape and transform their subjectivities. Specifically, themes emerging from these conversations included descriptions of mothering as a site of *desire, joy and fulfillment*, but also of *distress and resistance*.

#### *The Desire for Mothering*

All women in this study evoked the desire to be mothers. In this relatively small group of women, there was not one single situation where pregnancy happened against women's will. Two mothers, however, confided that their pregnancies had been totally unplanned. These women led a sexually active life but being disabled thought they could never get pregnant. So they were not using any method for contraception. When they discovered they were expecting a child, both reported shock and surprise. Currently, however, these women too declared experiencing mothering as a source of reward and pride.

The strong desire to mother has to be understood in the context of powerful ideologies and norms that discourage maternity among disabled women by viewing them as unfit and unable to live sexual and reproductive lives. *Leonor*

was very bold about this when she explained me some of the reasons behind her desire to have a child:

«I wanted to show everybody that [my husband] is a normal man, and that we have a sexual life as anybody else. Maybe we have a different sexuality – [he] knows I have no feeling if he touches me on my leg; maybe I have more sensibility on my neck, or on my ear, or in any other part of my body; maybe we more often make love than engage in the pure sexual act. But [getting pregnant], that was also to teach people!»

*Leonor* was committed to destabilize dominant ideologies by carrying the «proof» of her own and her partner's sexual and reproductive abilities – her son. What could seem like just a reverberation of traditional motherhood – achieving a respectful status through maternity – is thus turned in her words upside down. In this way, in a truly feminist fashion, *Leonor* reveals a politicized notion of mothering, making her personal experiences and decision about bearing child a broader political statement, aimed at transforming patriarchal ideologies and disabling negative understandings of disability and disabled women.

#### *Mothering as a Site of Joy and Fulfillment*

Women in this study talked extensively about the joy and sense of fulfillment they got from mothering. Feelings of joy and fulfillment typically began when women found out they were pregnant but continued throughout the early years of life of their children, and even into their teenage period and adulthood. Systematically exposed to prejudicial and discriminatory messages which construe them as asexual beings with no desire or ability to conceive and care for a child, many disabled women in this study approached maternity with anxiety and doubts about their own capabilities.

One of the most demanding periods in terms of care for all mothers is the first few years of a child's life. For mothers with physical and sensory impairments these demands can become more complex, particularly given the lack of resources and supports available. With the help of their partners and sometimes their own fathers too, mothers in this study developed ingenious solutions to adapt cribs and beds, baby bath tubs, and changing tables, and created devices for safely transporting their babies. Being able to care for their children as autonomously as possible, just like other mothers do, was thus another source of joy and fulfillment for mothers with disabilities, particularly during this early period. Women cherished the sense of responsibility and competence they got from successfully caring for an infant or a young child. This role enabled these women to reconfigure their social identities and replace the stigma of dependency often associated with disability, with the prestige and status that comes from being a «good» mother and carer.

For the majority of the mothers in this study, the joy and fulfillment of mothering persisted as children grew up. Women mentioned children's achievements in school, their positive social skills, even their attractive outlooks as reasons for continuing to experience mothering as a place of joy and fulfillment. They viewed children's successes as the result of their (adequate) maternal work, thus confirming to themselves and others their mothering abilities.

### *Mothering as a Site of Distress*

Along with the highlights, mothers discussed the dark side of mothering – mothering as a site of distress, pain and conflicting emotions. Two mothers for instance spoke of the difficult times faced during their children's teenage years, when boys and girls challenge parental authority in new and provocative ways. Another mother – *Mariana* – was dealing with her adolescent son's problems in accepting her disability. After being scorned by his peers in the private school he was attending because of his mother's disability, the boy was rejecting her presence in school events. *Mariana* was accepting of her son's decision, hoping that by doing so she helped keep the communication open between the two. But the emotion surfacing as she shared her story with me denoted that for *Mariana* mothering was at the time being experienced more as a source of pain and sorrow than of happiness.

For a few mothers, distress started right at the moment they got pregnant. The great joy of finding they were expecting a baby was entangled with moments of great anxiety, where women to some extent capitulated to prevailing social myths and fears of replicating disability.

Fears around the reproduction of disability were expressed by many mothers in this study. In an era where technology has become one of the founding ideologies of motherhood (Rothman, 1989; 1994) most women had voluntarily submitted to medical tests and exams in order to confirm, even before considering conception, whether they could have healthy babies. Only one mother – *Lurdes*, who is a blind woman in consequence of glaucoma, an hereditary condition running in her family – confided that she avoided doing any tests for fear of the results, and decided to take the risk, «at least once». Much like «fear», the notion of «risk» in this context suggests that high levels of distress encompass some disabled women's reproductive choices.

Throughout the conversations many women shared concerns about the potential impact of their disability on children's lives and relationships. Some like *Celmira* and *Clara* were afraid their children would grow up to dislike and feel ashamed of them because they are disabled; others like *Lúcia*, *Luísa*, *Margarida*, and *Sara* were fearful of becoming a burden to their daughters and sons, given the lack of formal supports available in Portugal for people with disabilities and the progressive nature of their own impairments. Unable to find a job and thus forced to depend on her mother for herself and her daughter's subsis-

tence, *Maria* expressed her frustration and sorrow about being incapable of providing for her child «as moms are supposed to do». *Margarida* summed it all up when she commented:

«[Mothering] has been a stressful process all along. First because it was difficult to get pregnant, then when I got pregnant (...) it was the fear of losing the baby at any time. I thought that this fear would end the day she was born ... and other fears started. So, I think I'll be afraid all my life».

Many non-disabled mothers (and fathers) can perhaps relate to this sense of permanent «anxiety», which is, in some ways, just the flip side of «preservative love» as Sara Ruddick described. What is unique about the mothers in this study, however, is that disablism contributes to, defines and shapes these experiences and emotions in particularly harmful ways. In other words, much of the pain and distress these disabled mothers go through is avoidable, and could vanish or at least be significantly reduced if women were mothering in a society that celebrated, accommodated, and supported their different needs, valued their lives as equal in worth and dignity, and protected their rights in equal terms with all other citizens.

«That is not, however, the kind of society in which these women live. Instead, Portuguese mothers with disabilities are confronted with ableist myths which stigmatize them as asexual beings, construe them as «dependent» and unfit, and distrust their abilities to care for others. Faced with no expectations of, and no support for their needs, they are discouraged from pursuing life goals available to all others. Yet some women resist demeaning labels and attitudes, and by embracing sexual, reproductive, and mothering roles, they make a political statement about their equal dignity and human rights. For these women, mothering becomes a site of resistance».

#### *Mothering as a Site of Resistance*

In analyzing how non-disabled mothers resist dominant discourses of motherhood, Erika Horwitz noted that, «sometimes their resistance was not manifested in their practices but in their ideologies and perception of themselves». She further observed that resistance is a «complex» process, better characterized as a «continuum» which gets «reflected in the degrees of empowerment versus struggle that each participant experienced» (Horwitz, 2004: 46). Along similar lines, mothers interviewed for this research evidenced different types and degrees of resistance, and revealed in a myriad of ways their views on what constitutes «good enough» mothering.

Given the traditional power of medical discourses in shaping disabled people's lives, *resisting medicalization* emerged as one important domain of struggle for many of these women. Resisting medicalization involved at the most radical level overtly challenging medical authority by asserting women's will in the face of doc-

tors and other medical staff's opposition. They refused to let their lives be ruled by medical concerns and priorities, and took their destiny in their own hands.

Pervasive cultural myths which reduce disabled people's lives to conditions medically defined can severely restrain life opportunities and choices. In their journey through mothering, many women encountered (and resisted) such prejudiced ideologies and attitudes, often coming from their closest family – parents, siblings and other relatives – who sought to deny them the right to be mothers. *Reclaiming the right to mother* was thus another form of resistance found in this study, as *Mariana's* story so poignantly illustrates:

«My parents ... I didn't ... I didn't have the courage to tell them until I was sure myself. I waited for a few months; I waited until the doctors told me that there were no problems. Still, I was very careful in telling them, because the first reaction they had was saying: "Oh but we have to interrupt [the pregnancy]. We have to interrupt!" (...) Their first reaction was to pick up the phone and "let's find someone to do an abortion"».

*Mariana* was 38 years old when she got pregnant; she held a university degree and was working in a steady job in the public sector. She had bought her own apartment, and at the time she got pregnant, she was sharing her home and her life with a loving, caring partner. Despite all these accomplishments, sufficient to construe anyone else as an independent being and someone able to make decisions on her own, *Mariana's* parents deemed their right to interfere in such a radical way and make that ultimate verdict upon their daughter's body and life. *Mariana* refused to accept her parents' advice and gave birth to a son. Her parents though, continued to suffocate her with love and overprotection, as she recounted:

«When my son was 3 years old his father and I split. (...) At that time my parents insisted that we come to live with them, but my project was more than having a son, it was building a family. And if the family used to be three people, from then on it would have to be only two [*emotion in her voice*]. So I stayed in my house, I stayed with my son. When he was six years old and was about to start school, I faced another big problem. (...) I became deaf as a consequence of my illness. (...) Once again my parents asked me to come live with them. Once again I thought, "I can't because the life I have chosen so far, if I go back, will lose all its meaning" – and so we stayed. (...) We never left our home».

*Mariana's*, and other women's accounts reflect the continuous struggles mothers with disabilities take on in order to achieve what non-disabled people can take for granted – the right to live meaningful sexual and reproductive lives, to found and live in a family of their own. Pervasive notions of «abnormality» and «deficit», which our societies use to define disabled women's bodies and lives, served to block any perception of their abilities and/or potential achievements.

Disabled women in this study resisted by redefining their limits and proving society was wrong. Better than anyone else these women know their own bodies and are aware of their unique possibilities and limitations. Therefore, they are not ready to relinquish to others, whether parents, relatives, doctors or someone else, the power to decide upon and shape their lives. What these mothers resisted was not impairment itself or the restrictions it potentially imposed. Rather, they refused to accept that their atypical embodiment constituted a legitimate basis for any form of social and economic discrimination, marginalization or oppression.

Resisting conventional views about motherhood thus involved more than just challenging stereotypical images and conceptions; it required the strength and courage to redefine maternity itself, by developing alternative and new forms of mothering.

### The Ethics of Maternal Care

The third dimension which emerged from mothers' accounts in this study related to the values guiding their practices. The work of the ethicists of care has highlighted the relational nature of care, and outlined the values that should guide such relations as «attentiveness», «responsibility», «competence», and «responsiveness» (Tronto, 1993). These moral standards have also been described by mothers in this study as directing their maternal practices.

All mothers, even those who were no longer required to perform intensive physical care, perceived themselves as *attentive* to their children's needs and evolution, and responsible for their care and well-being. Mothers further valued *competence*, perhaps because this was an area where they were most exposed to public judgment. So for these mothers, who strived to achieve quality in the care they provided to their children, it was particularly rewarding to be recognized as competent and a role model to others, as *Clara*, a mother with significant physical impairment, recounted:

«[My co-worker] she was really scared about everything ... she wouldn't give her new infant a bath and she would often call me and ask me what to do, for example when the baby had stomach pain, because they often have that. And that made me feel happy, because I had some experience already and I'd say to her – "do this or do that" – and she would actually listen. And then one day she told me: "Don't be offended but when I think I can't do something I always remember you, because I saw you giving [your daughter] a bath and I was impressed! If she can do it I can do it!" And that's when she stopped being afraid of giving her daughter a bath; before she would always call her mother-in-law (...) to help her. And I felt proud, because this was a person without any disability, and she had more problems caring for her newborn than I ever did! [laughing]

Some mothers talked about how they had adjusted their mothering practices as children grew old, thus attempting to remain *responsive* to their interests, abilities and needs. That was, for instance, the case of *Mariana* who, as described before, refrained from participating in schools events to respect her son's expressed wish. This and other examples indicated how mothers perceived maternal caring relationships as holistic and interconnected across dimensions of «caring about», «taking care of», «caregiving» and «care-receiving» (Tronto, 1993).

Further to the values of attentiveness, responsibility, competence, and responsiveness, women in this research highlighted the importance of *reciprocity* in their maternal care relationships. By reciprocity I do not imply that children were burdened with the care of their disabled mothers, as a recent literature on young carers is suggesting (e.g. Bibby and Becker, 2000; Cree, 2003; Dearden and Becker, 2004). Rather, I define reciprocity as the *ability of children to perceive and acknowledge their mothers' unique circumstances and needs, and adjust their own behaviour accordingly*.

Reciprocity, in this sense, is not a value unique to disabled mother-child relationships, but it certainly achieves in this context a great significance. In fact, to successfully carry out their mothering and caring tasks, disabled mothers depend in great part on children's ability to recognize and act in ways that are respectful of mothers' specific needs. To foster such an attitude, many mothers told me that they took the time to talk to their sons and daughters and explain to them the nature and implications of their impairments. So, at least in part, *reciprocity* emerged in consequence of mothers' intentional efforts. Mothers further emphasized that from a very young age some children «intuitively» perceived the difference in their mothers' embodiment, and started behaving in a responsive way as a result. Mothers who were wheelchair users, for example, observed that their toddlers would turn to their fathers, not to them, for physical activities. They also noted that young children were usually more obedient and calm when around their disabled mothers than when around other non-disabled adults. Whether intuitive or deliberately cultivated, *reciprocity* as a value embraced by both mothers and children made child management and control for mothers with disabilities a much easier task. Here's an example of how relying on her young son's reciprocity enabled this mother, a blind woman, her to supervise his playtime in a public space:

«I would pick him up from school and we'd go to the park. He often asked me to go to the park and I remember thinking – “and now, how can I go to the park with a three-year old when I can't see?” I was always very plain with him; I always explained my limitations to him. I'd say: “Look, here's the deal, I'll take you to the park, but we'll go to a small park because it's easier. And you have to promise me something. You know mom can't see you, and I cannot know where you are with my eyes. So you have to talk to me. When you change places you always have to let me know where you are, so that we keep the connection”. And that's what he would do.

He would leave the monkey bars and say “mom, now I’m going to the swing”, “mom, now I’m going to the monkey bars”, and he would keep the connection talking to me like that».

«Keeping the connection» – isn’t that what care is all about? By nurturing and valuing *reciprocity*, mothers with disabilities are also educating their children, whether male or female, to become caring individuals, women and men attentive and accommodating of the needs of others. In this sense too, mothering with a disability transcends the sphere of personal experience of those involved in each specific mother-child interaction to achieve a broader political dimension with potential impacts on the social fabric of interpersonal relationships and social care.

### **Concluding Remarks: Mothering with a Disability – Equal and Diverse**

This paper has sought to begin addressing a gap in the feminist literature on mothering by focusing on women who are mothering (and caring) with a disability. In doing so, I have responded to DiQuinzio’s call for a «paradoxical politics of mothering», one which rather than reducing mothering experiences to one totalizing account, articulates their complexity by detailing the conditions and situations which shape and reflect intersections of disability and motherhood.

As illustrated across the three dimensions explored – maternal practices & thinking, experiences and meanings of mothering and ethics of maternal care – mothering experiences of disabled women were found to be in many ways similar to those of non-disabled mothers described in the literature. But disability also emerged as a factor of differentiation in these women’s lives. In short, both commonality and difference permeated their stories. Elements of *difference* were evident for instance, in the emphasis on *self-preservation*, which expressed these women’s acute awareness of the material conditions of their bodies and impairment effects. Like other oppressed groups (particularly black women, e.g. Collins, 1991/2007; hooks, 1990/2007) disabled mothers also tended to view maternity as a site of *resistance*, yet in distinct and perhaps unique ways – above all, they resisted bio-medical conceptions which reduced their bodies and lives to medically defined and controlled conditions; and they also resisted normative conceptions of motherhood, which excluded alternative ways of practicing motherhood, notably those involving diverse forms of embodiment. Finally, more than all others, in achieving the standards of attention, responsibility, competence, and responsiveness that guided their maternal practices, as they guide relations of care in general feminist ethicists would argue, mothers with disabilities nurtured *reciprocity* as a founding value in the interactions with their children. Reciprocity enabled these mothers to establish authority and control in the

relationship, particularly in the context of a hostile environment pervaded with physical barriers.

O'Reilley (2007) has defined feminist empowered mothering as mothering that is lived from a position of *agency, authority, authenticity, and autonomy*. Certainly, mothers with disabilities in this study have struggled for autonomy and self-determination in carrying on their mothering responsibilities. But for them, autonomy is achieved, not through an emphasis on independence but through close alliances with their children, whom they raise in authenticity vis-à-vis their impairments and the implications it has in their lives, and whom they teach to willingly accommodate mothers' needs. In this sense I suggest the term *interdependence*, rather than autonomy, to convey the meaning of maternal empowerment for this group of mothers.

In an era where «intensive mothering» (Hays, 1989) and the primacy of the child seem to be creating another form of oppression for mothers in general, looking at the strategies women who are mothering with disabilities have developed to achieve personal empowerment and realize their human rights has thus potentially much to offer to all of us.

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*Artigo recebido em 30 de Outubro de 2010 e aceite para publicação em 1 de Março de 2011.*