AG AboutGender
International journal of gender studies

https://riviste.unige.it/aboutgender

DOI: 10.15167/2279-5057/AG2020.9.18.1199

Vol. 9 N° 18 anno 2020
pp. 23-49

Love, Care and the Undisciplined Body. A critical analysis of Disability, Citizenship and Motherhood

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Abstract

This paper aims to contribute to the recent debate on disability studies through a series of theoretical reflections on how women with physical disabilities experience their motherhood, examining the interconnections between motherhood, disability and citizenship which expand the definition of "caring" into intimate settings. In Italy, there is little research on how disabled women live the experience of becoming and being mothers and the impact of ableism and sexism on motherhood because of toxic discourses and stereotyped representations that imagine motherhood and disability as incongruous. It is essential to incorporate new perspectives that observe the ways in which non-normative bodies inhabit and expand the relationships of love, care and intimacy (Mapelli 2018). Disabled women offer the opportunity to attribute new meanings to *intimate justice* (McClelland

2014) and to break down the oppressive system that produces disabilities and marginalises disabled bodies.

Keywords: care, disability, ableism, motherhood, citizenship.

1. Introduction

The idea that people with disabilities can become parents continues to meet with considerable resistance because of the *ableist idea* that *doing parenting* requires not only love, care, and desire but also a productive body that can independently carry out the activities of the care and education of children. In fact, disabled people are hindered and discriminated against, especially in their reproductive choices and in their decision to “become” parents. Disabled people, imagined by society as sexually “neutral-dependent-incapable”, encounter different cultural and social barriers in expressing their desires and their “right to love”.

Why does the idea that disabled women can also be “mothers” upset us? Why does the cultural and social imaginary struggle to recognise “unprecedented” forms of intimate and affective relationships? Why is it considered scandalous that a disabled woman can have the desire and pleasure of “being” a mother? How do ableism and sexist discourses and representations place women with disabilities in relation to sexuality and motherhood? What is the impact of assistive technologies on mothers' relationships with their partners and children? How do mothers construct meanings around children’s needs and their own motherhood? How are gender and care expectations and the division of family tasks discussed and negotiated?

There are various objections to disabled parenthood that refer to the myth of the “natural” and “heteronormative” family; for example, “to raise a child you need a mother and/or a father with normalised and able bodies”, “fear of transmitting the disease to the children, and “fear of not being able to raise children”. In particular, the desire for motherhood clashes with the barriers and obstacles that women with disabilities encounter both during and after pregnancy, such as the lack of socio-sanitary structures for pre- and post-maternity and, in the case of physical disability, the impossibility of reaching the cots or the incorporated stereotypes of the health care staff. We should be particularly attentive to the ways in which essentialist ideas about gender/disability/citizenship shape emotional and parental relationships in families with “disabilities”. A disabled woman is faced with a “triple exclusion” and a “triple discrimination”: as a woman in a society dominated by men, as a disabled person in a heteronormative society and as a mother in a traditional and patriarchal society (Malacrida 2007; Frederick 2017). Moreover, studies on the bodies of women with disabilities have focused little attention on the experience of motherhood in disability scenarios. Little is known about the maternity or paternity experience of a disabled person. Parents with disabilities are viewed with scepticism with regard to their ability to “be” parents and “do” parenting. In Italy, there is little research on how disabled women live the experience of becoming and being mothers and the impact of ableism and sexism on motherhood because of toxic discourses and stereotyped representations that imagine motherhood and disability as incongruous, reinforcing the (hetero)normative representation and medicalisation of disability.

Since the ideal model of motherhood includes women’s responsibility for the care of their children as well as their husbands and partners, it is likely that women are more vulnerable to abuse or violence or are blamed for not respecting the cultural norms of ideal mothers as protectors and guardians against the risks their children may face (Malacrida 2007; Frederick 2017). In this sense, it is necessary to reflect on experiences and affective relationships to overturn the ideal “canons” of the body, care, motherhood and citizenship to “tear the veil” of the *ableist privilege* that perverts our bodies and desires. We can think of *ableist privilege* as a kind of bubble from which we observe and measure our bodies, our identity and our experience. Therefore, the following pages indicate the desire to collect some reflections on possible common and parallel paths between motherhood and disability.

2. The context of motherhood in Italy

The Italian cultural and institutional scenario has always been characterised by a strong “maternalist” character that tends to celebrate motherhood as one of the founding values of the nation and as a goal that all girls and women should aspire to and realise (Veneri

2019). Women and their fertile bodies are considered strategic resources for the reproduction of a society in which whiteness, heterosexuality and ableism become the criteria for differential inclusion and recognition of the fundamental rights of citizenship (Butler 2004). As far as family policies and the organisation of care are concerned, Italy is characterised by the domination of the male-breadwinner model, by a strong traditional persistence and binary division of gender roles (Naldini 2016) and by a model of "intensive motherhood" (Hayas 1996) that is "indispensable" (Naldini 2016).

Italy is distinguished by a scenario in which maternity continues to be identified as a natural and essential condition. This model of maternity is encouraged by public discourses and social policies that contribute to building a "culture" of parenthood, particularly of good motherhood (Naldini 2016, 234), where the right to care is based on the reduction of motherhood to a purely biological function. This leads to a devaluation of responsibilities and competences for those women who decide to become mothers outside the heteronormative model and, above all, rejects thinking of female responsibility outside of any patriarchal or paternalistic framework (Pezzini *et al.* 2016, 143). Institutions, through their policies, not only define opportunities, constraints and needs but also contribute to creating dominant discourses and notions of gender, family and parenting, thus reinforcing ideals around motherhood, fatherhood, and the "best interests" of the child (Naldini 2016). In the Italian context, the ideology of the good mother is strongly encouraged by public discourse and social policies that propose a parental model of "intensive motherhood" in which the mother is responsible for the well-being of the child (Naldini 2016). It is no coincidence that this scenario led the scholar Hays (1996, 8) to use the term "intensive mothering" to indicate the social construction of being a "good" parent: "child-centered, expert-guided, emotionally absorbing, labor intensive, and financially expensive".

In Western culture, the ideal mother is positioned as a woman who loves naturally and who is always present in taking care of her child. Mothers are subject to various pressures, including cultural models that encourage certain attitudes and public policies that leave mothers with the problems of reconciliation (Naldini 2016). The "moralisation" of motherhood, which is promoted and celebrated by "expert knowledge", characterises mothers' experiences by triggering frustrations and guilt at not being able to do enough. It contributes to strengthening the role of *institutionalised heterosexuality* (Lind 2004) in social and family policies by restricting access to care and thus the recognition of a social right of citizenship to those persons who do not fall under traditional gender norms (Roseneil 2013; Lind 2004). There is an ambiguity in the model of citizenship that encourages motherhood linked to participation in the labour market and childcare and, at the same time, removes responsibility for the role of "non-standard" and "undesirable" persons. The ideology of motherhood feeds on skilful hiring that requires mothers to have bodily and emotional standards that conform to the model of the good citizen mother and worker. Disabled mothers become the pivot of a crisis not only of the traditional family but also of the deconstruction of the reproductive model. Disabled motherhood represents a challenge compared to the naturalistic and traditional conception of motherhood and produces new forms of citizenship that deconstruct the relationships among generativity, the body and parenting, going beyond the combination of motherhood and reproductivity. Mothers with a disability, within this scenario, find themselves at the centre of important social and cultural change (Pratesi 2018) because they not only overturn prejudices about "non-regulatory" parenting and maternity but also deconstruct a welfare model that encourages the procreative desire of heteronormative or "strong" families (Roseneil *et al.* 2013).

In Italy, women's right to decide autonomously about their own bodies continues to be problematic for many disabled women. The experience of mothers with disabilities highlights the contradictions of rights access systems. Moreover, these mothers must move in an Italian social context characterised by an "ableist order" that discriminates against disabled people as recipients of certain rights because they are considered deviant by bodily regulatory standards. Mothers with physical disabilities disrupt the relationship between desire, motherhood and social expectations, bringing new, positive meanings to disabled bodies.

3. Citizenship, Sexuality and the Body: gendering disability

The notion of citizenship has been applied to conceptualise issues concerning the membership of a society (Tarner 2001; Sépulchre *et al.* 2019). Several scholars in recent decades have used the concept of citizenship in relation to disability, and the concept of citizenship has been widely used in disability policies, disability research and disability activism. The self-determination of the rights of disabled people has produced a change in the way citizenship is conceived by questioning the naturalness and universality of the concept of citizenship as Eurocentric, male-centric and heterosexual. However, these characteristics presuppose a judgement of "ability", which depends on the qualities that the citizen should have: autonomy, independence, rationality, reproductive capacity, and the ability to be "productive" (Sépulchre *et al.* 2019).

Feminist literature has long considered how the concept of citizenship is linked to the body (Garland-Thomson 2005; Hall 2011). The bodies of people with disabilities have always been the subject of medicalisation by the medical profession and expert knowledge that often makes the same people feel wrong in their bodies. According to Sebastiano Benasso and Luisa Stagi (2018), in a society of individual responsibility and the end of the welfare state, the healthy and able body is an indicator of good citizenship and a correct lifestyle. The "disabled" body is evaluated through a system that hierarchises not only genders but also bodies according to neoliberalist/ableist beliefs (Mitchell-Snyder 2015).

The standardisation of disabled bodies becomes "a technology of good citizenship" (Benasso e Stagi 2018) that produces a body standard (Fritsch 2017) to make disabled people more desirable and conscious. The notion of "good citizenship" is closely linked to the notion of the body and the "normativity" of disabled people. The modalities through which disabled bodies move in the social space, inhabiting and incorporating it, reveal the dynamics of exclusion/inclusion that produce logics of domination, gender, and power. Such women are imagined as passive citizens with respect to the "normative" model of citizenship. This "presumption" of normalcy has led several authors to examine and extend the concept of citizenship, deconstructing the heteronormative conceptions inherent in the category of citizenship. Without entering specifically into the debates and multiple theoretical definitions concerning the concept of citizenship, for which I refer to a vast literature (Naldini 2006; Orloff 1993; Cherubini 2018), several authors, starting from the emergence of this "new intimacy" (Mapelli 2018) and "new sexualities", have attempted to reformulate the concept of citizenship as "intimate citizenship" (Plummer 2003) or as "sexual citizenship" (Richardson 1998) to emphasise the intimacy and sexuality practices of individuals in everyday interactions.

For example, Plummer (1995, 13) develops a conception of intimacy that intersects with different spheres of individuals' lives, both in relationships with friends, relatives, and parents and in the people's everyday experiences, emotions and feelings. In fact, when we talk about intimacy, Plummer notes, we refer not only to aspects related to the sexual dimension but also to family practices, the care and education of children and relationships with partners (Ivi). To this end, he uses the concept of "intimate citizenship" as "a sensitising concept which sets about analysing a plurality of public discourses and stories about how to live the personal life in a late modern world where we are confronted by an escalating series of choices and difficulties around intimacies" (Ivi). Plummer rejects citizenship as a set of practices and discourses that regulate the choices of individuals (Plummer 1995; Roseneil *et al.* 2012):

> Intimate citizenship looks at the decisions people have to make over the control (or not) over one's body, feelings, relationships; access (or not) to representations, relationships, public spaces, etc., and social grounded choices (or not) about identities, gender experiences, erotic experiences (Plummer 1995, 14).

This conceptualisation of citizenship and intimacy serves to demonstrate the interconnections between the public and private spheres and how intimacy practices are shaped by institutions, norms, and media discourse (Gabb 2010). Therefore, this concept of citizenship represents a "new way of thinking about citizenship that recognizes the importance of political, social and cultural transformations of recent decades, and grants a central importance to women's movements and lesbian and gay movements" (Roseneil 2012, 42).

In similar terms, Richardson (1998) elaborates the concept of “sexual citizenship” to take into account more than the dimension of social and political rights. In fact, this concept makes it possible to rework a new framework of “sexual rights” and thus frames sexuality in a “perspective that integrates desires and rights, intimacy and civil recognition, sexual bodies and legislative bodies” (Ruspini *et al.* 2010, 106). Richardson recognises that the extension of sexual rights and the recognition of a status of sexual citizenship is linked to the institutionalisation of a heteronormative model of sexuality, which subordinates sexual minorities to assimilating certain practices, discourses and ideas that are considered non-deviant:

> Heterosexuality is constructed as a necessary if not sufficient basis for full citizenship. In this sense, we can talk of the sexualisation of citizenship [...] certain forms of citizenship status are closely associated with the hegemonic form of heterosexuality (Richardson 1998, 84-85).

With respect to the sexuality of disabled people, the mainstream discourse on sexuality denies recognition of their sexual desires and autonomy and pathologizes their bodies as promiscuous and dangerous. Michael Gill (2015, 3) coined the concept of “sexual ableism”: “Sexual ableism is the system of imbuing sexuality with determinations of qualification to be sexual based on criteria of ability, intellect, morality, physicality, appearance, age, race, social acceptability, and gender conformity”.

This concept is useful to illuminate that ableism is not a neutral concept. How do normative assumptions about sexuality, capacity and autonomy continue to structure the choices to marry and to have a family and children and the practices of disabled women? How does ableist rhetoric guide the sexual imaginations of disabled women?

Within the heteronormative scenario, there are the requests for the sexual recognition of disabled people that represent resistance towards the current normative order. These actions of resistance and protest show the interweaving between the recognition of the new dimensions of sexuality and the production of new citizenship practices. For people with disabilities, being recognised as citizens means being recognised as subjects who claim the right to freely live their personal, sexual and family choices. The “right to sexuality” represents a new and positive discourse within the debate on citizenship.

Disabled bodies represent forms of “intimate citizenship” (Plummer 1995), and social inequalities become the scenario in which disabled mothers claim their right to be parents and form their “sense of kinship”. For this reason, the extension of the right to parenting to disabled mothers is a recognition of the inclusion of these individuals as ordinary citizens beyond their sexual orientation. It means being legitimately authorised as parents and caregivers and recognised in care practices between parents and children (Pratesi 2018). Intimate life becomes an object of battle in the public sphere (Plummer 1995).

In fact, the care and citizenship practices of these mothers represent an incredible resource to rethink welfare systems (Naldini 2018) according to inclusion principles that combine respect for differences and equality. For this reason, disabled mothers find themselves at the centre of a major social and cultural change because they challenge heteronormative notions about parenting and not only overturn prejudices about disability but also deconstruct a welfare model that encourages the procreative desire of the traditional or “strong family” (Roseneil *et al.* 2013) while marginalising homosexual identities to a substantial paradox: being good citizens and/or making good parents. In this way, the need to be legitimised as good parents is linked to the idea of the production of good citizens. It is a question of rethinking welfare that equally values and includes all citizens regardless of sex, gender, ethnicity, ability or sexual orientation and, above all, that does not create an idea of census citizenship in access to rights (Naldini 2018; Casalini 2015). Within such a framework, mothers with disabilities question and report to reconsider the heteronormative model of sexuality, procreation, and reproductive capacity. These new non-regulatory intimacies (Mapelli 2018) transcend the boundaries of the private sphere, intersecting with sexual, political and bodily dimensions (Ivi) and bringing new practices of sexual relations to the public scene:

> Practices such as these within non-normative intimacies – between friends, non-monogamous lovers, ex-lovers, partners who do not live together, partners who do not have sex together, those which do not easily fit the ‘friend’/ ‘lover’ binary classification system – and the networks of relationships within which these intimacies are

> sustained (or not) have the following significance: they decentre the primary significance that is commonly granted to sexual partnerships and mount a challenge to the privileging of conjugal relationships in research on intimacy (Roseneil *et al.* 2004, 137).

3.1. Gendering dis/ability

Disability is not a neutral experience. According to Thomas (1997), disability is “gendered” and has a different impact on the experience of being a man or woman with a disability. The UN Convention on the Rights of the Disabled recognises “multiple discrimination” against disabled women due to the intersection of disability and gender. Feminist disability studies (FDS) have explored how gender and disability categories, along with other identities, intersect and how sexism, ableism, power, racism, classism and heteronormativity intersect in the everyday life of disabled women.

According to Asch and Fine (1988) women with disabilities face “sexism without the pedestal”, because they face different forms of violence and discrimination and are understood as asexual and deviant from the gender norm. Since gender represents a *social structure* (Risman 2004) that defines the roles, opportunities, constraints and expectations that are attributed to belonging to one or another gender, it is interesting to understand how women with disabilities are *undoing gender* or *re-doing gender* (West, Zimmerman 1987) in requests for ideal motherhood and parenting practices and the complex articulations that reveal sexuality, disability and the body in gender inequalities. The overlap between gender and disability is instrumental in creating a structure of inequality of access to resources and producing a difference between men and women, between fertile and infertile subjects, and between disabled men and disabled women (Risman 2004; Connell 1995).

In the case of women and girls with disabilities, they are expected to conform to gender patterns and to expectations and responsibilities of care. The contrast between women without disabilities, as independent and self-determining, and women with disabilities, as dependent and vulnerable, is often represented and used in common-sense discourses to support a hierarchy between bodies that reproduces masculine ideas: not all women can be mothers, not all women can make decisions about their bodies, and not all women can have a sexual relationship. For this reason, it is necessary to understand how family life is shaped by ability and sexism and the results of this intersection in family and care practices.

4. Re-conceptualising care

The aim of this section is not to conduct a complete analysis of the issue of care but rather to reflect how disability studies might extend the notions of care, citizenship, and mothering. The concept of 'care' is an ongoing part of sociological debates and is a global experience (Pratesi 2018; Kittay 1999; Ottaviano 2020). Several authors have examined the concept of care, its dimensions, and emotional boundaries in care practices. Care is understood as an activity that allows one to observe the relationships between actors and institutions and as a public or private responsibility carried out by services and involving family, friends and relatives (Naldini 2006, 92-93). This lens can lead us to examine both the macrointeractions between those who "receive the care" and those who "give the care" and the microinteractions of "doing care/undoing care" (Pratesi 2018). According to Pratesi (2018, 51):

> The experiences of care produce results of emotional stratification at the micro level that are reflected at the macro level. [...] conceptual categories of *gender, sexual orientation, care* and *emotion* can be more explicitly reframed as *public* processes involving status and power dimensions as well as *private* psychological and emotional processes.

Grasping the relational dimension of care means giving weight to the emotional and relational ties that bind individuals. Care is a set of embodied practices (Pratesi 2018; Ottaviano 2017) that allows us to observe the *relational dimensions* between actors and institutions as a public or private responsibility carried out by services and involving family, friends and relatives (Naldini 2006, 92-93). Care, Ottaviano suggests (2017) has to do with the body and its putting into play, with emotions and relationships, the ability/incapacity of a subject. The bodily experience in healing activity and the perception of the materiality of the body through physical contact in the healing relationship circumscribe the meanings around the physical vulnerability not of the body but 'through' the body. Care is a contradictory category in disability studies. Historically, within the medical literature, disabled people have been positioned as passive recipients of care. Garland-Thomson (2011 in Rembis, 2016, 146) suggests that feminist disability studies on care have brought attention to the gendered and relational nature of care and the need to take seriously the materiality of bodies and the meanings we attach to them. In the biopolitical age of biomedicalisation, care and disability are intermixed in family life (Ivi). Care is embedded in the experience of the people involved in caring relations, which are constructed at the intersection of gender, race, class and ability. Care emerges as a site of inequality that cuts across gender and the body, where the definition of "good care" is related to a person's ability to offer care (Rembis, 2016; McLaughlin 2008). One of the merits of feminist disability studies has been its overturning of the image of disabled mothers from *care-receivers* to *care-givers* (Olsen and Clarke, 2010) and changes to the view of disabled people as asexual and childish (Ivi). Moreover, the notion of *interdependence* highlighted by Kittay (1999) draws attention to how dependence is always socially constructed and relational. Care relationships automatically make us vulnerable to the presence of the other person, determining the *experience of precarity* that characterises all social and affective relationships (Butler 2017).

The recognition of the right to care as a right of both care-givers and care receivers and as a form of responsibility represents a recognition of social citizenship rights and involves reconsideration of welfare and family policies by taking into account new types of family forms, care arrangements, reproductive labour, and gendered and generational kinship. Consequently, care responsibilities become spaces of inclusion and exclusion for these mothers who decide to become parents beyond the image of care-taking subjects. The elements of care relationships highlighted by the ethics of care literature allow for a broader understanding of the histories, complexities, obligations, and responsibilities of care relationships and how this might affect carers' social inclusion (Hill *et al.* 2017). Caregiving is considered one of the main arenas of "doing gender" (West and Zimmerman 1987; Souralova 2016).

The Western world, caregiving work and motherhood are considered "a cultural motif that functions to symbolically structure female adult biography" (McMahon 1995, 25 in

Souralova 2016, 42). According to Souralova (2016, 42), “women build their ‘normal biographies’ by responding to normative gender orders in which femininity and caring are inevitably entwined”. There is a dialectical relationship between care and femininity: care is gendered as a female activity, and femininity is reaffirmed by care (*Ibidem*). Bringing in care means unmasking the binary gendered thought that underlies certain ideas of masculinity and femininity (Pratesi 2018, 30). Care is an expression of family relationships. Family care illustrates how individuals behave within families, in parent-child relationships, within couples, in sexual relationships or in any other relationship that is experienced as “closely connected”. Care embedded in family practices is therefore a peculiarity of family relationships. Thus, Morgan (2011) notes that care practices are intertwined with “family practices”. He explains:

> The ‘caringscapes’ perspective is significant in a variety of ways. First, it provides another way of decentring the family. The points of departure are issues to do with care or health rather than with 'the family' and its supposed functions. Yet, family relationships are clearly implicated within this framework but in a much more fluid way. Second, this approach provides a ready way in which issues of structured inequalities and power may be incorporated. These considerations remind us of the steepness or distance of key features within a given care landscape. Finally, this approach provides links between individuals and their life trajectories, their social configurations and relevant social institutions, all these being located within a temporal framework (Morgan 2011, 3).

Attention to family practices allows us to grasp the ways in which individuals construct their care “doing”, allowing us to see how the normative models, the dimensions of power and the activities of giving and receiving care with respect to “being a family” are reinterpreted in daily life. The perspective of family practices allows us to grasp the heterogeneity and complexity of daily experiences of intimacy, care and parenting (Morgan 2011).

4.1. Disabled Mothers and young carers: care as a border zone

In "child-centric" societies, the desire to become a parent and have children can be very strong and strongly precious (Faircloth 2013; Hays 1996). In fact, there has been a profound change in the way children are considered and valued (Zelizer 2009). While non-disabled women are expected to become mothers, women with disabilities face several obstacles if they decide to become mothers and carry out their procreative project. According to Frederick (2017, 79), the presumption that disabled women cannot have babies occurs in conjunction with the "project of normalcy", in which their needs and rights are often obscured and invisible. Motherhood and disability are seen as incongruent, and disabled women are marked as "risky mothers" because they openly defy neoliberal values that prescribe that disability should be prevented through reproductive self-regulation (Ivi). Disabled women experience an "imperative of childlessness" (Ivi) and are imagined to be inadequate for children's care. In contrast, when disabled women decide to become mothers, they feel pressure in comparison to the ideal of good mothers/ideal citizens (Malacrida 2007; Goodley 2014; Fritsch 2017).

In the case of mothers with disabilities, this discourse becomes even more pervasive as they move between trying to claim their reproductive desire and being legitimised in their role as mothers. The advent of a child in this arena serves to emphasise the gendered and contested nature of parenting. While ideal motherhood is both unattainable and blameworthy for all women, for women with disabilities, it is a particularly challenging construct to negotiate (Malacrida 2009). In other words, the ableist gaze pushes them to "pass" as non-disabled (Fritsch 2017; Campbell 2009) through the embodiment of traditional expectations of femininity (Malacrida 2007).

Mothers are expected to dedicate considerable time, energy and love to their children's development. Neoliberal ableism discourse reinforces mothers' individual responsibility and blame for raising children who are at constant risk. Women with disabilities are subject to double stigmatisation and negative judgements about their care and responsibility: hegemonic ideas about femininity, attractiveness and dependence make women vulnerable to social isolation or sexual and emotional exploitation (Malacrida 2009). Following Cappellini (2019, 15), "the ideology of intensive mothering clearly has structural optimism (regarding the potential for a future good life for the family, and in particular the children) […] intensive mothering may well represent an affective (sub)regime of the dominant affective regime of neoliberalism”. The idealisation of good motherhood becomes a cruel device against women with disabilities who may encounter problems that make ideal motherhood difficult, if not impossible, to achieve. Disabled women may resist their stigmatised identity by trying to hide their bodily difference or to ‘pass’ as a supermom to gain acceptance and recognition (Thomas 1997; Grue e Lærum 2002; Malacrida 2009; Lappeteläinen 2018). The risk of losing the right to care for their children constrains disabled mothers to “perform” themselves as “normal”. Furthermore, intensive mothering conceptualises children as “vulnerable, princesses and innocent beings”, which implies ongoing care to protect children's needs (Hays 1996; Zelizer 1994). In fact, childcare has become the arena in which tensions between the public responsibilities of the state and the private responsibilities of parents are blended. For this reason, childhood is increasingly seen as a social problem (Oakley 1994, 17) in which judgements and paternalistic rhetoric about children’s best interests are mixed. With respect to cultural and institutional ideals of good motherhood, parent/child relationships are expected to reproduce an “ablecentrism order” that regulates the expectations of care and responsibility. The bonds of dependence and interdependence are drawn and transformed into daily interactions, in “being in connection” with others and in “depending on others” (Naldini 2006).

According to this vision, the parental relationship expresses a relationship of interdependence where care is placed at the centre of generational dynamics and family life and the boundaries between needing care and raising a child are confounded. Consequently, Keith and Morris (1995) coined the expression *young carer* to analyse children and young adults who have informal caring responsibilities, often for a family member. As Battalova (2019, 11) writes:

> Disability plays a crucial role in negotiating the relationship with children. Women often blame themselves for putting too much burden on their children. Nonetheless, children often become conduits for accessibility; they can ask for help and can help their mothers navigate inaccessible spaces. Notions of care and help are wrapped up in class and marriage status, inaccessible spaces, and mother-child dynamics

Their role in care work highlights the tensions between an inclusive model of society that, on the one hand, leverages on the individual and his or her ability to empower himself or herself; on the other hand, it highlights the lack of support for disabled women. Additionally, Fritsch (2020, 250) notes that help from children is often necessary in an ableist world. In fact, Grue and Laerum's research (2002, 679) reported the following:

> The majority of the women were conscious of the role their children had when it came to help them. They experienced, however, that even if other people shared their opinions about how important it is for children to have certain obligations, they somehow considered it differently when the child helped a disabled mother rather than a non-disabled mother. Children's helping was seen within a discourse of disability and not within a discourse of socialisation. Within a discourse of disability, where the children are often seen as assistants for a disabled mother, questions about how the children are growing up can easily arise.

To overcome the tension between children's agency and disabled parents' rights, it is necessary to rethink the *relational and intra-corporeal* (Fritsch 2015) *dimension* between individuals and the social context to understand how all the actors involved, including children, *practise* and (re)-*make* new notions of citizenship, care, childhood and parenting. It is necessary to understand the involvement of children in negotiating and/or resisting caring roles (Olsen *et al.* 2003).

5. Men as caregivers of disabled women: potential social transformation?

How does disability impact the husbands/partners of disabled women? What are their social expectations, and how do they position themselves in relation to their partner's disability? How is male caregiving positioned in relation to dominant ideas of masculinity? How have men's responsibilities as partners/fathers been conceptualised?

The concept of hegemonic masculinity (Connell 1995) reveals a prominent paradigm in which gender order is understood and represents an expression of the patriarchal social structure:

> The hegemonic representation of masculinity contains in itself a relationship between body and subjectivity that is only apparently contradictory: a male body carrying a subjectivity composed of exuberance and powerful desire, and at the same time the ability to dominate emotions, which is counterbalanced by a female body from which the expression of an autonomous desire has been socially removed and whose emotional dimension would preclude the expression of an ethical exercise. The male body is represented as an expression and instrument of an active subjectivity, the female body is represented as a constraint that precludes a full subjectivity of women (Ciccone 2019, 42, my transl.[1]).

Ideals of masculinities continue to demand heteronormative standards to maintain male power and domination. The rhetoric of the crisis of masculinity prevents men from processing their vulnerability (Ciccone 2019) through the removal of their corporeity (Ottaviano 2020).

However, in recent decades, authors such as Kimmel (2010), Hanlon (2012), and Elliot (2016), starting from the concept of hegemonic masculinity, have extended this definition to consider the experiences and practices of 'being' a man. Several scholars in the field of men's studies have examined male participation in care settings by employing the concept of "caring masculinities" (Hanlon 2012; Elliot 2016) to investigate the relation between care, gender and masculinities (Dermott 2016; Doucet 2015). Men's participation in providing care, nurturing and intimacy suggests an important aspect of the discussion of changes to hegemonic masculinity and a movement away from the traditional provider role by adopting the "new and involved" model of fathering (Connell 2006; Miller 2011). However, men's caregiving experiences for women with disabilities have been ignored

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[1] Original text: "Questa polarizzazione non distingue tra loro maschilità differenti (per quanto evidentemente assuma differenti declinazioni e articolazioni) e la compresenza di queste polarità non mostra una contraddizione, ma è costitutiva di una costruzione simbolica che organizza in modo gerarchico l'ordine di genere. La rappresentazione egemone della maschilità contiene in sé una relazione tra corpo e soggettività che è solo apparentemente contraddittoria: un corpo maschile portatore di una soggettività composta da un'esuberanza e un potente desiderio, e al tempo stesso dalla capacità di dominare le emozioni, cui fa da contraltare un corpo femminile di cui è stata socialmente rimossa l'espressione di un desiderio autonomo e la cui dimensione emotiva precluderebbe l'espressione di un esercizio etico. Il corpo degli uomini è rappresentato come espressione e strumento di una soggettività attiva, il corpo femminile è rappresentato come vincolo che preclude una piena soggettività delle donne".

and underdeveloped. Male primary caregiving for family members is a culturally invisible phenomenon. In her study of disabled mothers in Russia, Alfiya Battalova (2019; 8) noted that most disabled mothers said that their husband's support was very important. In her analysis of partners' involvement with disabled women in care activities, she notes two important ways of support: physical/childcare support and financial support. These aspects are important to reflect on the relationship between disability, gender equity and non-disabled caregiver males. For example, it is necessary to consider whether the involvement and support of partners of women with disabilities also translates into greater equality in relationships and gender roles and whether partners are also fathers 'involved' in childcare and husbands are 'egalitarian' towards their partners. Care work performed by men should re-think the affective lives of men and women. Looking beyond the idea of the hegemonic notion of manhood, Ottaviano (2017, 172, my transl.[2]) notes:

> Care [...] can be seen as a threshold from which to somehow 'measure' the evolution and change in gender relations. A cure that, evidently, has to do with the body and its putting into play, with emotions and relationships, with the ability/incapacity to say and to say, with the silences of (between) women and men (Ciccone, Mapelli 2012) [...] Putting the body into play, showing one's vulnerability – as a subject/object of care – making one's emotional relationships explicit, learning to say emotions – rather than acting under control or without control – can become precious resources to go beyond role stereotypes, beyond patriarchal imperatives, beyond gender cages.

Ottaviano (2020, 135) suggests an idea of "male educational care", the involvement of men in care practices, where caring and vulnerability become new paradigms with neoliberal and individualist discourse. Extending Ottaviano's analysis, I propose to observe

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[2] Original text: "La cura […] può essere guardata come una soglia dalla quale "misurare" in qualche modo l'evoluzione e il cambiamento delle relazioni tra i generi. Cura che, evidentemente, ha a che fare con il corpo5 e la sua messa in gioco, con le emozioni6 e le relazioni, con la capacità/incapacità di dirsi e di dire, con i silenzi di (tra) donne e uomini (Ciccone, Mapelli 2012) […] Mettere in campo il corpo, mostrare la propria vulnerabilità – come soggetto/oggetto di cura – esplicitare le proprie relazioni affettive, imparare a dire le emozioni – piuttosto che agire sotto controllo o senza controllo – possono diventare risorse preziose per andare oltre gli stereotipi di ruolo, oltre gli imperativi patriarcali, oltre le gabbie di genere".

the experiences of the care practices of non-disabled caregiving men for their disabled female partners to understand how intimacy, care, social expectations and power coexist and the outcomes of these tensions. Being a non-disabled man involved in caring for a disabled women could give space to o*ther narratives* that embrace love and sexual activity (Raney 2011) and the way that men *perform* their masculinity and their role as fathers and partners with respect to their partner's disability. Compared to the mainstream representations of assistance in disabled/non-disabled relationships, the burdens between the caregiver and the care recipient are often confused. In caring for their disabled partners, a non-disabled man brings an understanding of "masculine reflexivity" on the vulnerability and reciprocity of the *precariousness* of bodies (Butler 2017; Ottaviano 2020).

6. Conclusion

The right to have children, to marry, to have a family life and to raise children are important social and sexual rights but remain unacknowledged and unaddressed in social and disability policy, which obscures the moral and social dimensions of *disablism*. Thinking about disability by interpreting it not as a condition of inferiority and failure leads to re-thinking "our" bodies and the *illusion of ability/ableism.* Following many feminist disability scholars, I consider the able-bodied/disabled binary as a way to understand the processes of embodiment and neoliberal discourse on risk, gender and health (Fritsch 2017; Goodley 2014). Bodily ability shows itself as an *invisible social structure* that permeates our relations with the social environment and that we take for granted. Just as gender "has revealed the existence of an order in which differences become hierarchy" (Stagi *et al.* 2017, 47), ableism also shows the existence of an *invisible order* that contributes to defining normality and the relations of privilege between able/disabled people. Campbell (2009) argues that *ableism* is not only a matter of ignorance or attitudes towards disabled people; it is a set of beliefs and practices that presuppose to "enable" and "adjust" disabled people according to the standard of ability. In the context of a hierarchy of bodies where the healthy, normalised, white, male body is the 'norm', it is important not only to deconstruct and de-colonialise symbolic and normative order but also to re-affirm the "margin" and remove the shame from "imperfection". Indeed, as Stagi (2010, 17) writes, 'It is always possible to start again from the body to be what we want to be and not what society expects us to be'. Thinking about "margins" and "imperfection" as characteristics of our subjectivity requires us to abandon *sensationalized*, *ableist and ideological* narratives about our bodies. The normative ideals of autonomous and independent living that revolve around the lives of people with disabilities support, as Fritsch (2017) says, neoliberal forms of care that celebrate disability as an individual problem that can be overcome, for example, with the help of assistive technology. Childcare requires a great amount of physical endurance for most people. Utilising childcare aids and adaptive techniques is essential for mothers to perform their childcare tasks (Fritsch 2017; Tuleja *et al.* 1999). The impact of adaptive babycare equipment has been dramatic in most family situations (Ivi). The ability to perform work such as diaper changing and feeding unaided becomes the measure of a competent mother (Ivi). The perceived inability of mothers with impairments to realise such tasks independently provides the basis for their scrutiny by professionals (Malacrida 2007; Frederick 2007).

These reflections highlight another problem: the interconnections between care work and capacity requirements in neo-liberal contexts. As McRuer (2006) and Fritsch (2017) suggest, the *paradigm of productivity* and *neoliberal forms of care* contribute to establishing a normative way of "being", producing hierarchies between different disabilities (some disabilities are included, while others that do not conform are excluded), emphasising personal responsibility and reinforcing social exclusion and discrimination. For this reason, it is essential to incorporate new perspectives that observe the ways in which non-normative bodies inhabit and expand the relationships of love, care and intimacy (Mapelli 2018). By listening to the stories of disabled women, we tell how the body, gender and disability are represented and how ableism intersects with heterosexism, classism and racism and is internalised in order to attribute new meanings to *intimate justice* (McClelland 2014) and to break down the oppressive system that produces disabilities and marginalises disabled bodies.

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