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Re-Constituting Care
A Rights-Based Approach to Disability, Motherhood, and the Dilemmas of Care

This essay focuses on disabled mothers to problematize the discourses on care articulated by both the feminist and the disability community. Feminist literature on care has rightly emphasized the unequal burden and dependency that care work creates for women, but has largely neglected the fact that many disabled women are still fighting for the right (and resources) to mothering and caring for their families. The disability community, by contrast, has placed great emphasis on autonomy and independence for care-receivers, but has often forgotten that models of care based on direct payments are not suitable to all, and may even contain the potential for exploitation of care providers. Following Jenny Morris (2001), in this paper I argue that a human rights framework can help us move beyond these limitations. By emphasizing the inherent dignity of all human beings, a rights-based approach is likely to advance an ethic that de-genders care, promotes diversity and plurality of forms of care, and ensures that supports are adequate and available to those who give, as well as to those who receive care. In addition, in light of the recently approved United Nations Convention on the Human Rights of Disabled Persons, re-constituting care on the basis of human rights remains our best stake to start pressing for social change right now.

Not all women, of course, desire motherhood but those who do can usually take their right for granted. Like some other women Irene was longing for a child. Unlike others however, Irene had to put up with ignorance, prejudice, and discrimination in her quest to become a mother. First doctors told her she "couldn't get pregnant" because her physical impairments would prevent her from conceiving a child and carrying a pregnancy to term. And then after she *got* pregnant, they encouraged her to get an abortion suggesting that the baby would be "brain damaged" because of all the medication she was taking. Irene replied, "I don't care; he's a gift."

Despite the anxieties of health providers, Irene's child was born healthy and without any known disabilities. Yet her story, recounted by Juliene Lipson and Judith Rogers (2000), powerfully speaks of the many barriers facing mothers with disabilities—particularly in this case, society's fears that they can only produce defective babies, and the increasing acceptance (inclusive within the women's movement) of selective abortion (the abortion of foetuses identified as disabled) which is viewed by disabled people as an indication of how their lives are devalued in our society. Much like Irene, countless women with disabilities have been excluded from motherhood, their sexual and reproductive lives subjected to tight social control and regulation, notably through institutionalization and forced sterilization. Perceived unfit to carry on the tasks and responsibilities involved with being a "good mother," many have lost custody of their children in divorce and others have had their children removed from their care by welfare agencies (Traustadottir, 1990; Gill, 1997; Kallianes and Rubenfeld, 1997; O'Toole, 2002).

Social control of women's sexual and reproductive lives has always been a hallmark of women's subordination in family and society (Petchesky, 2003). But if disabled women, like other women, have been constrained in their reproductive choices, their experiences of oppression in this domain have differed from those facing their able-bodied sisters in significant, and yet much less discussed, ways. And it is also this silence that I want to challenge here, by raising critical questions about the erasure of mothers with disabilities from academic literatures, and their invisibility in society as well.

To undertake this task, I choose to focus on care. Not because motherhood and care work intersect, even overlap, to the point that mothering has become for some a paradigmatic case of caring (see, for example, Held and Noddings cited in Bowden, 1997); rather because a focus on care enables me to look at both sides of the relationship, the *carer* and the *cared for*, and to address the complexities that emerge when these two roles become entwined in the same subject. It is thus from the angle of care that I propose to engage with this discussion. Specifically, I want to problematize discourses on care as they are articulated by both the feminist and the disability communities, in order to move beyond the limitations in each of them. Exploring tensions and complementarities in these theoretical approaches through the lens of human rights I hope to suggest a more inclusive model in which to frame continuing debates on care.

Feminist perspectives on care

Traditionally, care work has been women's work. Janet Finch and Dulcie Groves are among the first scholars who drew attention to the financial, emotional and physical costs for women resulting from their primary involvement with care responsibilities within the domestic sphere. Their seminal work *A Labour of Love* published in 1983 explores "different facets of women's experience of caring, the dilemmas that caring poses for women, the tensions between paid

work and unpaid caring" (2), and discusses policy dimensions in relation to each of these topics. Finch and Grove's work was instrumental in exposing how caring roles shape women's lives and identities and how in this process women are disadvantaged both financially and personally. Their suggested alternatives to existing modes of caring include "caring leaves" and part-time jobs with adequate levels of income and protection, and the provision of "high quality residential services" for disabled and elderly people. Here their propositions are in sharp conflict with the demands of the disability community to live more "independent lives" (Morris, 1993; 1997; 2004).

With women's labour force participation continuing to rise during the eighties and the nineties, more recent discussions around care tend to be framed by the broader debate on work-life balance (see, for example, Hochschild, 1997; Duxbury and Higgins, 2001; Pocock, 2003; Mutari and Figart, 2004). It is generally recognized that while women are increasingly represented in the labour market, patterns of domestic and carework remain largely unchanged and workplaces continue to be organized around an ideal worker that mostly resembles the male, care-less breadwinner, with a wife at home taking charge of the social reproduction needs of the family (Duxbury and Higgins, 2001; Pocock, 2003). Caught between a work environment hostile to those with care responsibilities and a household structure resisting to adapt to the new realities of their lives, women are found to be experiencing high levels of role overload and stress, struggling to combine paid work with their traditional care-giving tasks (Duxbury and Higgins, 2001; Pocock, 2003). Those who resolve this conflict by reducing paid working time are marginalized in the labour market and often face increased job insecurity and enjoy less social protection (Pocock, Buchanan and Campbell, 2004). For increasing numbers of them in single-parent families, the challenge has become even more difficult.

These difficulties stem from an organization of both work and welfare based upon assumptions about the division of labour in the market and the family that no longer reflect our present day realities and disproportionally disadvantage women. With the goal of promoting full gender equity in work-places and households, the examination of the relationships between paid and unpaid (care) work and welfare has thus become a central issue for feminist researchers. Scholar work on care from a feminist perspective is therefore increasingly exposing the ways in which these relationships are gendered and advancing new modalities of organizing work and welfare, which recognize and value care work and promote a better share of caring responsibilities (see, for example, Lewis, 1992; Fraser, 1994; Lewis and Giullari, 2005).

Despite highlighting gender inequalities in current arrangements of care and offering innovative models to overcome them, this literature may be criti-cized for ignoring the experiences of those receiving care. While the ways in which care responsibilities affect and shape women's lives are amply debated, there is no concern about how different ways of organizing care impact those who require assistance to perform daily life activities. This issue is particularly

contentious today within the disability community who has been active in demanding the right to live "independent lives" (Morris, 1993). The next section explores understandings of care within the disability field and the policy options put forward on the basis of these understandings.

Disability and the debate on care

Many scholars in the disability community (e.g. Oliver, 1991; Morris, 1993, 1997, 2004; Barnes, Mercer and Shakespeare, 1999; Shakespeare, 2000) have voiced important critiques of the social relations of power between the providers and receivers of care and have been advocating for a greater empowerment, choice and control over their lives in the form of direct payments to the people requiring care (rather than to carers) enabling them to buy their own assistance services.

Michael Oliver (1991) was amongst the first to identify the ways in which society and the medical profession in particular have constructed disabled persons as "dependent" by focusing on the limitations of individual impairments while ignoring or obscuring the role that restrictive environments and disabling barriers play in preventing persons with disabilities from enjoying a life with quality in the mainstream society. Casting disabled persons as "dependent people" leads to overprotective and paternalistic attitudes on the part of professionals and families (Morris, 1993). It is often assumed that caring, more than help with daily living activities, involves taking responsibility for the person requiring help. Consequently, people with disabilities experience limited autonomy and are denied the ability to control their lives.

From the perspective of the disability movement, feminist research on informal care, rather than challenging these views, has in some ways contributed to reinforce them. Jenny Morris (1993) claims that by focusing on how caring restricts women's opportunities for paid employment, this literature not only perpetuated notions of people with disabilities as "dependent," but also silenced the voices and experiences of those who were receiving care—the category of women was constructed as non-disabled, with no recognition that women make up the majority of those with disabilities, nor that many disabled women are also informal carers.

Particularly in the British context, feminist academics' concerns with equal opportunities for women, identified as "informal carers," failed to consider equal opportunities issues for those who need assistance. Therefore, these scholars ended up advocating services for disabled people such as residential care, which persons with disabilities contest on the basis that those solutions deny them fundamental human rights. As Morris (1993) explains:

> Feminist researchers have failed to confront the fact that informal carers only exist as an oppressed group because older and disabled people experience social, economic and political oppression. The consequences of old age and impairment include a high risk of poverty,

a disabling experience of services, housing and environment, and the general undermining of human and civil rights by the prejudicial attitudes which are held about old age and impairment. These are the factors which create a dependence on unpaid assistance within the family. The sexual division of labour in society in general and the family in particular explains why it is that two-thirds of informal carers are women; it does not explain why the role exists in the first place. (49)

To the extent that the ideology of care has led to perceptions of disabled people as powerless and has rendered them dependent upon family members and professionals, it must be abandoned (Morris, 1993; 1997; 2004; Barnes, Mercer and Shakespeare, 1999). What people with disabilities need is empowerment, not care, as expressed by the Independent Living Movement (ILM). In the ILM model, independence is not about self-sufficiency or the ability to perform particular physical tasks; it is about control over the processes and decisions that affect one's own life. The bedrock of the ILM is direct payments and access to personal assistance over which the disabled person exerts choice and control. Through such schemes, it is argued, not only does the person who requires help have the power to determine how that help is delivered, but also family members are liberated from the obligation of caring, thus allowing for the development of more equal and reciprocal relationships within the family and in society at large. In short, cash payments and personal assistance are seen as offering disabled people more empowering and inclusionary possibilities (Morris, 1993; 1997; 2004; Oliver, 1996; Barnes, Mercer and Shakespeare, 1999).

Direct payments are already being implemented in a number of European countries (Denmark, France, Austria, the Netherlands, Germany, Britain) as well as in the U.S. and Canada. The results, however, have been controversial. As Clare Ungerson (1997) notes, this increased commodification and marketization of care may have critical effects on the labour market position and social security rights of the carers employed under such arrangements, who often find themselves exposed to very exploitative and unregulated working conditions. Intersections of gender, class, and race may further operate here, reinforcing existing inequalities for certain groups, as the low levels of payment involved and the "women's work" required in these jobs may make them look particularly suitable to poor, unskilled, and/or immigrant women (Ungerson, 1997). A new vision for social policies that enable people with disabilities to live independently as citizens in their communities must not ignore these arguments, which speak to broader concerns of equity and social justice.

Most importantly, while redefining disability as a form of social oppression, activists and scholars working within the ILM framework have often ignored the issues facing disabled women, especially those who are mothers and carers. Their analyses are typically gender-blind, portraying disabled people

as a homogeneous group; in reality, however, these approaches mostly echo male-centric perspectives while the specific realities and concerns of disabled women have remained obscured (Traustadottir, 1990; Begum, 1992; Morris, 1993; Gerrschick, 2000; Lloyd, 2001). Research on mothers with disabilities has shown that even when a male partner is present, disabled women continue to be the main carers in the family, a role they tend to see as a key source of pride and identity (Thomas, 1997). In this context, the help disabled women get, for themselves and for their children, and the ways in which that assistance is provided, fundamentally shape their experiences both of disability and motherhood. Evidence suggests that such help is seldom available or appropriate, sometimes unwanted but forced upon or offered in ways that threaten disabled women's right to parenting (Thomas, 1997). Yet despite their relevance, disabled women's experiences of mothering and motherhood rarely get discussed in disability studies" approaches to care. Thus, I argue, creating a space for the voice of disabled mothers is critical if we want to understand the modes of social and economic oppression that compound disablism in contemporary society. In the last section, I attempt to integrate insights from both disability studies and feminist research on care in order to move beyond the limitations in each of these models and devise a more inclusive analytical and policy framework based upon the respect of human rights for all.

Moving forward: Contributions for an alternative model of care

Any effort to reconcile the demands for recognition and autonomy of both caregivers and care recipients needs to challenge the divide between *carer* and *cared-for*, and the inherent relationships of domination and subordination in it. This is also the starting point of the feminist ethic of care, which asserts that we are all vulnerable and therefore all likely to need care sometime in our life (Williams, 2001; Sevenhuijsen, Bozalek, Gows and Minnaar-Mcdonald, 2003). Feminist ethic philosophers reject the ideal of the "independent citizen" emphasizing instead that people are immersed in systems of "nested dependencies" (Kittay, 1999), and need each other in order to live good lives. In this sense, they argue, *interdependence* is a better concept to describe the relational nature of care than the usual binary of dependence/independence. Care is a central aspect of human existence, an ongoing process involving four dimensions— "caring about," "taking care of," "caregiving" and "care-receiving" (Tronto cited in Sevenhuijsen et al., 2003). These dimensions and their corresponding values are viewed as interconnected and interdependent and, in this sense, the approach of the ethic of care stresses that care processes are holistic and should be understood from the perspective of both caregivers and care-receivers (Sevenhuijsen et al., 2003). Recognizing that caring encompasses several dimensions also underlines that multiple possibilities of involvement with carework, beyond just "caregiving," exist. This is a more inclusive framework and one perhaps that better reflects the reality of mothers with disabilities, especially those with more complex physical impairments for whom the physical

tasks of childcare may be more challenging or even impossible. The stated values—"attentiveness," "responsibility," "competence" and "responsiveness"—are normative criteria that should guide us through the core moral dilemmas of all care relationship as represented in the "triangle of vulnerability, dependence and power" (Sevenhuijsen, 2002). Care relationships, it is acknowledged, can be supportive and empowering but also patronizing and oppressive both for the caregiver as well as the care-receiver. Therefore, a feminist ethic of care calls for policies, which recognizing the social importance of caring, provide adequate supports and real possibilities so that caregivers and care-receivers can choose the care arrangements that best suit their preferences and needs (Sevenhuijsen, 2002; Sevenhuijsen et al., 2003).

A "new political ethics of care" (Williams, 2001), based upon a broader conceptualization of social rights that asserts both work and care as vital dimensions of citizenship is thus necessary. The term "inclusive citizenship" encapsulates this new vision, in which participation in the labour market remains a right and an obligation of every citizen, but the rights of all citizens (men and women) to give and receive care are also protected (Knijn and Kremer, 1997; Williams, 2001). In practical ways, this involves a number of strategies and policies aiming at ensuring that care givers as well as care receivers "have a real choice about how they want to integrate care in their lives" (Knijn and Kremer, 1997: 333). In particular, it involves "the right to time for care" and the "right to receive care." Diversity and plurality of forms of care should therefore be recognized and supported but the moral worth of caring relationships must always be highlighted (Williams, 2001).

As described above, one clear way of improving voice, choice and control for disabled people is to provide direct payments and personal assistance schemes, as proclaimed by the ILM. The model presupposes a conceptualization of disability as a social phenomenon, rather than as the outcome of physical or intellectual impairments. This view however, is not unproblematic. More recently, authors such as Tom Shakespeare (2000) and Jenny Morris (2001) are increasingly recognizing the importance of personal experiences of impairment to disability politics and the debate on care. While still working from the perspective of the social model, and focusing on the disabling barriers that determine the quality of disabled people's lives, their project simultaneously considers bodies' experiences of cognitive, physical or communication impairments. Morris (2001) for instance, claims that disabled people have been forced to deny the negative experiences of living with impairment to avoid feelings of pity and prevent others from deciding that their lives "are not worth living." Research on mothers with disabilities has indeed shown that often women hide their own needs for assistance, even if at great personal cost, for fear that others may judge them as inadequate to fulfill the social obligations of "good enough" motherhood (Thomas, 1997). The difference that impairment makes, however, must not be denied; it should be celebrated as a fundamental dimension of human diversity. But it also must be confronted, for disabled people cannot

achieve full participation if due accommodation of their needs and specific resources are not provided. The way care is delivered affects the experience of impairment. The failure to provide assistance to disabled mothers on their own terms, for example, has been found to exacerbate feelings of vulnerability and insecurity on women who are already dealing with concerns about managing childcare tasks because of their impairment (Thomas, 1997).

In addition, disabled mothers with more complex care needs are at particular risk of abuse. Indeed, there is a special vulnerability, and thus a high potential for abuse, in care relationships in which someone depends on the assistant of someone else to perform very basic and intimate tasks of daily living such as bathing or dressing. Regardless the form that care may take, the critical issue is therefore to determine whether the care that is provided supports, promotes and protects fundamental human rights (Morris, 2001). A wide range of possibilities should thus be available: some disabled mothers may want to receive cash payments to purchase and control their own care services, but others might prefer to receive care and assistance from a relative or close friend; and while for some the task of recruiting, hiring and managing personal assistants is perhaps incompatible with the complex realities of their lives, accessible, high-quality formal services are necessary to ensure that their needs and those of their children are adequately considered and provided for.

How can we then reconcile the needs and aspirations of carers and care-receivers, and do it in ways that recognize and value care while protecting the rights and dignity of those involved in care relationships? With Morris (2001) I argue that an ethic of care founded upon sound human rights principles is likely to offer the normative standards and the political arguments on which to devise a more comprehensive and socially just care framework. Certainly I'm suggesting a conception of human rights that goes beyond civil and political rights and assigns at least equal importance to social and economic rights. Asserting the universality of human rights such a framework fundamentally reminds us that disabled and non-disabled women, we all are members of the human family and in this sense, "to deny the human rights of our fellow human beings is to undermine our own humanity" (Morris, 2001: 15). It also ensures that, regardless the level of communication and cognitive impairment, all voices *can* and *should* count in defining the needs and the form of assistance that is to be provided. Finally, an ethic of care framed by human rights principles guarantees that care is offered in ways that do not discriminate, segregate or exclude, but rather promote and support full inclusion and participation in all spheres of life.

Looking at care from the lens of human rights has yet another critical advantage—while emphasizing "all rights for all" this perspective brings attention to the additional measures that some people require to enjoy basic human rights (Morris, 2001). Indeed, to achieve substantial equality we need to take difference into account "in order to both identify the nature of inequality and pursue solutions tailored to the goals of full inclusion and participation"

(Devlin and Pothier, 2006: 12). In the case of disabled mothers, this invites us to expand the very notion of care to also include accessible environments, the provision of technical devices and non-conventional forms of assistance that enable women, even those with more complex physical or cognitive impairments, to access their rights to sexual and reproductive health, to parenting, to gain a living through work, to participate in politics, culture, recreation and sports. The recognition of these rights has become even more important today in light of the recently approved United Nations International Convention on the Rights of Persons with Disabilities.

A human rights framework when applied to the social relations of care, further offers the potential to better protect the rights of those who provide care, either formally or informally. By stressing the interconnectedness and interrelation of all human rights the framework prompts us to carefully consider the design of different forms of care, so that they do not end up reinforcing existing inequalities along gender, class and racial lines. Indeed, the comprehensive approach proposed by the human rights agenda requests us to look simultaneously at both sides of the care equation, the caregivers and the care-recipients, and in the solutions advanced even transcend the discursive dichotomies that in the past have often provided for the oppression and discrimination of one group by the other.

Essential to the rights framework is a reformed system of economic redistribution. Claims to disability rights depend upon a dynamic interplay of all rights (Ellis, 2005). An adequate standard of living is perhaps the most basic condition to a life with dignity. Whether discussing a minimum income, payments for formal or informal carers or cash for users, what is also important is that the amounts granted offer real possibilities to escape poverty and to achieve the economic security without which the enjoyment of all other human rights remain illusory.

Disability and the vulnerability that arises from it are not fixed, essentialist categories, rather result from the complex interaction of personal and environmental factors. But the priority given, or their neglect, to varying vulnerabilities reflects our social values. Changes in which issues of citizenship, equality and social justice are engaged will never be easy to achieve (Barton, 1993). Re-constituting care on the basis of human rights will certainly not solve all the problems and injustices that enclose the lives of disabled mothers, but the approach offers the advantage of setting up normative standards binding states and governments to legal obligations in the domestic and international scenes. Articulating a politics of difference in the universal language of human dignity and rights; such an approach, I argue, remains our best stake to start pressing for change right now.

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