

**The future of the welfare state: paths of social policy
innovation between constraints and opportunities**

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**Politics of Gender, Work and Care in Mediterranean
Welfare States: the case of Portuguese Families of
Children with Disabilities**

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Introduction

Balancing work and family life is a challenge for many families in contemporary Western societies. Increasing levels of women's participation in the labour force, and rising numbers of single parent and dual-earner families are the commonsense understandings for the dilemmas facing so many families today. Yet increasingly feminist scholars are showing how current work and welfare regimes fail in providing opportunities for an equal share of roles, earnings and benefits among men and women.

Focusing on the relationship between women and the welfare state, this literature has examined how social programs and social rights are gendered. Jane Lewis (1992), for instance, claims that the development of modern welfare states was sustained by a traditional and gendered conception of the family, in which men were assigned the breadwinner role in the labour market and women were expected to fulfill caring and homemaking tasks in the domestic sphere. Certainly, this male-breadwinner model is being challenged today in the daily practices of most families, where women pressured by economic necessity and/or self-satisfaction needs increasingly enter the labour market. However, it is ultimately the unchanging patterns and social norms of paid and unpaid work alongside with the inadequacy of existing mechanisms of social protection and labour regulation to support their role as women, workers and mothers (and that of their partners, as workers and fathers), that must be accounted for the high levels of stress families, and particularly women, are experiencing in our days. The result, in practice, is often that women who join the labour force assume the dual role of carers/housekeepers and workers, while men's roles, both in the public and the private spheres, tend to remain unchanged.

While a significant number of women have gained access to the labour market, women's primary responsibilities are still associated with the domestic realm. Therefore, when an increased care demand is presented – in consequence, for instance, of a child's disability – women come under tremendous pressure to leave the workforce and return to the home (Trautadottir, 1991). This might be particularly encouraged in societies with traditional patterns of family life such is the case of Portugal.

In this paper I set out to examine this issue with the double purpose of discussing its meanings and consequences for those who are providing as well as to those who are receiving care. Focusing on the Portuguese context, I thus explore how gender differences in care responsibilities in this country affect women's access to jobs and earnings over the life course and how such arrangements are contrary to people with disabilities' desires for greater independence and emancipation. I also review existing mechanisms of social protection and labour regulation available for families and families of children with disabilities within the Portuguese work and welfare regimes and I discuss their limitations for challenging gendered patterns of work and care that prevail in this society, and the dominant views of persons with disabilities as dependent people. Finally, after a brief overview of theories of care on both the feminist and disability studies literature, I suggest alternative ways of organizing work and welfare, which while offering a fairer and less stressful work-life balance for these families, can also contribute to the policy goal of an inclusive and un-gendered citizenship for those giving and receiving care.

Caring for a Child with Disabilities in the Family: Lessons from Abroad

In families where there is a child with disabilities, caring may become a critical issue. Disability often requires exceptional levels of care. Depending on the level of their impairments, some children may need constant attention and supervision. Others may have problems sleeping or may need to be frequently attended during the night. Attempting to work and provide care to a child with special needs appears to be particularly difficult for these families. We would therefore expect a greater involvement of both parents in caring tasks. However, even in such families, care responsibilities are hardly equally shared. On the contrary, literature consistently points to a strict division of labour assigning far more responsibilities for providing care to the disabled child to women than to men. Right across the globe, in Japan as in the United States, in Australia as in Europe, caring is women's responsibility (Traustadottir, 1991; Marcenko and Meyers, 1991; Freedman, Litchfield and Warfield, 1995; Porterfield, 2002; Meyers, Lukemeyer and Smeeding, 1998; Meyers, Lukemeyer and Smeeding, 1998; Schofield et al., 1998).

The consequences of such role structure in women's lives are complex and diverse. As research has shown, for many mothers of children with disabilities, care-giving responsibilities influence decisions about labour force participation: they're often constrained to engage in part-time work or to withdraw from the labour market to assist their disabled child (Freedman, Litchfield and Warfield, 1995; Porterfield, 2002; Meyers, Lukemeyer and Smeeding, 1998; Schofield et al., 1998; Hiroe, 2002). This in turn makes women largely dependent on their husbands, while reducing overall family income when at the same time disability often imposes substantial costs (Meyers et al., 1998). Not

surprisingly then, some studies found that a significant proportion of families with children with disabilities are living in poverty or experiencing financial difficulties (Meyers et al., 1998; Schofield et al., 1998).

Yet, in spite of the structural constraints surrounding their care-giving role, some mothers may experience care responsibilities as a source of satisfaction and pride. Traustadottir (1991) for instance, exploring the role of gender in caring for a child with a disability among American families found that for a group of mothers, caring for their disabled child was seen as an empowering experience. Finding a major source of identity in the caring work they performed, these mothers extended their care beyond their child and were active within the parents' movement and the disability field advocating for change on behalf of people with disabilities. However, as the researcher recognizes, issues of class, education and race are likely to intersect with experiences of mothering and caring for a child with disabilities – and in fact, the mothers in this group were all white middle-class women with a college education. Nevertheless, acknowledging the rewards and satisfaction that can be obtained through giving care within the family context is an important aspect of valuing care work and of claiming from society what Trudie Knijn and Monique Kremer (1997) referred to as “the right to time for care”. I shall return to this point later on in this paper.

Not all mothers of children with disabilities, however, are excluded from the labour market. Some choose, are forced or are able to combine work and family care responsibilities. For these, paid work is often seen as a welcome relief, a respite from demanding care responsibilities and a source of social support (Freedman et al., 1995;

Schofield et al., 1998). The sense of competence that these women can derive from their performance at work, in contrast with the feelings of frustration and difficulties that sometimes arise when dealing with the child's disability, is an additional reason that leads these mothers to a greater appreciation of their labour force involvement (Freedman et al., 1995).

In sum, the literature clearly indicates that the presence of a child with disabilities in the family often places additional demands for care. The responsibility to provide care for the disabled child usually falls on mothers, impacting their ability to participate in the labour market and to dispose of an important source of personal and financial rewards, while also affecting the financial situation of the whole family. In spite of the structural constraints that shape their lives, some mothers experience their caregiver role as an empowering and rewarding endeavour. The fact that these mothers tend to be white, middle-class, educated women, may suggest, among others, that they are more able to privately purchase care and to better advocate for the care services their children require, thus actually benefiting from a reduced share of the care work. With the background of the international literature on care and families of disabled children, let us now turn to the examination of the specificities of the Portuguese context.

The Portuguese Context: Residue of Tradition

While the issue of parenting a child with disabilities has not yet been seriously researched in Portugal, available data seem to indicate that caring responsibilities within Portuguese families are primarily ascribed to women. Statistics on labour market

participation for example (Table 1), show that over 25% of women working less than 30h/week do so because of their domestic and care responsibilities, whereas for men care work is never a factor pending on their decision to reduced paid working time.

Table 1
Reasons for Working Less than 30h/Week (%)

		1995	1998	2000	2001
Men	Has Household and Care Resp.	-	-	-	-
	Has Disability or Health Prob.	37,1	36,6	31,7	35,5
	Other	62,7	63,4	67,9	64,5
Women	Has Household and Care Resp.	27,8	21,4	31,0	28,6
	Has Disability or Health Prob.	13,1	22,6	20,9	20,2
	Other	59,1	56,1	48,1	51,0

Source: Eurostat/INE, 2004

Moreover, “having domestic and care giving responsibilities” accounts for 1/3 of women’s unemployment status while men never report this as being a reason excluding them from the labour force (Table 2).

Table 2
Reasons for Being Out of the Labour Market (%)

		1995	1998	2000	2001
Men	Is Studying or Getting Training	27,4	25,3	22,3	22,1
	Is Retired.	64,2	64,5	62,8	62,4
	Has Household and Care Resp.	-	-	-	-
	Other	8,4	10,1	14,5	15,5
Women	Is Studying or Getting Training	17,0	17,2	16,2	16,7
	Is Retired.	41,1	41,1	41,9	43,3
	Has Household and Care Resp	36,4	31,6	35,4	33,3
	Other	5,5	10,2	6,5	6,7

Source: Eurostat/INE, 2004

Statistics on participation in care-giving and domestic tasks point in the same direction, with women's rates of involvement in care and domestic work in the family consistently exceeding those of men (Tables 3 and 4). The only exception found relates to the fulfillment of administrative tasks, where more men than women seem to assume primary responsibility. The fact that these tasks often relate to the interface between the private and the public spheres again reveals the very traditional pattern in the division of labour within Portuguese families.

Table 3
Participation in Care-Giving Tasks (%)

	Men	Women
Physical Care for Children	46,0	54,0
Driving Children to Swim Lessons, Soccer,...	45,4	54,6
Playing with Children, Taking them to movies, theatres, concerts	45,8	54,2
Taking Children to Doctor's Appointments	45,8	54,2
Caring for Dependent Adults	44,2	55,8

Source: INE, Publicação do Inquérito à Ocupação do Tempo, 1999

Table 4
Involvement with Housework (%)

		Men	Women
Preparing Meals	Always	8,8	92,0
	Never	88,6	11,4
Cleaning House	Always	6,5	93,5
	Never	88,7	11,3
Doing Laundry	Always	5,1	94,9
	Never	87,6	12,4
Gardening	Always	43,4	56,6
	Never	48,9	51,1
Admin. Tasks	Always	55,2	44,8
	Never	41,7	58,3
Regular Shopping	Always	22,7	77,3
	Never	73,2	26,8

Source: INE, Publicação do Inquérito à Ocupação do Tempo, 1999

The 2001 Portuguese Population Census included for the first time information on disability. It is therefore possible to compare the rates of labour market participation among mothers and fathers of children with and without disabilities (Table 5). As expected, mothers of children with disabilities tend to report the lowest levels of participation in formal employment. The only exception is found among those mothering a disabled child seven to eighteen years old. This corresponds to the compulsory education period for disabled children in Portugal, where the law establishes the obligation of the public system to provide education for children with special needs (Ministério da Educação, D.L. 118/91). Therefore, it is also during the school years of their disabled children that mothers (and fathers) become more available to engage in paid work.

Table 5
Labour Market Participation of Fathers and Mothers by Disability and Age of the Youngest Child (Married Couples with at least one child under 25 years old)

	Child w/ Disability				Child w/out Disability			
	0-6	7-18	>18	Total	0-6	7-18	>18	Total
Mother + Father Work	7,39	29,55	16,96	53,91	9,47	29,40	28,17	67,03
Father Works + Mother Doesn't	4,29	19,34	14,80	38,43	9,22	12,71	5,77	27,70
Mother Works + Father Doesn't	0,42	3,18	4,06	7,66	0,98	2,42	5,27	5,27

Source: INE/Censos 2001

Not only are rates of participation in the labour market lower for mothers of children with disabilities compared to mothers of children without disabilities, they are

also lower for fathers (Table 5). This result suggests that in Portugal, as found elsewhere, families with disabled children may be experiencing financial difficulties. Finally, the fact that differences in terms of involvement in formal paid employment tend to accentuate for couples with children over 18 years old, indicates a pattern of continuing dependency on parents for care among adult disabled children in Portuguese society.

In terms of social protection and labour regulations Portuguese welfare and work regimes offer mechanisms to families that only apparently are 'family-friendly'. While, for example, both Maternity and Paternity leaves are available, the former provide employed and self-employed mothers 120 days of 100% paid leave or 150 days of 80% paid leave, while the latter offers only 5 days of 100% paid leave or a period equivalent to that which the mother would be entitled to in case she dies or is deemed unable, for reason of physical or mental illness, to take care of the child. In the absence of any of these circumstances, if the couple so decides, the mother can transfer to the father her right to parental leave, but even in this case she still has to take at least 60 days leave and only the remaining 60 or 90 days may be used by the father (Segurança Social, 2005). In this sense, this policy has been insufficient to challenge traditional patterns of domestic and care labour division within the household. The use of these very discrepant benefits is in itself quite different as men and women are concerned. While a significant number of women make use of their maternity leave, very few fathers benefit from their right to paternity leave (Table 6). Cultural traditions and perhaps a lack of information regarding the availability of these benefits may explain such dissimilar behaviour among Portuguese mothers and fathers.

Table 6**N° of Beneficiaries of Maternity and Paternity Leaves**

	1990	1995	2000	2003
Maternity Leave	58 958	64 034	76 898	78 672
Paternity Leave	-	933	12 931	40577

Source: IIES – Instituto de Informática e Estatística da Segurança Social

In addition to Maternity and Paternity leaves, there are some provisions to help employees with the care of children. Social security offers 30 days/year of 65% paid leave to parents who need to assist their sick children (until the child is 10 years old or regardless his/her age if the child has a disability). If the child has a profound disability or a chronic disease and is less than 12 years old, this leave can be extended to 6 months/year (Segurança Social, 2005). However, recent statistics on the use of this benefit again demonstrate the gendered nature of care in Portuguese society with the numbers of women taking advantage of this leave far exceeding those of men (Table 7).

Table 7

**Assistance to Child with Profound Disability/Chronic Disease
(Days of Leave Taken)**

	1990	1995	2000	2003
Total	4 211	37 250	144 281	161 888
Men	-	1 121	2 803	3 730
Women	-	36 129	141 478	158 158

Source: IIES – Instituto de Informática e Estatística da Segurança Social

Other benefits available for Families with children with disabilities include a Supplement to Family Allowances, which is a variable amount according to the child's age; finally, persons with disabilities of all ages are entitled to a Benefit for Assistance by a Third Person, if they're deemed dependent on personal care for over 6h/day. However, the amounts provided by both the Family Allowance Disability Supplement and the Benefit for Personal Assistance are very low, varying between approximately 59 and 115 Euros (Segurança Social, 2005).

To sum up, while Portuguese mothers of children with disability are giving up their participation in the labour force to care for their disabled child, they're not entitled to any significant financial compensation for this important social role. On the contrary, they are likely to face serious financial hardship. Yet, because of the way social, economic and political structures operate in the Portuguese society, many may continue to be forced to do so. On top of cultural expectations that generally tend to ascribe caring roles to mothers rather than to fathers, the scarcity of formal support services for the population with disability in the country leave families with no other alternative than to rely on each other and look after the disabled child on almost nothing more than the family's own resources. Furthermore, the prevalence of the medical model of disability in the Portuguese society drives families into a constant search for therapies and medical care for their child which involving complex arrangements in terms of transportation and scheduling are often difficult to fit into a standard paid working day; no to mention the fact that the few services available for children with disabilities are increasingly demanding active parental

involvement and some are even home-based (as for example Early Intervention programs), again requiring high levels of schedule adjustment from the parents which are hardly compatible with regular paid working time. While not dismissing the benefits that these new policy and program orientations may likely bring about for the disabled child, it seems important also to consider their gendered impact in terms of families' organizing patterns and allocation of care responsibilities. Finally, but perhaps most importantly, the wage discrimination against women that persists in Portuguese society, within a context of lack of adequate support services, leaves little choice as to which of the parents should be the breadwinner and which should stay home to provide care for the child with disabilities (according to data from the Ministry of Solidarity and Social Security in 2000, the average monthly salary of women made up 77% of the average salary of men).

In short, despite an apparent progressive look, Portuguese work and welfare regimes (with the exception perhaps of the education system) embrace a paradigm in which disability has been reduced to a family matter, and families are expected to be the primary care-givers while state welfare assumes a mere supplemental role. But families actually seem to mean mothers, who often in isolation and exclusion from the labour market perform their unpaid care labour in the invisibility of the domestic sphere.

In spite of the improvements introduced in disability-related policy, since Portugal became a full member of the European Union in 1986, these developments have taken place mainly in the form of new regulations with limited enforceability. In fact, as Hvinden (2003) points, there is no convergence in the systems of disability protection in Western Europe. There are perhaps signs of a trend toward greater similarity in terms of

general goals and policy principles, the *regulation* side of social policies (for instance expressed in official support for aims like promoting equal opportunities, fuller participation in economic and social life, independent living and combating discrimination, poverty and exclusion), but so far this has not led to a convergence at the level of outputs or the *redistribution* side of policy instruments. Moreover, neo-liberal policies at European level and their focus on global market competitiveness impose constraints at national level in terms of deficit control and put pressure on public budgets that further limit the ability of member states to increase levels of public expenditure. This is particularly problematic for Southern European countries such as Portugal, where levels of spending and numbers of beneficiaries in disability protection have been traditionally lower than in other regions of Europe, and where therefore an additional spending effort would be necessary to improve the life standards of persons with disabilities and their families.

In the context of a residual welfare model such it is the one these days in Portugal, families and particularly mothers with disabled children are forced into a care-giving role that many may not wish or be prepared to take on. And this will likely be a lifelong role, as service provision is even scarcer for adults than for young children with disabilities in Portugal (Simões, 1999). In addition to the financial inadequacies that have been described, this forced role raises a number of important questions related to the human and civil rights of the person with disabilities who under present circumstances is also “forced” to receive care from his/her family. Before further exploring the contours of this problem and the ways in which scholars in the disability movement have addressed it, we need to look at how care has been theorized in the feminist literature.

Feminist Perspectives on Care

Janet Finch and Dulcie Groves are among the first scholars drawing 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 sets up the tone of the debate and continues to be referenced today in the most recent research on the field. As the authors write in the Introduction, the book explores “different facets of women’s experience of caring, the dilemmas that caring poses for women, the tensions between paid work and unpaid caring” (p.2) and discusses social 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 among others ‘caring leaves’ and part-time jobs with adequate levels of income and protection, as well as 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 the issue of care, even when context-specific, tend to be framed by the broader debate on work-life balance (see for example in Canada: Duxbury & Higgins, 2001; in the U.S.: Hochschild, 1997; in Australia: Pocock, 2003; in Europe: Mutari & Figart, 2004). It is generally recognized that while women are now increasingly represented in the labour market, patterns of domestic and care work 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 & 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 & 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 & Campbell, 2004). For increasing numbers of them, in single-parent families, the challenge may become even more difficult.

These difficulties stem from an organization of work and welfare based upon assumptions about the division of labour in the market and the family that no longer reflect the realities of our days, and disproportionately disadvantage women. In order to formulate new models of social and labour market policies that pursue the goal of full gender equity in workplaces and households, the examination of the relationships between paid and unpaid (care) work and welfare becomes a central issue for feminist researchers (Lewis, 1992). Such approach exposes the ways in which these relationships are gendered and gives rise to new ways of organizing work and welfare that recognize and value care work and promote the sharing of it.

In envisioning such a women-friendly post-industrial welfare state Nancy Fraser (1994) for example, devises two constructs: the Universal Breadwinner and the Caregiver Parity Models. The Universal Breadwinner is committed to promote women's

employment. In this sense, this model would emphasize programs and services (such as for instance childcare and elder daycare) aimed at liberating women from unpaid responsibilities so that they can take up full-time employment on terms comparable to those of men; it also would include efforts to remove equal opportunities obstacles within the workplace. The Caregiver Parity, in contrast, is focused on supporting informal care work. Here the aim is not to make women's lives similar to men's but to elevate informal domestic labour to the levels of dignity and material reward provided by formal paid work. Therefore, programs associated with this model would include caregiver allowances at levels adequate to support a family, as well as multiple workplace reforms to facilitate the combination of supported care work with employment. However, as Fraser notes, neither of these models would be able to completely eliminate gender inequalities. In fact, both would fail to radically challenge the current gender order because "neither values female-associated practices enough to ask men to do them too; neither asks men to change" (p.610). Thus, she concludes, "the key to achieve gender equity in a post-industrial welfare state is to make women's life patterns the norm" (p.611). In other words, only models that induce men "to become more like most women are now" (p.611), that is, that encourage and support an equal share of work and care responsibilities between men and women, and enable them both to combine these roles in a less stressful and less difficult way, will be likely to achieve full gender equity. In Fraser's words, this ultimately calls for a "deconstruction" of gender, to overcome the fundamental opposition that subsists between breadwinner and caregiver roles and their respective associations with masculine and feminine identities.

Eileen Aplebaum (2002) goes even further. In suggesting a “shared work/valued care” model for our contemporary societies, she stresses the need of sharing good paid jobs and caring responsibilities between men and women, as well as of involving communities and public institutions in the provision of high quality care; but additionally, she calls attention to the working conditions of care workers, as a crucial dimension of a work and welfare model that values care. The “shared work/valued care” model is not yet fully implemented in any advanced industrialized country, but Aplebaum sees some encouraging signs in policies being developed now in the European context, particularly the Swedish extensive supports for working parents and the new Dutch regulation on “Adjustment of Hours”, which allow parents/workers to reduce hours on their job to attend care needs of the family.

More recently however, Jane Lewis and Susanna Giullari (2005) have criticized EU policies for being ambivalent in regards to the goal of gender equity. They argue that by being defined in terms of increased female employment and neglecting the issue of household work distribution, gender equity policies at European level, have done little to challenge female (and male) traditional patterns of involvement with care and domestic work. With women’s participation in the labour market becoming increasingly instrumental within the European strategy for competitiveness and growth, policies designed to promote the reconciliation of work and family responsibilities have tended to focus on women alone, rather than on men and women. In this context, flexible forms of employment and the commodification of care work are seen as the key means to achieve more female labour-market participation. However, as Lewis and Giullari (2005) point out, flexible jobs seldom offer the levels of payment and security of “good” jobs and there

is a limit to the care work that can be commodified. More than a physical task, care involves relationships and feelings, and is shaped by cultural meanings and expectations. These emotional and “passive” dimensions of care are not possible to commodify and therefore “the issue of how [care] is shared, not just between individuals and the collectivity, but also between the men and the woman in the household must be addressed” (p.88). This leads the authors to propose a “universal carer/worker-worker/carer” model, in which care would become a recognized and valued dimension of human life and a more equal share of care responsibilities between men and women promoted and supported (Lewis & Giullari, 2005).

Despite highlighting significant problems with current arrangements and advancing innovative models, this literature may be criticized for ignoring the experiences of those receiving care. While it is amply debated the ways in which care responsibilities affect and shape women’s lives, there is no concern about how different ways of organizing care impact those who require assistance to perform daily life activities. As I noted before, 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 proposed on the basis of these understandings.

Disability and the Debate on Care

Many scholars in the disability movement (e.g. Oliver, 1991; Morris, 1993; 1997; 2004; Barnes et al., 2000) have voiced important critiques of the social relations of power between the providers and receivers of welfare services and have been claiming for a

greater empowerment, choice and control over their lives in the form of direct payments to the people requiring care (rather than the carers) enabling them to buy in their own assistance services.

Mike Oliver and others (1991) have identified 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 and 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. Much of the knowledge and the social attitudes towards disabled persons throughout the 20th century was influenced by such medical perspectives which continue to inform social assistance programs for this group of population in many parts of the world (Hiroe, 2002; Rioux, 2003). Such paradigm has profound consequences for the lives of those with disabilities and their families. As Jenny Morris (1993) points out, casting disabled persons as ‘dependent people’ leads to overprotective and custodial attitudes on the part of professionals and families. Often it is assumed that caring, more than help with daily living activities, involves taking responsibility for the person requiring help. In consequence, 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 contributed in some ways to reinforce them. 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

(and for that matter old people too) as 'dependent', but also silenced the voices and experiences of those who were receiving care: the category of women was constructed as non-disabled and non-elderly, with no recognition that women make up the majority of disabled and older people nor that many disabled and older people are also informal carers (Morris,1993).

Particularly in the British context, where this debate developed around government policies on 'community care', feminist academics' concerns with equal opportunities for women, identified as informal carers, failed to consider equal opportunities issues for those who need assistance and 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 and civil 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. (p. 49)

To the extent that the ideology of care led to perceptions of disabled people as powerless and rendered them dependent upon family members and professionals it must be

abandoned (Morris, 1993; 1997; 2004; Barnes et al., 2000). What people with disabilities need is empowerment, not care, as expressed by the Independent Living Movement whose centrepiece 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 the person who requires help has 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 (Morris, 1993; 1997; 2004; Barnes et al., 2000). To the extent that such debates involve demands for material resources in articulation with new cultural definitions of the disabled subject, these claims seem to echo Nancy Fraser's assertion that justice today requires both *redistribution* to overcome socio-economic inequalities and *recognition* to redress cultural processes and practices that systematically disadvantage one group vis-à-vis others (Fraser, 1995).

Direct payments are already being implemented in a number of European countries (Denmark, France, Austria, the Netherlands, Germany, Britain) as well as in Canada and the U.S. The results are however also 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 about social justice and equity. 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 new and more inclusive framework based upon the respect of human and civil rights for all.

Conclusion

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 should start by challenging the divide between carer and cared-for, and the inherent relationships of domination and subordination in it. Solveign Reindal (1999) offers here an interesting perspective when he asserts human condition as one of intrinsic vulnerability and interdependency. From the recognition that we are all vulnerable it follows that we are all likely to become caregivers or care receivers sometime in our life, and in this sense the dichotomy is dissolved. With Fiona Williams (2001) I would argue this is the basis on which a re-conceptualization of care and a re-evaluation of the basis of entitlement for the provision of services and social benefits to those who give and those who receive care should occur in our contemporary societies. This approach would certainly entail a new appreciation of the moral, social and economic worth of care, and contribute to the development of what Williams refers to as a “new political ethics of care” (Williams, 2001).

This new ethics is based on a broader conceptualization of social rights that asserts both work and care as vital dimensions of citizenship. In T. H. Marshall's (1949) typology of civil, political and social rights, social citizenship encompasses several human rights, such as the right to housing, employment, education and income, but the right to give and receive care is left aside. As Knijn and Kremer (1997) have shown, such conceptualization was based upon assumptions about the role of women in the domestic sphere, but it has also served to reinforce the gendered character of care and to instate a gendered citizenship. Only when care becomes a citizenship issue, rather than a women's issue, can care (both giving and receiving) and citizenship be de-gendered (Knijn and Kremer, 1997). 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 (Williams, 2001; Knijn and Kremer, 1997). 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, p.333). In particular, it involves "the right to time for care" and the "right to receive care". Unpaid care leaves, payments for care and statutory regulation of part-time work with adequate social security provisions are important conditions for informal care-giving, but moral claims should not constrain "the caregiver's right to make an autonomous choice *not to provide care*" (Knijn and Kremer, 1997, p.333; emphasis added). Similarly, while receiving care from a relative or a volunteer may in many cases prove to be a good solution, the right to receive care implies accessible, high-quality institutional care and the

ability to purchase care services for the groups of citizens who need it (Knijn and Kremer, 1997).

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). This in turn requires a “re-evaluation of paid and unpaid care, as well as the principles that govern the recruitment, pay, conditions and training of care workers” (Williams, 2001, p. 487). Finally, as Williams (2001) reminds us, asserting the fundamental importance of an inclusive citizenship calls for an acknowledgement of the voices of all involved in the social process of care, particularly those who have been historically marginalized – people with disabilities, older people and unpaid carers.

But the reinvigoration of an ethics of care, on the basis of a broader and de-gendered conceptualization of citizenship, also requires a transformation of the workplace regulations and culture, particularly the reform of the male employment model, which continues to dominate. At this regard, policies aimed at reducing working time, such as shortening working week and regulating over-time, are certainly also necessary (Lewis & Giullari, 2005; Williams, 2001). In sum, interventions on time (both working time and time to care), availability of financial resources (in the form of cash to buy care and cash for carers) and increased provision of care services are all important dimensions to consider (Lewis & Guillari, 2005) in order to achieve a better balance of work/life needs in the three different but connected areas of human life: the “personal time and space”, the “care time and space” and the “work time and space” (Williams, 2001; pp.488-489). As Williams (2001) points out, all these areas are interlinked – for some people caring for a

family member is rewarding and empowering, while for others work performance and relationships are key to personal well-being. In this sense, “thinking across these areas allows us to prioritize the opportunities to give and receive care and to normalize (and I would add de-gender) responsibilities for giving care and support and needs for receiving care and support” (Williams, 2001, p. 489).

In the Portuguese context, an alternative welfare regime that could favour an easier work-life balance for both men and women parenting a child with disabilities while recognizing and protecting the rights of the care givers and those of the care recipients, should include, among others:

- improved and diversified service provision for children and adults with disabilities, based on principles of accessibility, affordability, quality, flexibility and users’ control;
- direct payments for people with disabilities receiving care and regulated working conditions for paid carers;
- changed rules on the use of parental and care leaves to encourage greater participation of fathers in care work;
- decent levels of disability-related benefits;
- reinforced pay equity policies to combat wage discrimination against women in the labour market and to favour a more equitable share of care-giving responsibilities among men and women.

Importantly too, these measures need to take place within a broader policy commitment to a barrier-free and safe, caring environment, in which education must play a critical role in promoting the value of a de-gendered ethics of care.

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