

Family, disability and social policy in Portugal: Where are we at, and where do we want to go?

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Abstract

Families of children with disabilities face greater demands for support and care, which often extend into the child's adult life. Disability thus offers a critical lens to explore interconnections between welfare state structure, gender and the family. This paper examines these intersections and discusses their implications for persons with disability and their carers. Focusing on the Portuguese context, where gender differences in care tasks within the family are still evident, existing mechanisms of social protection are reviewed and their limitations discussed. The 'independent living' model and the concept of personal assistance are advanced as alternative ways of organizing welfare.

Introduction

A distinctive characteristic of the welfare regime in Southern European nations is the central role of families in the provision of supports to their members (Leibfried 1993; Ferrera 1996; Silva 2002). In families where there is a child with disabilities, demands for support and care tend to be more significant, and often extend well into the child's adult life. Disability thus offers a critical lens to explore the interconnections between welfare state structure, gender and the family.

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This paper sets out to examine these intersections with the double purpose of discussing its meanings and consequences for those who provide care (mainly women) as well as to those who receive care (a majority of them also female). Focusing on the Portuguese context, it first shows how gender differences in care responsibilities for children with disabilities affect women's access to jobs and earnings over the life course. Against this backdrop, mechanisms of social protection and labour regulations available for families caring for children with disabilities in Portugal are reviewed and their limitations, for both challenging traditional gendered patterns of work and care and dominant views of persons with disabilities as "dependent", are discussed. The paper further debates how such arrangements are contrary to people with disabilities' desires for "independent living" and self-determination. Finally, it proposes alternative ways of organizing work and welfare, which might offer a fairer distribution of care and work in these families, while also contributing to the policy goal of an inclusive citizenship for those who provide, and those who need, care.

Gendered Patterns of Care and Work in Portugal

While the specific issue of parenting a child with disabilities has not yet been seriously researched in Portugal, available data indicates that care responsibilities in general, within Portuguese families, are primarily ascribed to women. Statistics on labour market participation for example (Table 1), show that 'looking after children or dependent adults' is one of the reasons leading women to part-time work, whereas for men care work is never a significant factor pending on their decision to reduce paid working time.

Table 1 - Main Reasons for Part-Time Employment in Portugal – distribution by sex

	2003		2006		2009	
	M	F	M	F	M	F
Could not find FT job	21,6	27,5	30,0	36,7	37,1	38,4
Fam and pers respons	19,4	9,2	17,5	9,3	12,0	6,2
Own illness or disab	:	:	13,6	25,5	14,8	27,4
Looking after children or dependent adult	:	15,0	:	9,7	:	6,8
In education or training	10,8 (u)	5,3	8,8	4,0	11,4	5,6
Other reasons	47,4	43,3		14,8	23,1	15,6

Source: Eurostat/ LFS - Special Values: (u) unreliable/uncertain data, : not significant

Moreover, ‘looking after children or dependent adults’ explains why over 7% of women **do not seek employment** in Portugal. This is a very significant proportion, given that, according to the last census, people with disabilities also make up of around 7% of the Portuguese population (Census 2001). Furthermore, it is interesting to note that for men, ‘looking after children or dependent adults’ is not indicated as a reason excluding them from the labour force (Table 2).

Table 2 - Main Reasons for not seeking employment in Portugal – distribution by sex
 (adults aged 20-65 years old)

	2006		2007		2008		2009	
	M	F	M	F	M	F	M	F
Own illness or disab	20,2	13,4	18,6	13,9	17,5	13,8	16,7	13,5
Fam and pers respons	3,2	27,1	3,2	27,0	3,0	26,6	3,3	26,2
Looking after children or dependent adult	:	8,4	:	7,6	:	7,6	:	7,5
In education or training	26,9	17,3	25,7	15,4	25,7	14,8	27,4	15,5
Retired	36,7	20,0	39,8	22,4	43,3	22,6	41,3	24,1
Think no work is available	:	1,7	:	1,6	:	1,5	:	1,2
Other reasons	11,6	12,1	11,5	12,2	9,3	13,2	9,6	11,9

Source: Eurostat/INE, Special values - : not available

Statistics on the uses of time, although now 10 year-old, 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 – distribution by sex

	Men	Women
Physical care for children	46,0	54,0
Driving children to swim lessons, football,...	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 of Men and Women – distribution by sex

		Men	Women
Preparing Meals	ALWAYS	8,8	92,0
	Never	88,6	11,4
Cleaning the house	ALWAYS	6,5	93,5
	Never	88,7	11,3
Doing the 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 was therefore possible to obtain and 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 with disabilities				Child without disabilities			
	0-6	7-18	>18	Total	0-6	7-18	>18	Total
Dual-earner couples	7,4	29,6	17,0	53,9	9,5	29,4	28,2	67,0
Working Fathers	11,5	48,9	31,8	92,3	18,7	42,1	34,0	95,4
Working Mothers	7,8	32,7	21,0	61,6	10,5	31,8	33,4	75,7

Source: INE/Censos 2001 (calculations by the author on the basis of the dataset file provided by INE)

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 are at greater risk of poverty. Finally, the fact that differences in terms of involvement in formal paid employment tend to accentuate for couples with children 18 years old and over, indicates a pattern of continuing dependency on parents for care among adult disabled children in the Portuguese society.

Disability, Care and the Welfare State in Portugal

What are then the social protection and labour regulations of the Portuguese welfare and work regimes available for these families? As it is now well-documented in the literature, the cluster of nations that makes-up the Southern European welfare regime is cha-

racterized by the late development of the welfare state, which to date remains rudimentary and highly fragmented. The Portuguese welfare state did not really take shape up until the 1974 democratic revolution which removed the authoritative right-wing government that ruled the country for over 40 years (Marques 1997; Santos et al. 1998; Leiria 2000; Salvado 2008). The various schemes successively implemented, however, only recently started to attend to their gender impacts and therefore, traditional patterns of domestic and care labour division within the household have been allowed to prevail, and gender differentials in the take-up of existing benefits are still evident. An example within the wider population is found in relation to parental leaves: while a significant number of women make use of their maternity leave, still few fathers (although in increasingly higher numbers) benefit from their right to paternity leave (Table 6). Strong cultural norms and perhaps a lack of information regarding the availability of these benefits may explain such dissimilar behaviour among Portuguese mothers and fathers.

Table 6 - Number of Recipients of Maternity and Paternity Leaves

	1990	1995	2000	2003	2005
Maternity Leave	58 958	64 034	76 898	78 672	76 127
Paternity Leave	-	933	12 931	40 572	43 395
% of paternity leave recipients in relation to maternity leave recipients	-	1,5%	16,8%	51,6%	57%

Source: IIES – Instituto de Informática e Estatística da Segurança Social (up to 2003) and INE/ Instituto de Informática, IP (2005)

In addition to the benefits available to the general population, the Portuguese welfare state contains specific provisions to help families care for their disabled children (see table 7). These include: a supplement to family allowances, a special education benefit, a life-long disability allowance, and an allowance for assistance by third person.

Table 7 - Benefits and Supports for Families with Children with Disabilities in Portugal

Benefits and Supports	
Supplement to Family Allowances	Means-tested for children with disabilities up to 24 years old €59,48: up to 14 years old €86,62: 14-18 years old €115,96: 18-24 years old
Life-Long Disability Allowance	For children 24+ years old , who are unable to engage in paid work; €176,76
Allowance for Assistance by 3rd Person	For dependent family members who need at least 6h/day of personal care ; €88,37
Special Education Allowance	For children attending private (profit and non-profit) special schools; means-tested, varies in accordance with the tuition
Complementary Parental Leave	For working parents of children with disabilities up to 6 years old; 3 extra months leave at 25%
Paid Leave to Assist Child or grand-child with disability or chronic illness	Up to 6 months for a maximum of 4 years ; needs-tested (medical statement); at 65%
Part-time work for workers with family Responsibilities	Up to 4 years if the child has a disability or chronic illness
Reduced working time to assist a child with disabilities	Up to 5h/day for children up to 1 year old; needs-tested (medical statement)
Right to flexible working time	Regardless the age of the child with disabilities
Training for work reintegration	The employer should facilitate access to training and update for workers who benefited from extended leave to assistance to a child with disabilities

Source: Segurança Social, 2010

Moreover, social security offers 65% paid leave to parents who need to assist a child with disability or a chronic disease; this leave can be extended to 6 months/year up to 4 years (Segurança Social, 2010). 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 8).

Table 8 - Number of Users of the Leave for Assistance to Child with Profound Disability/Chronic Illness per Sex

	2004	2005	2006	2007	2008
Women	941	908	827	854	822
Men	39	40	36	36	38
% of male users in relation to female	4,1%	4,4%	4,3%	4,2%	4,6%

Source: IIES – Instituto de Informática e Estatística da Segurança Social (up until 2003) and INE/Instituto de Informática, IP (remaining)

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, 2010).

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 are entitled to only very modest financial compensation for this important social role. They are thus likely to face serious financial hardship, given that disability is in itself likely to increase family expenditures. Yet, many may continue to be forced to do so. On top of cultural expectations that continue to ascribe caring roles to mothers rather than to fathers (Rêgo, 2010; Perista, 2010), 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 (see table 9). Finally, but also importantly, the wage discrimination against women that persists in Portuguese society, within a context of lack of adequate disability 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 2006, the average monthly salary of women made up only 71% of the average monthly salary of men).

Table 9 - Provision of Formal Support Services for Adults with Disabilities in Portugal

Typology of Formal Supports		Nº of Providers	Capacity
Resources Centre	Information, guidance and support services as well as socio-cultural activities	26	2444
Occupational Activities Centre	Daycare for adults with severe disabilities	323	11564
Residential Care	Temporary or Permanent residential institutions for youngsters and adults with disabilities who cannot stay with their families	194	4459
Group Home	Small residential units for youngster and adults with disabilities	4	20
Home Care	Personal care in the home	27	1006

Source: Carta Social 2008

In short, despite some progress, Portuguese work and welfare regimes continue to 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 the context of a rudimentary welfare state, 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 in Portugal is even scarcer for adults than for young children with disabilities (Baptista, 1999). In addition to the financial inadequacies that have been described, this forced role raises a number of important questions related to the human rights of the person with disabilities who under present circumstances is also “forced” to receive care from his/her family.

Disability and the Debate on Care

Indeed, many scholars in disability studies (e.g. Oliver, 1991; Morris, 1993; 1997; 2004; Barnes et al., 2000) have voiced important critiques of the social relations of power in traditional forms of welfare provision for persons with disabilities and have been claiming for greater empowerment, choice and control for disabled persons. Direct payments to disabled people requiring care (rather than to their carers), enabling them to buy in their own assistance services, has often been the solution claimed for.

Michael Oliver (1991) and others 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, they argue, has been influenced by such medical perspectives which continue to

inform social assistance programs for this group of population in many parts of the world, including to some extent Portugal (Pinto, 2009; Fontes, 2009; Rioux, 2003; Hiroe, 2002). 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 attitudes on the part of professionals and families. Often it is assumed that caring, more than help with daily life 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 rights. As Morris (1993: 49) 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.»

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 must be abandoned (Morris, 1993; 1997; 2004; Barnes et al., 2000). What people with disabilities need, these authors claim, 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). Let me now turn to an exploration of this concept.

Personal Assistance: a Building Block for Independent Living and Social Participation

«Independent Living means that we demand the same choices and control in our every-day lives that our non-disabled brothers and sisters, neighbours and friends take for granted. We want to grow up in our families, go to the neighbourhood school, use the same bus as our neighbours, work in jobs that are in line with our education and interests, and start families of our own.» (Independent Living Institute, 2010)

Independent Living as a policy concept is about supporting disabled people to live their lives as full citizens and have choice and control over the way in which their care is delivered. In a number of European and North America countries, over the past 20 years there has been a radical shift from a welfare system, which has treated disabled people as dependent, passive recipients of 'care', towards a growing recognition of the

need for a new approach that enables disabled people to assume an active role in determining how their needs are met. Central to the concept of Independent Living are the principles of choice and control. The concept of Independent Living is based upon a social, rather than medical, model of disability. The social model recognises that people are disabled by barriers – social, economic, and attitudinal – in society, rather than by impairment in itself. Choice and control, therefore, depend on the removal of these external barriers.

Despite terminological differences, there is general agreement amongst disabled activists and their allies that the philosophy of ‘independent living’ is founded on four basic assumptions. These include, as described by Colin Barnes (2007):

- that all human life, regardless of the nature, complexity and/or severity of impairment is of equal worth;
- that anyone whatever the nature, complexity and/or severity of their impairment has the capacity to make choices and should be enabled to make those choices;
- that people who are disabled by societal responses to any form of accredited impairment – physical, sensory or cognitive – have the right to exercise control over their lives; and
- that people with perceived impairments and labelled ‘disabled’ have the right to participate fully in all areas, economic, political and cultural, of mainstream community living on a par with non-disabled peers.

The recently adopted UN Convention on the Rights of Persons with Disabilities dedicates an article to this important issue. Article 19, ‘Living independently and being included in the community’, states that State parties to the Convention:

...recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community.

To do this they are to ensure that:

- a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.'

In brief, then, independent living means that disabled people should be able to decide where and how they live, with access to a range of services (especially personal assistance) to support their life in the community. It does *not* mean that disabled people must do things for themselves, or live on their own. Rather, as stated in a recent report by the Academic Network of European Disability Experts «the *goal* of independent living for disabled people is that they should have choice and control over the decisions, equipment and assistance that they need to go about their daily lives, so that they can participate in society on the same basis as other people. » (Townsend et al., 2010: 8).

Independent living requires access to services like appropriate transport, housing education, employment and training, but among all these factors, 'Personal Assistance' services (often referred to as PA) emerges as a key element for people with disabilities to achieve self-determination and independent living. Typically PA support involves personal services (help with getting up, using the toilet, bathing, dressing, eating etc.), domestic services (cleaning, washing, shopping and looking after children and so on) and social services (helping with work, visiting friends, going to the cinema and other leisure activities) and requires a number of principles, notably:

- Disabled people control and manage staffing, either functioning as employers or using the service of a personal assistance agency
- Disabled people control the ways in which personal assistance is carried out. They instruct their assistants and decide which services are carried out and which not

- Disabled people control the services' budget and its management
- Disabled people decide where assistance is carried out: Personal assistance can take place in private homes, in the public, at the workplace, at a holiday resort, paying visits to friends etc.

PA services are already implemented in a number of European countries but delivery options widely vary. The ANED report (Townsend et al., 2010: 26-27) describes the following different types:

- **Full choice and control** - One country (Sweden) is supporting self-directed personal assistance, with (predominantly) use of mainstream services as the main delivery option for disabled people. This indicates that Sweden is offering its disabled citizens full choice and control over the support they need to live independently, with (almost) equal access to the same mainstream services as other non-disabled citizens.
- **Twin-track approach** - Twelve countries (Slovakia, Finland, Netherlands, Denmark, Austria, Germany, Ireland, United Kingdom, Spain, Belgium, Norway, France) are currently providing 'twin-track' support, where options for self-directed personal assistance for independent living co-exist alongside more traditional service-led and directed options. Here we might suggest that these eleven countries are offering their disabled citizens partial choice and control over the support they need to live independently, with some degree (albeit limited in some places) of equal access to the same mainstream services as other non-disabled citizens.
- **Low choice and control** - Nine countries (Poland, Estonia, Italy, Bulgaria, Romania, Latvia, Lithuania, Portugal, Iceland) are also offering co-existing support as above, but where the personal assistance element is **not** self-directed (i.e.: disabled people can access some sort of personal assistance via a variety of means, but have no control over its planning or implementation in terms of recruiting staff, planning activities, managing the staff and the budget, etc). In many of these countries, the concept of personal assistance is at a very early stage of development (e.g. Poland, Lithuania, Latvia), is not widespread (e.g. Bulgaria, Italy),

or is significantly limited in its scope (e.g. Portugal, Iceland, Bulgaria). In the case of these countries, we might suggest that they offer their disabled citizens very little choice and control over the support they need to live independently.

- **No-control** - One country (Czech Republic) is only providing service-led support for people to live in the community, or independently (in isolated cases). Here we could say that these disabled citizens have no choice and control over the support they need to live independently. In the Czech Republic, disabled people can apply for a direct payment to purchase services to support independent living, but in reality people have no choice over how to spend their budget since they can only choose from what is currently available from local service providers. And in some places this might only be their local institution.
- **Non-existing** - In two countries (Greece, Malta) it appears that there is virtually no support whatsoever, service-led or otherwise, to enable people to live independently, either in their own homes or in other community-based residential provision (including with families).

Not only delivery options are varied, the services being covered under PA are also distinct across countries. According to the ANED report, for the vast majority of the 22 European countries where some form of personal assistance is available this is focussed predominantly on support at home including support with tasks such as: house-keeping (laundry, cleaning, paying bills, correspondence, etc); food planning, shopping, preparation and cooking and personal care (washing, dressing, etc), and in some cases support to access social and recreational activities. Only in two countries (Iceland, Belgium) personal assistance to disabled people was found to include support with caring for children, so it is unclear whether this is an area of need that is supported more widely or not. In some countries, PA additionally included an information, advice and advocacy component. Finally, in twelve countries personal assistance involved support with employment and in seven others PA was available to disabled people to support education and training. (Townesley et al., 2010: 28-29)

Assessing the impact of PA services

There is very little research that has specifically set out to measure the outcomes of PA and independent living. Based on reports of disability experts from all European countries, ANED has attempted to gather some evidence regarding the impacts of this policy option (Townesley et al., 2010). Drawing from studies of countries so diverse as Slovakia, Belgium, Finland, UK, Norway and Austria, the ANED report suggests that PA contributes to improve the quality of life of disabled men and disabled women and increase their perceptions of independence (Townesley et al., 2010).

A thorough assessment of the costs and benefits of independent living has also been carried out recently in the UK (Hurstfield et al., 2007) involving a comprehensive literature review complemented with five case studies. This study has documented particular enhancements for people with disabilities in independent living mechanisms in terms of health status, satisfaction, participation in society, motivation, self-esteem and greater degrees of choice. These benefits significantly outweighed the benefits that were found for conventional forms of support.

In addition to positive impacts at the individual level (in the emotional and physical well-being of users) independent living options also appear to be more cost effective than conventional systems of support (Townesley et al., 2010; Hurstfield et al., 2007). For instance, the ANED report states that according to two studies in Sweden, the introduction of support for Independent Living through personal assistance has saved taxpayers at least 29 million SEK since 1994. This is due to the fact that in an open market, personal assistance costs less overall than home help services provided by public agencies (Ratzka, 2007: 47). And in Italy the cost of living independently was found to be 1/3 of the cost of institutional living (Townesley et al., 2010).

While research is beginning to evidence the benefits of direct payments, PA and independent living, critical voices have also raised. Clare Ungerson (1997) for example has noted that the increased commodification and marketization of care embodied in direct payments and PA schemes 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 policy 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 all these insights to devise an inclusive framework based upon the respect of human and civil rights for all – those who provide and those who need care.

Conclusion

Moving forward: contributions for an alternative model of welfare

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 lives 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 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 absent. 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: .488-489). As Williams (2001) points out, all these areas are inter-linked – 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: 489).

In the Portuguese context, an alternative welfare regime that would promote independent living, social participation and self-determination for people with disabilities 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:

- direct payments for people with disabilities to enable the purchase of PA support services;
- regulated working conditions for paid carers involved in PA services;
- improved and diversified service provision for children and adults with disabilities, based on principles of accessibility, affordability, quality, flexibility and users’ control;
- decent levels of disability-related benefits, for as Barnes (2007) reminds us «the main self-determination issue for disabled people is not simply about service de-

livery mechanisms, but about whether levels of resources are sufficient to deliver the required services»

- 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 environment which promotes and values all human lives.

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