



## The Right to Care? Social citizenship and care poverty in developed welfare states

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## The Right to Care? Social citizenship and care poverty in developed welfare states

### Abstract

#### *Purpose*

There are clear theoretical, policy and practice tensions in conceptualising social or long-term care as a 'right': an enforceable choice. The purpose of this article is to address the following questions: Do disabled and older citizens have the right to long-term care? What do these rights look like under different care regimes? Do citizens have the right or duty to \*provide\* long-term care? We know that both formal and informal care across all welfare contexts is mainly provided by women and that this has serious implications for gender equality.

#### *Approach*

In this article, the author takes a conceptual approach to examining the comparative evidence from developed welfare states with formal long-term care provision, and the different models of care, to challenge feminist care theory from the perspective of those living in care poverty (i.e. with insufficient access to long-term care and support to meet their citizenship rights).

#### *Findings*

Drawing on her own comparative research on models of long-term and 'personalised' care, the author finds that different models of state provision and different models of personalised care provide differential citizenship outcomes for carers and those needing care. The findings indicate that well-governed personalised long-term care provides the best outcomes in terms of balancing potentially conflicting citizenship claims and addressing care poverty.

#### *Originality*

The author develops new approaches to care theory based on citizenship and care poverty that have not been published elsewhere, drawing on models that she developed herself.

## Introduction

### Developing new theories and comparative models of care

In this article, the author will examine the development of several theories relevant to our understanding of the provision of long-term care and support to disabled and older people in developed welfare states. She discusses ideas of social citizenship and social rights to receive and give care, including sometimes conflicting disability rights and feminist perspectives; the role the state, the family and individuals play in providing care (and the gendered implications of this); whether the relatively new concept of care poverty (i.e. not receiving adequate care to meet needs) is helpful in alleviating some of the theoretical tensions inherent in a rights-based approach to care; and reinforces the importance of a gendered analysis of care.

The author will then use these theoretical frameworks and apply them to two empirical areas: a gendered analysis of different models of long-term care based on policies used in developed European welfare states in 2013-16; and a gendered analysis of the development of 'personalised' long-term care in developed welfare states during the same period (where disabled and older services users are nominally put in charge of their own long-term care services rather than these being directly provided by the state). These time frames are to provide a temporal and conceptual net to bound the analysis of policy development - which is of course a constantly moving and changing field. The purpose is to apply and test the theoretical frameworks against the empirical comparative policy evidence, not to repeat the exhaustive and up-to-date description of policies which can be found elsewhere. The author will then conclude with a discussion of the usefulness of the theoretical frameworks tested by the comparative policy analysis and draws out lessons to aid other scholars in comparatively analysing long-term care policies.

A note on terminology: throughout this paper, the author uses the terminology used by the disability rights movement (i.e. disabled people = people with chronic illnesses and impairments who are disabled by an inaccessible society, not 'people with disabilities' or people first language which is rejected by disability rights activists and scholars for being medicalised). 'Older people' is used to mean older people with chronic illnesses and impairments who need long-term care and support, and this is again the preferred term of the disability rights movement (who do not distinguish on the basis of age). 'Carers' is used to denote unpaid carers, usually kin (and most often, but not exclusively, women) and 'formal carers' is used to denote workers providing long-term care for payment (they may also be kin, depending on the particular context of long-term care delivery). 'Models of care' refer to those comparative models of long-term care developed by the author (in 2021), drawing on established work in welfare modelling but applying it particularly to long-term care with a gendered analysis.

## Social citizenship and the right to care

Citizenship can be defined as:

*... that set of practices (juridical, political, economic and cultural) which define a person as a competent member of society, and which as a consequence shape the flow of resources to persons and social groups...Citizenship is concerned with (a) the content of social rights and obligations; (b) with the form or type of such obligations and rights; (c) with the social forces that produce such practices; and finally (d) with the various social arrangements whereby such benefits are distributed to different sectors of society. (Turner, 1993, p. 2-3)*

Both the provision and receipt of care and support are crucial elements in supporting (or threatening) the social citizenship of individuals. Work is an important way in which people discharge their citizenship obligations: how that work is valued plays a significant role in whether those engaging in care work are able to be full members of their communities (Lister, 2003; Marshall, 1950; Rummery, 2002). Similarly, for disabled and older people who need care and support, how that is delivered (whether they can exercise choice and control over it, whether they can combine receiving with giving care, whether care enables them to participate in society, whether care is accessed as a social right) plays a significant role in whether they are able to act as full members of their community - their social participation, which is their ability to exercise choice and self-determination over their lives, shaped by their access to resources (Townsend, 1993; Sen, 1990). The idea of the ability to participate in social life framed by access to resources works also as a way to conceptualise care: both *access* to care, and the *giving* of care, can be seen as an important part of the resources which are both drawn upon and needed for social participation (Knijn and Kremer, 1997; Williams, 2001).

Theoretical definitions of 'care' have had a normative influence on, and been influenced by, scholarship in social policy which has looked not only at the *gendered* dimensions of care, but also other social divisions pertaining, for example, to ethnicity and class (Arber and Ginn, 1992; Bowes, 2006; Williams, 1995). The way in which social divisions can be exacerbated by long-term care policy has been highlighted by recent research into the global 'care chain', in which migrant carers contribute to the 'care deficit' experienced in developed welfare states (Hochschild, 2000), and the different ways in which individuals, groups, communities and the state provide care for their citizens is now a significant element in understanding national and international social policy (Ungerson, 2005). Understanding the relationship between caring *for* and caring *about* in long-term care is a site of theoretical and critical tension that goes beyond relationships between individuals and goes to the heart of the core concerns of social policy in meeting citizens' needs.

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3 One of the legacies of feminist research was that the values of justice and care have come to be treated  
4 as antagonistic and gendered (Crittenden, 2001), with care being understood as having essentially  
5 subjective, particularistic and emotional value. Knijn and Kremer (1997) argued that a justice  
6 framework can help us to conceive of the right to *receive* care, as well as the right to *give* care as a  
7 matter for citizenship, a framework also adopted by others (Sevenhuijsen, 1998; Morris, 2001; Bubeck,  
8 2002; Engster, 2007), making it increasingly difficult to sustain the claim that ethical values based on  
9 care violate the ideals of justice. Instead, the right to care – to give care, receive care and the right  
10 care for oneself - as Fiona Williams neatly summarised it (Williams, 2001), needed to be seen as the  
11 most fundamental of the struggles for justice.  
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19 A 'justice' model of care can be seen to resonate with a concern with social citizenship: it allows a  
20 focus on the social rights associated with care: both the right to have the *giving* of care recognised  
21 and legitimated, and the recognition of the right to *receive* care and support (Knijn and Kremer, 1997).  
22 This concern for care as an issue of justice has been central to the approach adopted by feminists and  
23 social justice campaigners to care and to research on caregiving (Barnes, 2001; Fine, 2007) where  
24 responding to the isolation, poverty and social exclusion of primary caregivers has become central to  
25 civic campaigns for the recognition of informal care.  
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31 Set against the concern to validate and recognise the value of care are concerns voiced by disability  
32 rights authors such as Morris (2001, 2004) and Brisenden (1989), who take issue with such arguments  
33 because they rely overwhelmingly on the theoretical and empirical perspective of those who *provide*  
34 care at the expense of the perspectives of those that *receive* care. For example, Waerness asserted  
35 that '*the receiver of care is subordinate in relation to the caregiver*' (Waerness 1984, p. 189), and  
36 Ungerson (1990) and Daly (2002) reaffirm the view that care recipients are 'dependent' upon  
37 caregivers because of their incapacity and inability to care for themselves. Brisenden (1989) has  
38 argued that relying for support on unpaid carers is exploitative and ruinous of relationships, and  
39 Morris (1997) takes this analysis further to argue that care is a form of oppression against disabled  
40 people.  
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49 Other authors such as Shakespeare (2000) and Finkelstein (1998) also reject the language and ethos  
50 of care, preferring a 'justice' model of self-determination, control and clearly defined and executable  
51 rights more in line with a citizenship framework: Kröger asserts that the disability rights and feminist  
52 perspectives are portrayed as being 'poles apart and fully incompatible with each other' (Kröger, 2009,  
53 p.406). Authors who have attempted to reconcile these positions have argued that a recognition of  
54 the reciprocal nature of care coupled with opening up of choice and control as envisaged through the  
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3 marketisation and personalisation of care services (see below) is a way of synthesising the opposing  
4 theoretical perspectives (Barnes, 2011; Lloyd, 2000; Rummery 2011; Watson *et al.*, 2004).  
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7 Reciprocity of care and the ability of markets to open up choice to those who give and receive care is  
8 easy to argue in situations of informal care, and where those with care needs are also giving care (for  
9 example, as parents, spouses, and carers) (Williams, 2001). However, the role of ethical care arguably  
10 becomes even more important when people are particularly vulnerable – for example, near the end  
11 of life, with dementia or profound impairments that make the exercise of choice difficult (Kittay, 2002;  
12 Brannelly, 2011). Policy and practice solutions that hinge on marketisation and personalisation that  
13 are designed to work in the area of disability may not easily translate into long-term care for older  
14 people.  
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21 If we argue that the state should provide care (Parker, 1992; 1993) and thus free both carers from the  
22 burden of providing unpaid care and the disempowering effect that has on those that need care, then  
23 the counterargument is that disability rights campaigners have fought long and hard to free  
24 themselves from the oppression, paternalism and segregation associated with state care (Keith, 1992;  
25 Kröger, 2009). Alternative solutions have been posited as placing care in the marketplace (Beckett,  
26 2007) but this faith in markets is not shared by feminist writers who argue that the feminisation and  
27 undervaluation of care work drives down wages and leaves formal carers open to exploitation and  
28 abuse, places additional burdens on informal carers, and leaves vulnerable people needing care  
29 unprotected (Rummery, 2021).  
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37 Social, demographic and political changes have led to a rising demand for long-term care and support,  
38 particularly for disabled and older adults, across developed welfare states (Pierson, 2001) due to  
39 improved longevity and wellbeing and a declining availability of family support. Understanding who  
40 undertakes, pays for, and receives care is a crucial part of understanding both the form and practice  
41 of oppression along the lines of gender, disability, class and age (Lewis, 2002). Whilst this has led to a  
42 rich empirical and theoretical tradition informed by feminist analysis, the perspectives of those  
43 *receiving* care have, with a few notable exceptions (e.g. Morris, 1993; Kröger, 2009; Lloyd, 2000) not  
44 necessarily been viewed through a theoretical lens informed by this perspective.  
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51 Recent years have seen several important changes in the policy direction in the provision of health  
52 and social services in order to cope with the increase in demand for long-term care, along with an  
53 increase in the politicisation of disability rights organisations, and in some cases older people's  
54 organisations. These campaigners have rejected state-provided long-term care services as being  
55 increasingly fragmented and unresponsive, and rejected relying on informal care as being  
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3 disempowering and exploitative (Brisenden, 1986; Morris, 2004). Disabled and older people are  
4 demanding more choice and control over long-term care and support services.  
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### 7 Care poverty and social citizenship

8 Care poverty is an analytical tool developed by Kröger *et al.*, (2019) based on the idea of unmet  
9 needs. They point out that systems are usually designed to meet unmet needs: but policymakers,  
10 not people with needs, define what those needs are. In health care it is usually defined in terms of  
11 access to health care (Allin and Masseria, 2009); in social or long-term care this is similarly defined in  
12 terms of access to care and support services (Brimblecombe *et al.*, 2017). Bradshaw (1972) was one  
13 of the first to acknowledge that access to care could mean care that was provided by relatives and  
14 that where this placed 'undue strain' on those carers, needs could be said to be 'unmet'. Williams *et*  
15 *al.* (1997) take a medical view of needs: they see them as being the result of disability (rather than  
16 impairment or chronic illness) and define unmet needs as occurring when the functional limitations  
17 of people are not compensated for by the availability of informal or formal care (Lima and Allen,  
18 2001).  
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28 However, this is problematic from a disability perspective. Although now somewhat dated, the social  
29 model of disability preferred by many writers asserts that it is not 'functional limitations' that make  
30 people disabled, rather it is the external structural oppression faced by those with chronic illness,  
31 impairments and functional limitations. In other words, people with functional limitations are  
32 'disabled' by society (including the environment, attitudes, organisations, political systems and so  
33 forth) (Oliver, 1990; Morris, 2004). Using this theoretical approach to disability, we can  
34 conceptualise the lack of adequate care as being part of the social oppression that disabled people  
35 with functional limitations. The framing of unmet needs, however, remains problematic: it is rooted  
36 in a sense of dependency rather than social justice: needs are not 'enforceable choices' the way  
37 social rights are (Marshall, 1950).  
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45 Kröger *et al.* (2019) propose that instead of unmet needs, we conceptualise the gap between the  
46 care and support people need and that which they have access to as 'care poverty':  
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49 *Care poverty means a situation where, as a result of both individual and structural issues,*  
50 *people in need of care do not receive sufficient assistance from informal or formal sources,*  
51 *and thus have care needs that remain uncovered. (Kröger et al., 2019, p.487)*  
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55 This formulation offers greater capacity for a social and disability rights-based approach to care.

56 'Poverty' as a concept has both ideological and epistemological roots: it is both something that can  
57 be defined, but also something that once found, merits policy action (D'Arcy and Goulden, 2014). It  
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3 is a contested term precisely because of this duality: poverty, by definition, is a negative state to be  
4 in and warrants attention (Brabant and Gramling, 1985). The contested definitions of poverty reflect  
5 the ability and willingness to address it as a social issue. Definitions are commonly separated into  
6 absolute poverty - the lack of basics needed to survive such as food and shelter, or achieve minimum  
7 capabilities (Sen, 1983) and relative poverty - a measure somewhere below the median income of a  
8 country (George, 1988; Townsend, 1993). Care poverty can therefore be seen both as a cause and  
9 consequence of oppression for people with functional limitations who need care as well as those  
10 who are expected to provide the care.

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12 This brings us back to the concept of social citizenship: of being a *full and competent member of the*  
13 *community* (Marshall, 1950). In order to be a full member of the community, a citizen needs to be  
14 able to access social rights: enforceable choices to resources in order to meet 'basic' needs such as  
15 housing, food and education. As stated above, a citizen unable to access these social rights could be  
16 said to be living in 'poverty', and welfare states were developed on the understanding that  
17 individuals cannot always access social rights through the market or other sources of income alone  
18 (Rummery, 2002). Care poverty could therefore be seen as the lack of access to adequate social  
19 rights to meet needs: and a situation that demands policy action.

### 20 21 22 Gendering the analysis

23 Care policy is an example of a social and structural issue that has profound effects on outcomes that  
24 can either exacerbate or reduce gender inequalities. Although this is changing, the evidence suggests  
25 that in developed welfare states, women bear the double burden of being responsible for childcare  
26 and/or providing care and support for disabled and older family members, and taking part in paid  
27 employment (Hervey and Shaw, 1998). This contributes to the gender gap in both public life, where  
28 women are substantially less likely than men to occupy senior positions in work, politics and civic  
29 society, and private life, where women are significantly more likely than men to be at risk of poverty  
30 and to bear the effects of economic pressures and welfare restructuring. The evidence suggests that  
31 care policy (both in terms of childcare and long-term care) in some types of welfare regimes achieves  
32 better outcomes than others (in terms of delivering equality, particularly gender equality) (Walby,  
33 2004).

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35 Developed welfare states have responded to the challenge of how to manage welfare and long-term  
36 care policies in such a way which limits the rising demand for resources, leading to a shifting of  
37 responsibilities across public sectors (for example, from health to social care, and from national to  
38 localised provision), and across sectors (for example, from state to private or third sector provision,  
39 or from state to family [or, indeed, family to state]) (Moffat *et al.*, 2012). At the same time, a variety  
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of international, national and local political, social and economic factors have led to changes in the governance of welfare, including increasing commoditisation of services and deprofessionalisation of practitioners (Newman, 2005). Rising demand for support and services has also come not just from demographic changes but also from increasingly politicised ‘user’ movements (such a disability rights organisations in the UK and the Netherlands, and older people’s organisations in the USA) who have rejected family/informal/unpaid care as exploitative (for both carers and cared-for) and state/formal/paid care as increasingly fragmented, unresponsive and dehumanising – indeed, rejecting the rhetoric of ‘care’ altogether and demanding social rights, empowerment and control over the type and level of support received instead (Morris, 2004). Increasing regulation of services in response to ‘consumer’ demand has only partially succeeded in responding effectively to these changes: new models of service delivery are being actively sought in response to these complex political, social and economic changes (Ungerson and Yeandle, 2007). However, any rise in the reliance on families to provide long-term care inevitably means that the burden of this will fall disproportionately on women, leading to widening gender inequality: particularly if the provision of such care is unpaid or not compensated by the state.

### New welfare models: gendered citizenship and long-term care

Care policy has been used to critique the standard Esping-Andersen (1990) way of modelling welfare regimes based largely on cash transfers and decommodification which ignored women’s caring labour, or used the option of women not having to provide caring labour for free (Knijn and Kremer, 1997). Elsewhere (Rummery, 2021), I have argued that if we look at the long-term care policies of welfare states with good gender equality outcomes, they fit into two models that overlap with Esping-Andersen’s typology: the Universal Model (Nordic model states such as Iceland, Norway, Denmark, Finland and Sweden); and the Partnership Model (neoliberal but not overly familial states such as the Netherlands, France, Germany, and Belgium).

### The Universal Model

The Nordic states are commonly held up as an example of universal state provision of services leading to high levels of gender equality. This is slightly misleading: there is no one ‘Nordic’ model of welfare, and even those states with high levels of state control over welfare and long-term care services have introduced forms of market and individual involvement in the provision of services. Comparative social policy experts have always questioned whether there really is one ‘Nordic’ model of welfare, and whether the difference between that and other models is as marked as is often claimed (Mahon *et al.*, 2012). Countries that fall into this model have normative policy frameworks that were heavily focused on gender equality. Aspirations towards gender equality informed the

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3 constitutions of these countries and also underpinned the development of welfare services. The twin  
4 commitment to gender equality and universality means that long-term care services have always  
5 been part of state provision (Rummery, 2021). Countries that follow this model include Denmark,  
6 Iceland and Sweden (Sigurðardóttir, 2013; Sigurðardóttir *et al.*, 2012; European Commission, 2013)  
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### 10 The Partnership Model

11 Countries that fall into the Partnership Model see gender equality as an important policy driver, but  
12 it is not necessarily the main, or even most important, factor underpinning the development of long-  
13 term care policies. They have developed welfare states, but do not view the state as necessarily  
14 being the only or main provider of services. The state is seen more as a driver of policy: setting a  
15 legislative framework and in some cases providing funding and services, but doing so in partnership  
16 with the market, with communities and families, and with individuals. There is a greater role played  
17 by municipal authorities than in the Universal Model, and thus sometimes a greater variation in the  
18 availability and quality of services. However, the state does play a strong regulatory role, and  
19 individuals do have important rights to access services. Countries in this model include the  
20 Netherlands and Germany (Rummery 2021).  
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30 The provision of long-term care has always been seen as the responsibility of the state to a certain  
31 extent in the Partnership Model, and the Netherlands in particular has seen relatively high spending  
32 in this area. Social rights to long-term care provided by municipalities have been a feature of this  
33 model since the mid-1980s, but many countries underwent substantial revisions in the 1990s and  
34 again in recent years, reflecting the growing demand for these services from an ageing population. In  
35 long-term care, the state is seen as having an important role, but not being the sole provider of  
36 services and support. Instead, support is seen as being funded and delivered in a partnership  
37 between the state, employers, the community, families and individuals.  
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44 However, the provision of care services is not just about the social rights of women as family carers.  
45 It is also, crucially, about the social rights of disabled and older people. State provision is not  
46 necessarily per se effective at addressing care poverty, particularly if disabled and older people are  
47 not in control of the care and support they receive. Here I turn my attention to the development of  
48 personalised long-term care services to see if they offer better social citizenship outcomes for both  
49 carers and those who need care and support.  
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### 55 Personalisation –cash for care – and social citizenship

56 Internationally, the evidence shows us that pressures emanating from an exponential rise in demand  
57 and many disabled people themselves becoming politically active and the move away from  
58 formalised residential care arrangements to varying degrees across the world resulted in the  
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3 development of various 'cash for care' schemes. These schemes vary considerably in their intentions,  
4 scope and how they function, they are essentially mechanisms whereby a disabled or older person  
5 receives a cash benefit in order to purchase help or services themselves, in lieu of receiving services  
6 or support directly. They can be seen as a way of 'commodifying' care (Ungerson, 1997) and several  
7 different models have emerged: tightly controlled personal care budgets allowing direct  
8 employment of formal care workers; care allowances paid directly to disabled and older people but  
9 not directly governed; income maintenance approaches (whereby allowances are paid directly to  
10 carers to acknowledge or compensate for the loss of earned income, usually only available to low-  
11 income carers); and directly paying informal carers to replace publicly funded formal care.  
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19 The evidence on the take-up of such schemes in the UK (where there are optional alternatives to  
20 direct state provision of care) suggests that it is generally articulate, younger, well-educated disabled  
21 people who are disproportionately represented amongst those who choose to use them (Spandler,  
22 2004). Take-up amongst older people, ethnic minorities and learning disabled adults remains  
23 comparatively low. Cash-for-care schemes are also likely to lead to a widening gulf between paid  
24 carers working in regulated, professionalised and protected formal care employment and paid carers  
25 working in private, unregulated employment, whether this is for a family member, direct employer  
26 or through the grey/black labour market. They are likely to further disenfranchise low-skilled, poorly  
27 paid women in comparison to their wealthier, better-educated sisters and to widen social divisions  
28 within and across genders. In low-income families where the use of the cash payment is fairly  
29 unregulated (for example, in Italy), it is likely, based on what we already know about the distribution  
30 and use of money in low-income households, that gender differentials will emerge, with women  
31 more likely to use the payments to purchase care and men being more likely to use the payments as  
32 part of the general household income (Vogler and Pahl, 1993). Where cash-for-care schemes are  
33 used to route money to informal family carers this can have the effect of creating, or reinforcing  
34 dependency relationships both inter-generationally (for example, between learning disabled adult  
35 children and parent/carers; or between daughters/daughters-in-law and parents) and intra-  
36 generationally (for example, between spouses). Finally, the use of unregulated and unsupervised  
37 cash-for-care payments, both to pay family carers and directly employ unskilled care workers, has  
38 the result of commodifying intimate and sometimes unarticulated relationships and expectations,  
39 with the possibility of exploitation and abuse of vulnerable parties on both sides (Ungerson, 2004).  
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55 Notwithstanding the issues and concerns raised above, the evidence across all the schemes,  
56 particularly in comparative and qualitative studies (see, for example, Ungerson and Yeandle, 2007;  
57 Glendinning and Kemp, 2006) suggests that such schemes do appeal to both users and paid and  
58 unpaid carers. It is possible for disabled and older people to simultaneously be employers (for  
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3 example, of personal care workers), carers (for example, of spouses, children, or grandchildren),  
4 workers (whether full or part-time, paid or unpaid, voluntary or involuntary, or a combination of all  
5 of these) and to be exercising citizenship rights and duties in other complex ways (Lloyd, 2000;  
6 Rummery, 2007).  
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10 The advantage of cash-for-care schemes over the alternatives (i.e. formal state provision or informal  
11 family provision of care and support) is that giving choice and control to disabled and older people  
12 enables them to purchase care and support that fits in with both statutory and informal networks,  
13 and enables them to carry out their own caring and other duties (Rummery, 2006). Further, cash-for-  
14 care schemes are a very effective way of filling in gaps between service provision that are not easily  
15 addressed by formal provision while the effects of freeing people up (to be parents, spouses and  
16 children, rather than carers and/or cared-for) can have a significantly positive effect on the  
17 wellbeing and relationships of all concerned.  
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#### 24 *'Familial': Italy and Austria*

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26 Both Italy and Austria rely on the family as the default to provide care, with Italy, in particular, seeing  
27 very little development of formal long-term care (Gori, 2003; Pavolini and Ranci, 2006) and Austria  
28 also has comparatively low levels of investment in formal long-term care (Bettio and Platenga, 2004).  
29 Individual care payments (the use of which is not governed) have been developed and are used to pay  
30 family members or employ care workers (Hammer and Österle, 2003; Österle, 2001), often on the  
31 black (unregulated) labour market or employing migrant workers (Gori and Da Roit, 2007; Ranci, 2007;  
32 Kreimer and Schiffbaenker 2005). Lack of regulation means that payments are not always used for  
33 care, and workers have very little employment protection. The Austrian system is slightly more formal  
34 and regulated than the Italian system, but it still relies on family care (Österle and Bauer, 2012).  
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#### 43 *'Liberal': United Kingdom and United States*

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45 These systems rely on the family to provide care by default (leading to gendered inequality) but do  
46 provide some state-sponsored long-term care. Both the UK and USA have developed local systems of  
47 direct payments/personalised/Self-directed Support which mean that disabled and older people are  
48 now able to apply for payments in lieu of directly provided services: these payments are usually used  
49 to directly employ formal care workers, or purchase care from not-for-profit care agencies. Payments  
50 are governed and must be spent on care, although there is a relatively free market for providers  
51 (Rummery, 2006; Mahoney *et al.*, 2000; Keigher, 2007).  
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#### 57 *'Controlled': The Netherlands and France*

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3 Although relying on the family to a certain extent, both the Netherlands and France have seen the  
4 introduction of personalised care payments (Weekers and Pijl, 1998; Pijl and Ramakers, 2007; Martin  
5 and Le Bihan, 2007), allowing recipients to choose to receive direct payments in lieu of directly  
6 provided state services. These schemes are relatively strictly regulated, providing a degree of  
7 protection for directly employed care workers and making it impossible to directly pay workers on the  
8 'black' or unregulated market (Bresse, 2004; Rummery, 2021).  
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#### 10 11 12 13 14 *Governance and cash-for-care schemes*

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16 Two issues pertinent to the governance of cash-for-care schemes emerge from an analysis of the  
17 schemes in the six countries under discussion. Firstly, there is the issue of national versus  
18 regional/local governance. Where schemes have been developed which allow for a degree of localised  
19 discretion in their implementation (e.g. UK, USA and, to a certain degree Italy) there is considerable  
20 scope for inequalities and inequities inherent in the system to have a gendered impact: (for example,  
21 in the different types of employment protection available to workers, and the differential impact  
22 commodifying care can have on family relationships). Secondly, there is the issue of the governance  
23 of the schemes themselves: how they are operated, how users are made to account for the ways in  
24 which they spend money, and the level of policing and surveillance that gives the state control over  
25 individual's lives. Some schemes (e.g. UK, the Netherlands, France) are highly regulated, which, on the  
26 one hand, offers a degree of protection both to potentially vulnerable users and workers (and  
27 particularly in the case of France, offers valuable employment protection to potentially exploited  
28 groups of care workers who are overwhelmingly women), but which, on the other hand also gives the  
29 state a life-course and social divisions.  
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32 In some respects, the introduction of a marketised, consumerist mechanism such as cash-for-care  
33 schemes into an area that was previously the domain of either the private, familial sphere or the  
34 public, statutory sphere is likely to create and exacerbate social divisions already apparent between  
35 different social groups. Take-up amongst older people, ethnic minorities and learning disabled adults  
36 remains comparatively low. These findings echo concerns across other areas of welfare provision that  
37 consumerist-driven reforms will tend to favour those best-placed to benefit from the market by  
38 exercising choice, voice and exit (6, 2003). In other words, the gulf between middle class and poorer  
39 disabled and older people is likely to be made greater by the introduction of cash-for-care schemes,  
40 as is the gulf between middle class and poorer carers, with the former being more able to exercise  
41 choice about the level and type of care work they undertake than the latter. As discussed above, cash-  
42 for-care schemes are also likely to lead to a widening gulf between carers working in regulated,  
43 professionalised and protected formal care employment and those working in private, unregulated  
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3 employment, whether this is for a family member, direct employer or through the grey/black labour  
4 market. They are likely to further disenfranchise low-skilled, poorly paid women in comparison to their  
5 wealthier, better-educated sisters and to widen social divisions within and across genders.  
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9 Furthermore, the impact of cash-for-care schemes on power relationships within the family sphere  
10 across the life-course and across generations remains unexplored, but there are reasons to voice  
11 concern about several aspects. Firstly, in low-income families, where the use of the cash payment is  
12 fairly unregulated (for example, in Italy), it is likely, based on what we already know about the  
13 distribution and use of money in low-income households, that gender differentials will emerge.  
14 Secondly, where cash-for-care schemes are used to route money to informal family carers this can  
15 have the effect of creating or reinforcing dependency relationships both inter-generationally (for  
16 example, between learning disabled adult children and parent/carers) and intra-generationally (for  
17 example, between spouses). Finally, the use of unregulated and unsupervised cash-for-care payments,  
18 both to pay family carers and directly employ unskilled care workers, is risky: money in a highly  
19 consumer-oriented capitalist society is power, and the person controlling the money in a care  
20 relationship is in a position to be able to exert power and influence over the person who does not:  
21 and any relationship involving the exertion of power and control over another person is open to the  
22 possibility of the abuse of that power and control. Better-educated, better-skilled and better-paid  
23 women are likely to be in a better position to avoid the potential abuse and exploitation suffered by  
24 lower-education, lower-skilled and lower-paid women in these situations, leading to greater  
25 inequalities between different groups of women (and sometimes men).  
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### 37 38 *Wellbeing and citizenship*

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40 Notwithstanding the issues and concerns raised above, the evidence across all the schemes,  
41 particularly in comparative and qualitative studies (see, for example, Glendinning and Kemp, 2006;  
42 Ungerson and Yeandle, 2007) suggests that such schemes do appeal to both users and formal and  
43 informal carers, and it is worth exploring some of the gendered dimensions of why this is the case.  
44 Firstly, cash-for-care schemes are a way of recognising the complexity and reciprocity that  
45 characterise many caring relationships. One thing that both feminist and disability rights researchers  
46 and campaigners have pointed out is that people's identities within the social world are not easily  
47 divided into binary distinctions: public versus private, user versus carer, worker versus non-worker. It  
48 is possible – indeed, usual – for disabled and older people to simultaneously be employers (for  
49 example, of personal care workers), carers (for example, of spouses, children, or grandchildren),  
50 workers (whether full or part-time, paid or unpaid, voluntary or involuntary, or a combination of all of  
51 these) and to be exercising citizenship rights and duties in other complex ways (Rummery, 2007; Lloyd,  
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2000). The advantage of cash-for-care schemes over the alternatives (i.e. formal state provision or informal family provision of care and support) is that giving choice and control to disabled and older people enables them to purchase care and support that fits in with both statutory and informal networks, and enables them to carry out their own caring and other duties (Rummary, 2006).

Secondly, cash-for-care schemes are a very effective way of filling in gaps between service provision that are not easily addressed by formal provision – for example, by enabling users to employ workers who cross the ‘health/social’ care divide, or by allowing users to purchase support for themselves in a caring role (e.g. as a parent) – which can have the result of ameliorating the effects of power dependencies within families. Exercising choice and control is empowering not only for users but also for carers: being able to choose when and how to care and being able to choose not to care can reduce the disempowering effects of having to provide care because no other options are available. As women are still the primary carers in families, their concerns are with the wellbeing of all their families, and a policy development that has the effect of increasing the wellbeing of all members of the family is one to be welcomed.

Finally, if we move away from a neoliberal economic analysis of cash-for-care schemes as being a way of trapping women into low-paid, unskilled care work towards a more nuanced understanding of the value of care work and an ‘ethic of care’ (Sevenhuijsen, 1998), both for carers and cared-for, we can conceivably argue that giving women the opportunity to engage in that work for payment, even if that payment is low, is possibly opening up citizenship opportunities in a way that is preferable to some of the alternatives available. For example, engaging in care work, particularly if freely chosen, is arguably less dangerous and exploitative to low-paid migrant workers than other black-market alternatives.

## Conclusions

### Long-term care, social citizenship and care poverty

The evidence above has looked at two ways of addressing care poverty: through different models of state intervention; and through allowing disabled people access to income to purchase care and support. Which of these models addresses care poverty most effectively: which leads to better outcomes (in terms of being enabled to be a ‘full and competent member of the community’) for those who need and provide care?

The Universal Model of state provision has the advantage of not relying on women’s unpaid labour to provide care. Through institutional provision of formal care services, women’s ability to be competent members of society is not compromised. However, we cannot assume that providing universal services necessarily addresses care poverty. If those services are not designed to meet disabled

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3 people's needs more widely than basic existence (washing, eating, dressing, etc.) and do not allow  
4 disabled people full social participation then they can be said to be living in relative care poverty (i.e.  
5 the service they receive to meet their needs puts them at significantly below the median for social  
6 participation in their political and economic context). State paternalism does not necessarily enable  
7 disabled people to live lives as 'full and competent members of the community' (Roulstone, 2013).  
8 The Universal model of long-term care is designed to mitigate against women's poverty, not disabled  
9 people's.

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11 The Partnership Model of state provision does place women at risk of providing underpaid care  
12 support (but not usually completely un-recompensed). In that respect, it is not as successful as the  
13 Universal Model in addressing women's poverty, but it does enable women who are carers to 'be a  
14 full and competent member of the community' by paying them for providing care, both as formal and  
15 family carers. In addition, it gives disabled people far more choice over the provision of care than the  
16 Universal Model. It uses marketised means to enable this choice, which in itself has some problems,  
17 but largely the provision through the market or quasi-market of care services gives disabled people a  
18 social right to care in the sense of an enforceable choice: they enforce their choices through choosing  
19 their provider in a way that is not possible in the Universal Model. We can therefore argue that this  
20 model of state provision has the potential to address care poverty.

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22 However, neither of the state-led models of provision are as effective at providing choice and control  
23 to both disabled people, and paid carers, as the personalised care schemes. Some do not function as  
24 well as others: the more highly governed schemes such as France and the Netherlands offer greater  
25 protection for disabled people and carers than the more laissez-faire schemes such as Austria and  
26 Italy. If we conceptualise care poverty as being both not receiving enough assistance from both formal  
27 and informal sources (Kröger *et al.*, 2019) AND as a social and political issue that needs addressing,  
28 then personalised care schemes appear to offer the best outcomes. By being in charge of purchasing  
29 the kind of help and support they need, disabled people have to overcome both functional limitations  
30 and social oppression, without placing undue pressure on family carers (or indeed forcing family carers  
31 to provide support in the face of lack of alternatives, which places both disabled people AND carers in  
32 poverty and reduces their social participation). Properly governed personalised care schemes accept  
33 that the state has a responsibility to address care poverty, but also recognises that what the outcome  
34 of having 'needs met' means needs to be decided by disabled people, not the state. It also recognises  
35 that you cannot rely on underpaid or unpaid women to provide care at significant risk of their own  
36 poverty. Care poverty is most effectively addressed by personalised long-term care schemes rather  
37 than either state or partnership provided services.



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