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Care poverty and conflicts in social citizenship: the right to care?

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Introduction

In this chapter the theory of care poverty is placed in the context of other theories of care, providing an overview of the conflicts inherent in these theories, including the idea of 'social citizenship' – the right to access resources to meet needs, in this case care needs. Ideas about care poverty are used to offer a theoretical way of synthesising previous conflicting theories of care, testing this against kinship versus formal care provision.

Conflicting theoretical models of care

'Care' is a contested site of critical tension in contemporary social theory, policy and practice, and theories of care poverty draw on several histories to reframe and understand this tension. Feminist scholarship has highlighted the importance of understanding the intersection between emotion (Bowden, 1997) and labour (Twigg, 2000) – including the physical, emotional and economic costs of that labour (Himmelweit, 1999). Theorists have sought to distinguish between caring *about* and caring *for* (Knijn and Kremer, 1997) and the ethical dimensions of that tension (Tronto, 1998). Care is also understood as having both ethical and competency dimensions for both family (informal) and professional (formal) carers (McKechnie and Kohn, 1999). Crucially, care, whether it takes place in a formal or informal relationship, needs to be viewed as being a *social* relationship: an often complex and difficult relationship involving power and dependency (Lloyd, 2000). This power and dependency relationship is not simple, and involves the risk of loss of autonomy and independence, and the risk of exploitation, on both sides (Fine, 2005).

Theoretical definitions of 'care' have also 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 (Williams, 1995). Poverty and inequality in care has been highlighted by research on migrant care workers, who work to address care poverty in developed welfare states (Hochschild, 2000). Understanding the relationships between state, community, family and individual responsibilities for care is now accepted as part of mainstream social policy analysis (Ungerson, 2005). Caring *for* and *about* people is no longer seen as a private relationship between individuals but one of public concern.

The strength of feminist research in this area does mean that the values of justice and care are seen as both gendered and oppositional (Crittenden, 2001) – care having emotional and subjective value. Knijn and Kremer (1997) argued that a justice framework can help us to conceive of the right to *receive* care, as well as the right to *give* care as a matter for citizenship, making it increasingly difficult to sustain the claim that ethical values based on care violate the ideals of justice. Williams (2001) frames it as the *right* to give and receive care being a struggle for social justice.

A 'justice' model of care can be seen to resonate with a concern with social citizenship: it allows a focus on the social rights associated with care: both the right to have the *giving* of care recognised and legitimated, choice over whether and how to provide care supported, and the recognition of the right to *receive* care and support (Knijn and Kremer, 1997; Williams, 2018). Reformulating care as an issue of justice underpins the political approach to care adopted by feminists and social justice campaigners and to research on caregiving (Fine, 2007). It is important, when thinking about care poverty, to note that the political response to the isolation, poverty and social exclusion of primary caregivers draws heavily on the feminist framing of care as a matter for civic justice.

Set against the view of care as site of social justice are the voices of disability rights authors such as Morris (2001; 2004) and Brisenden (1989). Their concern with the view of care as social justice is that this framing relies on the empirical and theoretical perspectives of those who *provide* care, excluding those who *receive* care. To illustrate this, Waerness asserted that 'the receiver of care is subordinate in relation to the caregiver' (Waerness, 1984: 189), and Ungerson (1990) and Daly (2002) assert that care receivers are 'dependent' upon caregivers due to incapacity and inability to care for themselves. Brisenden (1989: 10) has argued that relying for support on unpaid carers is exploitative to both care giver and receiver. Morris (1997) argued that care itself is a form of oppression against disabled people – because care involves removing choice and control from disabled people (who are assumed to be unable to exercise it), it cannot be empowering.

Kröger (2009: 406) asserts that the disability rights and feminist perspectives are portrayed as being 'poles apart and fully incompatible with each other'. Reciprocity appears to be the key to unlock this stalemate: reconciliation of these conflicting positions has been achieved by some authors by arguing that the marketisation and personalisation of care services is a way of achieving social justice in care for both givers and receivers (Watson et al, 2004).

Theoretically, opening up choice to both givers and receivers of care recognises its reciprocal nature and empirically can be supported in the case of informal care, and where those with care needs are also giving care (for example, as parents, spouses and carers) (Williams, 2001). However, in cases of vulnerability of care recipients, the role of ethical care arguably becomes even more important – for example, near the end of life, with dementia or profound impairments that make the exercise of choice difficult (Brannelly, 2011; Rogers, 2016). This means that practically, and therefore also theoretically, relying on choice does not work to achieve social justice for all those who give and receive care.

One argument, particularly supported by Nordic feminists, is that the state should provide care (Parker, 1992). This would free carers from having to provide unpaid care if they do not want to, and reduce the risk of abuse and disempowerment on care receivers. However, disability rights campaigners have fought long and hard to free themselves from the oppression, paternalism and segregation associated with state care (Kröger, 2009). We could look to the market rather than the state (Beckett, 2007) but belief in markets as a way of achieving social justice is not shared by feminist writers. They point out that undervaluing of care work is due to its feminisation, which itself drives down wages. Marketising care also places formal carers at the risk of exploitation and abuse, and it can place additional burdens on informal carers. There is a high risk of leaving vulnerable people needing care unprotected (Pascall and Lewis, 2001).

Improved longevity and well-being, and declining availability of family support, can be seen as social policy successes, but they have led to a rising demand for long-term care and support across developed welfare states (Barber et al, 2020). The form and practice of oppression along the lines of gender, disability, class and age need to inform our understanding of the payment for and provision of care (Lewis, 2002). Most theoretical developments concerning the role these different constituent parts play in the 'welfare mix' which draw on feminist theory have focused on the gendered roles associated with *providing* care. Feminist analysis of care has given us a rich empirical and theoretical basis to draw on. However, the perspectives of those *receiving* care have, with a few notable exceptions (Kröger, 2009), not necessarily drawn on this heritage. In this chapter theoretical frameworks are drawn on and developed that are concerned with both those *providing* and *receiving* care to address this gap.

Increasing demands for services coupled with the politicisation of disability rights organisations have resulted in important changes in the policy direction in the provision of care services. In particular, there has been a rejection of state-provided long-term care services as being increasingly fragmented and unresponsive, and of reliance on informal care as being disempowering and exploitative (Brisenden, 1989; Morris, 2004).

Social citizenship and the right to receive care

Citizenship can be defined as:

> [T]hat 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: 2–3)

For Marshall, 'citizenship is a status bestowed on those who are full members of a community' (Marshall, 1992 [1950]: 18). Social citizenship is affected both by giving and receiving care, partly because work is an important way in which people discharge their citizenship obligations. The valuation and form of that work (whether it is paid or unpaid, whether it is recognised and recompensed, whether it is freely offered, whether it protects from or increases the risk of poverty) directly affects whether those giving care are able to be social citizens (Marshall, 1992 [1950]; Lister, 2003). For care receivers, how care 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) has a direct effect on their social participation, which is their ability to exercise choice and self-determination over their lives, shaped by their access to resources (Sen, 1990; Townsend, 1993). Social citizenship means the ability to participate in social life, which is affected by access to resources. This works also as a way to theorise care: the *giving* of care and having *access* to care are seen as an important part of the resources which are needed for social citizenship (Knijn and Kremer, 1997; Williams, 2001).

There is an inherent tension in conceptualising care as a citizenship right. Rights are 'enforceable choices' (Turner, 1993): they are claims that can and should be enforced by the state on behalf of individual citizens. It takes resources to enforce rights: civil rights are meaningless without a police force and criminal justice system to enforce them, and political rights similarly need a democratic political and judicial system (Barbalet, 1988). Care can be conceived as a 'social right' (Marshall, 1992 [1950]), that is, a right to resources to meet needs. As with other rights, resources are needed to protect access to those rights. However, unlike civic and political rights, which can essentially be seen to have little impact in terms of costs to individuals (it costs very little to not infringe the rights of others or to vote), social rights do have a cost to individuals (Plant, 1992). The production of welfare generally involves people: practitioners in fields such as education, health, welfare, criminal justice and so on. Giving their labour is not a no-cost endeavour – although as professionals they receive remuneration, if working in the 'caring' professions they are giving emotional as well as physical and intellectual labour (Kittay, 2002).

An example of this can be seen in the 'right' to health care in developed welfare states. A citizen has the right – the enforceable choice – to access health care, but this does not translate into an enforceable choice to any particular service or treatment. Marshall (1992 [1950]) illustrated this by articulating that under the newly formed British National Health Service, every citizen had the right to be registered with a General Practitioner and to be seen by a doctor when ill. However, the treatment or service then offered is contingent on the professional judgement of the practitioner and the availability of resources (Rummery and Glendinning, 1999). If we translate that to care – particularly care provided or commissioned by the welfare state, rather than family care – someone in need of care can have an enforceable choice to accessing an assessment of needs, but not any specific service to meet those needs. The power to allocate resources to meet needs resides in the practitioner acting on behalf of the state (Ellis, 2011), which they often do by exercising discretion or acting as street-level bureaucrats (Trappenburg et al, 2020). Crucially, the person requiring care has very little say in the allocation of those resources.

There is another conceptual problem with seeing care as a social right. As was explored earlier, care is not just physical labour for the person providing it, it is also emotional labour that entails costs (Himmelweit, 1999). Moreover, if care is to be provided ethically, we cannot divorce the emotional labour: care means caring about as well as caring for (Sevenhuijsen, 2003). Care that is not provided in an ethical, emotional way will almost inevitably be disempowering, paternalistic and mechanistic for both parties. Even the physical labour of care is not one that can be easily decoupled from the material reality of bodies providing that care: it is often intimate and personal, and needs to take account of the material and emotional reality of the person receiving as well as the person providing the care (Kittay, 2011). How then can we have an enforceable right to receive care when that would involve enforcing emotional labour in a way which feminists would recognise as being difficult at best and abusive at worst?

Here there is a clear difference between care that is provided by families, and that which is provided by formal, paid carers. A care relationship between someone needing care and a practitioner providing it can be negotiated like any other employment contract. An exchange of payment for labour gives both the provider and receiver of care protection through the ability to freely choose whether to enter the contract, and the terms of that contract. There are of course limits to that choice: on the care receiver side, there may be little choice of provider who can provide care in a way that the receiver needs; on the care provider side, there may be little choice on wage negotiation or pressure to accept undesirable conditions of work. Payment also does not remove the need for emotional connection between caregiver and recipient: there needs to be trust for intimate care to take place without fear of abuse. It does, however, offer both parties the opportunity to exit the caring relationship and reduces the risk of exploitation. In this way care can be conceived of as an enforceable choice: the enforcement is through agreeing the terms of a relationship that can be altered or exited by either side if the terms are unsatisfactory, but which can reasonably be expected to be fulfilled if satisfactory. Mladenov (2016) goes so far as to argue that this intimate employer/employee relationship between the givers and receivers of care is part of the fundamental human rights needed by disabled people to achieve equality.

This is not the case if care is provided by family members. When kinship bonds are involved, personal relationships cannot realistically include a 'right', as in an enforceable choice, to receive care. The only way the choice can be enforced is through emotional and familial ties and responsibilities: by definition these are only breakable in extreme circumstances, probably involving the breakdown of the relationship itself. Feminism would point out that you cannot have a right to care any more than you can have a right to sex: both choices, to be enforced, would involve access to emotional and/or physical intimacy, and any enforcement of that intimacy would by definition be exploitation or abuse. Care relationships within families are also difficult to conceive as rights-based because of the 'burden of gratitude' (Galvin, 2004) experienced by the care recipient, which means they cannot rely on or control the care given.

However, this is not to say that paid care is unproblematic from a social rights perspective. Hughes et al point out that: 'As "master" of "his" own destiny and PA [personal assistance] at "his" command, the disabled person is able to acquire control over many of the mundane but vitally important aspects of everyday existence which, hitherto, were delivered, if at all, to a timetable that suited the "carer"' (Hughes et al, 2005: 263). Masculinist language has been deliberately used here to highlight that this is a justice model of care – responding to the 'annihilation of the autonomy of the other' (Bauman, 1993: 11) that Morris (1993) and others have criticised. However, by deliberately separating the ethical, emotional aspects of care and turning it into a simple contractual exchange, Hughes et al (2005) reveal an important theoretical and ethical issue. If the power in the caring relationship has moved from the caregiver to the care receiver, that does not, per se, address a power imbalance in the ability to enforce social rights: it simply switches roles.

It should be noted that countries that have developed personalised care have often done so as a cost containment measure, rather than embracing the ideological emancipation of those who need care. In the UK, for example, direct payments are a way of shifting the rising costs of state-provided care onto service users (Pearson, 2000). In countries such as France and the Netherlands, payments are seen as a way of supporting a mix of family and formal care, and avoiding unsustainable growth in demand for state care from an ageing population. In more familial welfare states such as Austria and Italy, care payments directly to care users are more of a way to 'formalise' family care and support migrant labourers to provide intimate personal care, reducing demand on state services and replacing familial care. The ideological basis that dictates how, and in whose interests, the policy of personalised care operates is about neoliberal individualisation of responsibility, rather than a rights-based approach to the emancipation of care users (Rummery, 2009).

Demands for the personalisation of care came, particularly in neoliberal welfare states, from strong disability/user led political organisations. Personalisation has been much slower to take shape in the Nordic/Scandinavian/universal welfare states: schemes there tend to be seen as additional to, rather than replacing, state-provided care. A strong ideological commitment to gender equality in these states recognises the problem that unpaid care in families disproportionately falls on women, and thus care services have within the context of welfare state provision been seen as universal and the responsibility of the state rather than individual families. However, that commitment does not necessarily translate into a commitment to user empowerment: the state not only decides who should receive care, but who should give care (and the nature and timing of that care). Hence it is the state, rather than individual carers, who take on the oppressive side of care – that 'annihilation of the other' that concerned Bauman (1993) and Keith (1992). Moreover, if practitioners are employed by the state to provide care, the way that care is provided is dictated by employers and professional practice: not by the care user. While there can be said to be a meaningful 'right' to access social care, it does not necessarily translate into full citizenship.

The right to give care

Social citizenship does not just involve rights to access resources. It also involves duties and obligations which accompany those rights: 'if citizenship is involved in the name of rights, the corresponding duties cannot be ignored' (Marshall, 1992 [1950]: 41). In most developed welfare states, the right to access resources to meet needs is contingent in some ways on contributing to the cost of the welfare state through work – usually either through taxation or insurance or a mixture of both. Therefore, for citizens to have a right to receive care, they must have contributed in some way to the provision of that care. Depending on the ideology and configuration of the welfare state in question, there are various ways in which that can happen. Welfare states which are based on an ideological commitment to state provision of services usually have work-based citizenship duties, as do those of a neoliberal bent. As Sainsbury (2009), Lister (2003) and others have pointed out, discharging your citizenship duties via the direct provision of care to your family has always been seen as bestowing a second-class citizenship on women, compared to those who engage in paid work. This can be seen through relatively low welfare benefits for carers, lack of paid leave or work-based support for carers, and lack of investment in support services for family carers. Nevertheless, the reliance on family carers in neoliberal welfare states is high (ILO, 2022).

Can the option to give care be seen as a social right – an enforceable choice? To some extent, in the case of family care, it can be. Many welfare regimes offer payments to family carers, either directly, or routed through care receivers. However, these payments are almost always set low (in comparison to median wages, and in some cases even in comparison to poverty-alleviation benefits), reflecting the undervaluation of care work (particularly that done by family carers). Family members choosing to provide care under these payments are 'choosing' under constrained conditions: the income they receive will almost certainly put them, and their family, at risk of material poverty. Family care does, usually, fit the ethic of care precept of having an emotional connection component – but this can be dangerous if the intimate nature of relationships is put under strain by material poverty. Nevertheless, although constrained, it is still a choice. Some families prefer the emotional connection of a family carer, others prefer trained strangers to deliver intimate personal care, and these preferences are cultural as well as political, economic and rational.

Care can be an enforceable choice where family carers and/or care recipients prefer family over paid care: apart from very rare cases where abuse, neglect or harm is evident, the state has very few options to impose state care and remove family care. However, at the time of writing it was #internationaldayofdisabilityremembrance – a Twitter-led campaign to honour those disabled and older people 'killed by filicide, or family carers'. People over 60 are routinely not included in general domestic abuse statistics, but one small-scale survey estimated that around 120,000 older people in the UK are suffering from physical, psychological, emotional or monetary abuse – 40 per cent from a spouse and 44 per cent from an adult family member such as a parent, sibling or adult child. Although the extent of the problem is unknown, it is clear that providing and receiving care within family relationships places them under strain, and the intimate private nature of these relationships means it is easy to hide abuse. The right to provide care can too easily become the right to exert power and control in a dangerous way, and the hidden nature of care can lead to abuse of carers as well.

It should not, however, be supposed that the danger of the abuse of caring relationships is confined to those in family caring relationships. Two in three care practitioners working in residential care reported that they have engaged in abusive acts towards older residents (Yon et al, 2017), with some studies estimating that rates of abuse in community-based settings rose by 84 per cent during COVID-19 (Chang and Levy, 2021). Care workers are also at risk of violence and abuse in residential and domestic care settings (Ford et al, 2022).

Care poverty and social citizenship

I have argued that the idea of 'care poverty' as articulated by Kröger et al (2019) moves away from the idea of 'vulnerability' or a 'dependency' on a particular form of support – deemed demeaning by care recipients and those arguing for a social justice model of care – towards a more politically engaged understanding of care (Rummery, 2022): 'Care poverty means a situation where, as a result of both individual and structural issues, people in need of care do not receive sufficient assistance from informal or formal sources, and thus have care needs that remain uncovered' (Kröger et al, 2019: 487). This formulation allows us to engage with the idea of care as a social right with more political and epistemological power. Poverty is a contested concept: scholars and policy makers argue over whether it should be measured in absolute or relative terms (Sen, 1983; Townsend, 1993), and whether it is a cause or consequence of oppression (George, 1988). However, there is universal agreement that poverty – whatever it is or has been caused by – is something negative that merits policy attention and political action (D'Arcy and Goulden, 2014). It leads to social exclusion (Levitas, 1996), which has significant economic and social costs for the state.

Living with 'care needs uncovered' is detrimental in terms of social exclusion and citizenship. If there are no ways to enforce the choice to access resources to meet basic needs, then citizens will be socially excluded from being 'full members of the community' (Marshall, 1992 [1950]). Not only will they have their capacities to self-actualisation limited (Sen, 1983), they will also not be able to fulfil the duties part of their membership of the community. As noted earlier, the duty to be a citizen can be discharged in various ways: through paid and care work, but also through family and community engagement, parenting, grandparenting, volunteering and other myriad ways to enhance family and community life.

In the case of older citizens whose capacity to provide service has been diminished through frailty, most have spent a lifetime working, caring and paying taxes. Disabled parents often struggle to have their parenting recognised as a citizenship contribution: it is often pathologised by a paternalistic state that cannot recognise disabled people generally as engaged citizens, let alone caregivers. Even people who are severely impaired have personal relationships which are meaningful and contribute to families and friendships (Kittay, 2011). Disability rights scholars and campaigners have asserted that every contribution to social well-being is valuable, and addressing poverty means addressing oppression, alienation and lack of connection as well as addressing material needs (Campbell and Oliver, 1996).

Changing our conception of care from one of imbalanced emotional and material relationships to a site of political and ideological struggle opens up new ways to break away from the care receiver/caregiver dichotomy. This dichotomy does not always recognise the care *given* by disabled and older people – the often reciprocal nature of the emotional aspect of caring – requiring both an ethics and justice approach to understanding care demands. Care poverty offers the opportunity to make the area of care a political one, needing scholarly theoretical and empirical attention.

Care poverty and social citizenship from a comparative perspective

How useful is a reframing of our understanding of lack of sufficient care as ‘care poverty’ in understanding and evaluating contemporary developments in long-term care provision? Most ways of approaching comparative analysis of welfare regimes (or sectors within those regimes) have depended on categorising by systems: organisations, actors, funding and governance. Although these are useful, particularly those that have paid attention to welfare outcomes in terms of gender equality (Orloff, 2009), they do not give us the full story. Kröger et al (2019) argue that the idea of unmet need relied on policy makers defining need, and scholars measuring need in terms of access to long-term care (Brimblecombe et al, 2017). Care poverty, in contrast, is ‘lack of sufficient assistance’ (Kröger et al, 2019: 487), which allows for the possibility that access to care – whether that be through families or paid carers – in itself does not necessarily provide that assistance in a way that enables ‘being a fully competent member of the community’.

Conclusion

We have seen in this chapter how the conflicts underpinning an articulation and definition of care have to a certain extent led to an ideological and policy impasse between the needs of caregivers and care receivers. It has been articulated how using concepts derived from social citizenship theory offers a way forward in articulating care as a site of rights and duties, as well as one of emotional and physical labour and connection. It has also been argued that the concept of care poverty draws on the theory of care as a site of the operation of social citizenship: a site of publicly articulated rights and duties of citizens and states. This lends the idea of care poverty an ontological power: it enables us to talk about the need for care as a social right, to reframe our thinking away from vulnerabilities and needs and towards a more emancipatory approach to care provision. It also gives care a political power: poverty is universally seen not only as a negative state of affairs, but one which needs addressing, and one which states should be addressing as part of their duties towards their citizens.

However, care poverty is relatively new, in epistemological, ontological and empirical terms. While the work of developing care poverty as a nuanced and useful way to understand care will continue, it also needs to be empirically tested. As the lack of assistance that leads to care poverty could be addressed through personal, family, marketised or state means (or any combination of these), there is important work to be done in comparative social policy to examine the ideas, institutions and actors that exacerbate and alleviate care poverty, and this work has implications for policy and practice.

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