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Carers and Empowerment in the UK: A Critical Reflection

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This article provides a critical reflection on carer empowerment in the UK, an issue which has received limited attention in policy and research. The arena is characterised by considerable conceptual confusion around key terminology, carer, care and caring, and by limited understanding of the meaning and outcomes of carer empowerment. Despite increased national acknowledgment of carers, a politically active carers' movement and a number of policies intended to enhance the recognition and rights of carers, many carers remain invisible and receive little support from services, to the detriment of their own health and well-being. Addressing these challenges, alongside developing a robust theoretical foundation for taking the 'carers' agenda' forward, is needed if carers are to move towards a more empowered status in the twenty-first century.

Key words: Family carers, care, caring, empowerment.

Introduction

Over the last thirty years, social care policies in Western Europe have been underpinned by an assumption that people with dependency needs are best cared for by their relatives in the community (Means *et al.*, 2008; Pickard, 2008). A long-term demographic shift towards an ageing population, the continuing trend away from institutional care and improvements in the lifespan of children and adults with lifelong disabilities, have resulted in a significant rise in the number of people who need support to live in the community (Hudson, 2005; HM Treasury and DfES, 2007). There has been a commensurate increase in the number of family carers. Estimates suggest 12 per cent of the UK adult population (6.4 million people) are carers, a figure that is 10 per cent higher than in 2001. It is predicted that by 2037 there will be 9 million carers in the UK (Buckner and Yeandle, 2011) and that the likely demand for care from spouses and adult children in England and Wales will more than double over the next thirty years (White, 2013).

While there has been considerable research in the UK and Europe about carers' and policy initiatives aimed at supporting them, there has been little exploration of developments in relation to carer empowerment. This article aims to stimulate debate about the concept of carer empowerment and offers a critical reflection of its meaning and future potential. It is particularly timely both in light of the aforementioned growth in demand for family care and the likely increase in care intensity linked to supporting people with long-term conditions (Milne, 2010). That carers are also the subject of current health-related policy initiatives, and the specific focus of carers' 'strategies' in the different countries within the UK is also relevant (HM Government, 1999, 2008; Welsh Government, 2000, Department of Health, Social Services and Public Safety, 2006;

Department of Health, 2010a; Scottish Government, 2010). Further, carers are situated on the cusp of a shift away from the provision of public welfare services towards family and private care alternatives for those with dependency needs (Humphries, 2011).

Caring in the UK

Evidence suggests that three in five adults in the UK will become a carer at some point in their lives and that an increasing number will experience 'more than one episode' of caring (Carers UK, 2010: 5). Caring, especially intensive caring, is frequently embedded in long-term dyadic relationships; over a quarter (26 per cent) of all carers care for a spouse or a partner, more than half (52 per cent) care for their parents or parents-in-law and 13 per cent care for a son or daughter (Niblett, 2011; Carers UK, 2012a). Whilst carers are predominately female and aged over fifty years, a quarter are aged sixty-five and over and around 2 per cent are young people (Becker and Becker, 2008). For most young carers, caring begins when they are young children and continues throughout their entire childhood.

Just under half (48 per cent) of all carers provide care for twenty or more hours per week and a fifth (21 per cent) care for more than fifty hours; 14 per cent of carers look after two people. A significant proportion (70 per cent) of the cared-for population are over sixty-five and many have an age-related physical disability or chronic health condition. About a fifth (18 per cent) have both a physical and 'mental disability'[1] and 6 per cent have a 'mental disability' only (Health and Social Care Information Centre, 2010a, b). Key tasks that carers perform include preparing meals, shopping, cleaning, doing the laundry, administering medication, personal care tasks (such as bathing and dressing), social and emotional support, keeping an eye on the person they care for, taking them out and organising professional care. Examples of long-term conditions that place particular demands on carers are dementia (including Alzheimer's disease) and diabetes (Carers UK, 2012a; Larkin, 2012a).

Over the last twenty years, the contribution of family carers has been increasingly acknowledged (Pickard, 2008; Glendinning *et al.*, 2009a; Buckner and Yeandle, 2011). In 2010, the economic value[2] of family care in the UK was estimated to be £119 billion a year, a rise of 37 per cent since 2007. That the annual cost to the National Health Service (NHS) in 2009–10 was £98.8 billion is a useful comparative figure (Anderson *et al.*, 2009; Department of Health, 2010a). The greater recognition of carers both in policy and practice is also indicative of their promotion from 'the wings of welfare' to legitimate recipients of support in their own right. A number of health and social care policies explicitly focus on carers' rights to have their needs assessed, their health and well-being protected, and for there to be access to support, training and employment, as well as for carers to 'live a life outside caring' (Lloyd, 2006; Moran *et al.*, 2012).

Despite the (relatively) high level of interest in carers and their potentially powerful position as an informal 'workforce', limited attention has been paid to the issue of 'carer empowerment' (Ray *et al.*, 2009; Ridley *et al.;* 2010; Buckner and Yeandle, 2011). This is in marked contrast to the prominence given to 'user empowerment' in policy and research, an issue which has gained considerable political and analytical momentum over the last thirty years. The benefits of this for service users include greater visibility on the policy stage, a louder voice in discourse about welfare services and an increase in legally based enforceable rights in a number of key areas, such as employment and access to services (Means *et al.*, 2008; Matka *et al.*, 2010). Before turning directly to the issue of carer empowerment, the authors contextualise it conceptually, beginning with an overview of the meaning and credibility of key terminology.

Carer, care and caring

Although the term 'carer' is now widely understood to be a family member or significant other who provides unpaid care for a relative (or friend) with dependency needs, it is a contested term (Symonds and Kelly, 1998; Chamberlayne and King, 2000). In part, this is because 'carer' is not recognised as a label by many of those who actually 'do caregiving'; indeed, as many as half of all carers do not own the term (Lloyd, 2006). Some commentators even argue that it is a bureaucratically generated notion, turning 'what is a normal human experience into an unnecessarily complex phenomenon' (Molyneaux *et al.*, 2010: 422). That carers do not belong under one definitional umbrella and are a widely diverse population also contributes to inconsistency in the term's usage and confusion about its meaning. Also carers, especially older carers, may simultaneously be service users in their own right, adding further complexity (Warren, 2007; Rapaport and Manthorpe, 2008).

Carers' experiences are shaped not only by their personal responses to caring but also by a myriad of other factors. For instance, the experience of being a carer varies according to the number of hours spent caring, length of caregiving, type of care required, relationship, nature of the cared for person's needs and access to and acceptability of formal services. Key structural dimensions, including gender, age, race and sexuality, also profoundly underscore caring experiences (Ray *et al.*, 2009; Ridley *et al.*, 2010; Larkin, 2012a). Women, for example, who are the majority of carers, report higher levels of subjective burden, feel more obliged to give up paid work to care and are more reluctant to ask for an 'assessment of need' or support from services than their male counterparts (Milne and Williams, 2003). Older spouses tend to resist the 'intrusion' of 'outsiders' (including services) because they rarely identify themselves as 'carers'; this not only positions them in an oppositional status to their wife/husband but challenges the 'care contract' that underpins long-term marriage (Milne and Hatzidimitriadou, 2003; Arksey and Glendinning, 2007; Milne *et al.*, 2012). Additionally, they may resist intervention as a form of medical surveillance which might threaten the nuanced understanding older couples tend to have of their own situation (Milne, 2010). Many black and ethnic minority carers consider care to be a 'culturally inappropriate' (Lloyd, 2006: 954) term and as antithetical to family relationships; asking for help is often viewed as stigmatising (Seabrooke and Milne, 2004; O'Connor, 2007).

As caring is integral to many relationships, the distinction between caring as a normative activity and caring as an activity beyond the normative is problematic. In part driven by a need to expose this bifurcation, caring has been the focus of a number of different conceptual analyses (Bowlby *et al.*, 2010). Work in the 1980s tended to view care as a 'homogenous activity focused around the provision of instrumental support, and understood as one person "doing care to" another' (Ray *et al.*, 2009: 116). Feminist perspectives at this time emphasised the way that care was gendered and viewed as a 'natural' female activity (Hockey and James, 2002; Barnes, 2006). This body of work distinguished between 'caring about' and 'caring for'. The former involves *feelings* of concern whilst the latter is about the *tasks* of tending which were seen as being less about affective ties and much more about unpaid labour (Ungerson, 1983; Dalley, 1996). In the 1990s, the traditional view of the carer/cared-for dichotomy was challenged and analyses extended to relational aspects of care. Caring relationships were (re)characterised by 'interdependence and reciprocity' (Walmsley, 1993: 137) and as (often) being embedded in a shared life course and history (Nolan *et al.*, 2004; Lyon, 2010). The inherent mutuality and attachment that characterises many care relationships has also been emphasised in the growing body of literature on the 'ethics of care'. Although the focus of this work is essentially on the practice of care as a moral orientation, it has played an important role in highlighting the interest that carers, and those they care for, have in their shared experiences and well-being (Tronto, 1993; Sevenhuijsen, 1998). Another strand of the care discourse emerging in the 1990s can be found in post-modernist interpretations of power. These emphasise the way that 'power in caring relationships is constantly (re)created and (re)negotiated through interaction' and is therefore 'fluid, complex, and constantly shifting' (Dominelli and Gollins, 1997: 412). Not only did this perspective challenge the notion of caregiving as fixed and unchanging but simultaneously drew attention to *both* relationality and power within caring relationships.

Caring and care also 'evolve over time' (Bowlby *et al.*, 2010: 46), changing during the course of the care 'journey' and because of wider contextual factors, including policy changes. An example is the 'shift in the locus of care' for people with long-term conditions, from care in hospitals and care homes to care in the community (McGarry, 2008: 83). This has considerably increased the demands on family carers in that they are expected to perform tasks that constitute quasi-nursing activities; they are also expected to care more intensively and for longer.

The 'personalisation agenda', with its emphasis on self-directed support as a mechanism for enabling service users to determine their own care priorities is another policy initiative that has profound implications for carers (Browning, 2007; Department of Health, 2007; Glendinning *et al.*, 2009b). There is evidence that some groups are less likely to benefit from self-directed support than others, for example older people with complex needs. Additionally, carers are spending more time on administrative responsibilities 'as opposed to "hands-on care"' (Rosenthal *et al.*, 2007). Whilst some carers experience these changes as beneficial in terms of giving them more free time and improving their relationship with the cared-for person, others, especially older carers and dementia carers, report being anxious about the planning and management of the their relative's care (Larkin and Dickinson, 2011; Moran *et al.*, 2012). Research shows that insufficient information is available about the challenges of managing direct payments (Glasby and Littlechild, 2010). It is noteworthy that these changes are being introduced at a time of public sector austerity and a shrinking population of people 'eligible' to receive support from social services, self-directed or otherwise. A related concern is that carers are increasingly expected to 'pick up the tab for care' because public services do not meet care needs. This is particularly prejudicial to those on low incomes and those who are reluctant to define themselves as a 'carer' (Milne and Hatzidimitriadou, 2003; Humphries, 2011).

Carer visibility and recognition

That carers are more visible in public and professional discourse and are identified, albeit unevenly, as a distinctive social group, is now widely acknowledged. It is also increasingly recognised that carers are often disadvantaged by caring, especially over the longer term, and cannot be assumed un-problematically to look after their own needs (Molyneaux *et al.*, 2010; Carers UK, 2012b, c). Research about family care has been growing since the 1980s and can be credited, in part, with raising the profile of carers in the public domain (Parker, 1985, 1995; Twigg *et al.*, 1990; Stalker, 2003). In addition to 'counting carers' and defining what carers do, for whom and with what consequences, carer-related research has also 'helped to ensure that caring is prioritised as a significant issue for social policy and practice' (Barnes, 2006: 1).

A second, if not more important, driver behind the prioritisation of caring in legislation and policy has been the growth of a highly organised and politically active carers' movement in the UK and throughout Europe. This has maintained a strong focus on the rights carers have to support, to receive an adequate income, to work and improve their wellbeing (Roulstone and Hudson, 2007). Moreover, it has raised awareness of carers and carers' issues via the media and political lobbying (Bytheway and Johnson, 1998; Clements, 2009). A key product of the carers' movement is the establishment of carer-led organisations: Carers UK and the Carers' Trust are high profile UK wide examples, but there are also many vibrant local organisations too. At an EU level, Eurocarers[3] represents carers' interests and aims to influence policy making both within the EU and at a national level (Yeandle and Buckner, 2007).

Amongst the most significant policies that the UK carers' movement has been instrumental in demanding and shaping are the Carers (Recognition and Services) Act (HM Government, 1995) and the cross government Carers Strategies mentioned above. While these have aspired to increase carers' rights across the board, their specific aims are to: improve carers' levels of support; help them to fulfil their educational potential and combine paid work and care; acknowledge their value and importance; ensure that they are treated with dignity and respect by health and social care professionals; improve their access to information; and provide them with opportunities to be involved in service design and delivery as well as professional training (Yeandle and Buckner, 2007; Hatton *et al.*, 2008; Matka *et al.*, 2010; Social Care Institute for Excellence, 2011, 2012; Larkin, 2012a). The 2012 Care and Support Bill (HM Government, 2012) places a new duty on local authorities to assess and meet a carer's needs if they are deemed to require support now or in the future (Department of Health, 2007; Scottish Government, 2010; Carers UK, 2012c).

'Empowerment' and carers

The demonstrable increase in carer recognition in research and public discourse raises the question as to why 'carer empowerment' has received so little attention, especially when the empowerment of users has achieved such prominence (Beresford, 2007). Consideration of the meaning of the term 'empowerment' in the context of welfare services is a useful first step.

Since the 1990s, 'empowerment' has become an increasingly visible social and political aspiration for marginalised groups of service users, such as people with learning disabilities and those with mental health problems (Means *et al.*, 2008). Although it is a widely employed term, the way it is conceptualised varies 'from individual control at one end of the spectrum to a focus on the allocation of social and economic resources at the other' (Clarke, 2001: 8). Some commentators view it as a multilevel construct comprising a number of intersecting dimensions, such as psychological empowerment and community empowerment. These have beneficial and mutually reinforcing effects on each other in relation to, for example, subjective levels of psychological empowerment and perceived control (Clarke, 2001). In contrast, other work articulates empowerment as a specific outcome, for example the change of status from 'service user' to 'consumer' (Clarke, 2005). Although 'empowerment' means 'different things to different people' (Adams, 2008: 17), there is a degree of consensus about its use in its broadest sense as the dynamic process whereby individuals and groups gain or increase choice and control over key aspects of their lives in order to maximise their quality of life (Adams, 2003, 2008; Smith, 2008; Manthorpe *et al.*, 2009). This inevitably leads to philosophical debates about the extent to which, given limited resources, structural constraints and the nature of professional power, service users *can* have control over their lives and care decisions (Clarke, 2001; Laverack, 2005; Chinn, 2011).

Political economy approaches go further in arguing that it is simply 'a rhetoric that conceals the systematic stripping of forms of power and protection developed in western capitalist states institutionalised in conceptions of welfare, the public sector and realm' (Clarke, 2005: 453). This discourse highlights one of the core questions at the heart of any analysis of *empowerment*: the definition and conceptualisation of *power* itself. Different approaches to empowerment are informed by different theories of power, including: 'functionalist, pluralist, systems analysis, corporatist, Marxist, Habermasian, and Foucauldian' (Pease, 2002: 139; Smith, 2008). Not only is it a challenge to unravel the relationship(s) between power and empowerment but the relationship between empowerment and its intended beneficiaries, such as carers, is additionally complex and often opaque.

Where carer empowerment *per se* has been explored, it has often been in the context of user empowerment and improving practice in adult social care (Clarke, 2001; Kumpers *et al.*, 2005; Barnes, 2006; Smith, 2008). For example, recently carers have been co-opted into the practice-related framework of 'co-production' (Carr, 2010). Although co-production is intended to re-sculpt the relationship between users and services and accord far greater choice and control to users, it could be criticised for failing to take account of the needs and perspectives of carers. If a carer is part of the 'production' of care for, and/or with, the service user, their exclusion from decisions about its form and content is a primary dimension of *dis*empowerment. Further, if a user is 'necessarily dependent' on a relative to care for them, the issue of empowerment is by definition a shared one (Lloyd, 2010). Similar challenges arise in relationship to self-directed care: how far carers are purchasers or providers of care is a moot, and largely unresolved, issue. It may yet prove to be a brake on government aspirations to extend direct payments to as many service users as possible (Department of Health, 2010b).

Terminological and conceptual confusion also makes the operationalisation and degree of carer empowerment challenging to capture (Clarke, 2005; Gilbert and Powell, 2010). Relevant evidence suggests that carers are routinely overlooked and feel unsupported, powerless and marginalised; increased choice and control is *not* in evidence in the daily lives of the majority of carers (Glasby *et al.*, 2010; Molyneaux *et al.*, 2010; Ridley *et al.*, 2010). Despite the introduction of a number of policy initiatives over the last decade (see above), most carers 'do not get significant help from the formal care system' (Buckner and Yeandle, 2011: 3). Official statistics indicate that a very small proportion of carers (6 per cent) received assessments of their own needs in 2009/10 and that only 66 per cent of all those assessed received a service (Department of Health, 2010a; Niblett, 2011). Assessment practice by health and social care professionals can also limit carers' engagement with empowerment. Traditional practice tends to focus on providing information. Whilst information may have some potential to empower, when offered in a context constrained by resource limitations and unconnected to wider sources of empowerment, such as enhancement of carers' rights, its capacity to do so is severely limited (Matka *et al.*, 2010; Young *et al.*, 2011).

The 'penalties of caring' (Carers UK, 2010: 5) for people who receive inadequate support, or support that is insufficiently personalised, may be considered evidence of limited, or weak, carer empowerment. High levels of physical and mental ill health, low levels of access to leisure and education, exclusion from work, and financial hardship, are all commonly reported by carers (Buckner and Yeandle, 2011). Intensive carers are particularly vulnerable (Carers UK, 2008; Milne *et al.*, 2012). With reference to exclusion from work, one in five carers has to give up paid work to provide care. The estimated loss of earnings is over £11,000 per year per carer; this amounts to an annual loss of £5.3 billion to the UK economy (King and Pickard, 2013). Not only is this inefficient from an economic perspective but it also significantly increases the risk of poverty and exclusion for carers and the people they support. Public sector cutbacks, noted above, are likely to result in additional financial hardship and even lower levels of support from services than is currently the case (Buckner and Yeandle, 2011). Third sector organisations, particularly small local ones, are especially vulnerable, and yet these are precisely the agencies that provide the majority of support to carers. The impact of this withdrawal of support is likely to have significant detrimental effects on carer health and inclusion, the wellbeing of the cared for person and NHS and long-term care budgets (Larkin *et al.*, 2012).

Achieving carer empowerment?

History suggests that the existence of a coherent and robust body of literature, a powerful political movement and the passage of legislation to grant rights combine to achieve greater levels of empowerment. This is certainly the case for disabled people in the UK. The disability movement, which started in the 1960s, was one of the primary drivers behind the subsequent major shift in hegemonic ideas about disability and disabled people. It has also acted as a key political and social catalyst to improving the status and situations of many disabled people. Significant developments include the passage of legislation, such as the Disability Discrimination Act (HM Government, 2005) and increased rights to work, an adequate income and to live independently. In terms of outcomes, many (mainly younger) disabled people experience lower levels of discrimination, increased work opportunities and greater choice and control over their lives, including the type and nature of support services (Hughes, 1998; Oliver, 2004; Larkin, 2012b).

One of the key drivers of the disability movement was, and still is, its underpinning by a strong theoretical model, namely the social model of disability. This model asserts that it is not *impairment* itself that causes disability, rather attitudinal, ideological, institutional, structural and material barriers within society (Oliver, 2004). It has not only been instrumental in helping to address some of the key limitations to opportunity and engagement experienced by many disabled people, but it has raised their public profile and provided a coherent framework upon which to base arguments for social, political and economic inclusion. There have, however, been criticisms of its primary focus on the socio-structural determinants of disability, its lack of engagement with the 'full breadth of disabilities' and, historically at least, its exclusion of older disabled people and people with dementia (Shakespeare and Watson, 2001; Twigg, 2006; Milne, 2010).

The fact that the carers' movement lacks such a sound theoretical foundation restricts not only its capacity to take forward a political agenda, but also analysis of how it could (potentially) benefit from the work of other groups who have addressed issues of empowerment with positive effect (Oliver, 1996; Barnes, 2006). Existing theoretical and conceptual models tend to operate in separate spheres, such as attachment theory in psychology (Ainsworth and Bowlby, 1991) and the notion of 'nested dependencies' in gerontology (Kittay, 1999), and do not engage with the social or political dimensions of caring (Nolan *et al.*, 2004). That the social model has considerable analytical power raises the question as to whether it could be used as a basis for taking forward theoretical developments in the carers' field. Indeed, there has been some, albeit limited, deployment of the social model in relation to carers, notably in the dementia field (Morris, 2001; Kümpers *et al.*, 2005; Robinson *et al.*, 2010). Positive outcomes, such as how reframing dementia with a focus on a social model of disability allows carers to develop more effective coping strategies, have been noted. Extending this work to reframe the social model exclusively for 'carers', separately from the cared for person, has been criticised for leading to segregation (Fine and Glendinning, 2005). Moreover, the disability movement is, or at least was in its formative stages, uncomfortable with the whole notion of a 'carer'. Many disabled people resist being conceptualised as 'dependent' on a carer and as 'needing care'; the goals of the disability movement were squarely about achieving independence and rights for the disabled person as an autonomous individual and did not include relatives (Morris, 2005). More recent attempts to (re)define care as relational and about interdependency sit more comfortably with these aims and the mutuality that defines many dyadic care relationships may represent a closer alignment with the social model's potential to empower in a way that has not been, as yet, widely considered (Priestly, 2010). It is noteworthy that within disability discourse there are calls for the social model to shift toward being a wider inclusionary model of citizenship with its emphasis on universal rights and entitlements rather than 'needs' and 'otherness' (Morris, 2005). This debate may offer additional potential to review the citizenship model's applicability to carers, although work would still need to be done on how this model could inform the nature and outcomes of carer empowerment.

Carer empowerment in the 21st century: looking forward

If carers are to move towards a more empowered status in the twenty-first century, a number of key issues need to be addressed. Defining core conceptual issues poses a primary challenge. Who is a carer, the validity of 'carer' as a concept, and what is care, remain fundamental questions underpinning carer-related discourse. Such conceptual confusion impedes the development of a consistent approach to recognising and supporting carers. It has been suggested that adoption of a more widely accepted and inclusive term to replace 'carer' could, potentially, infuse the existing, rather stale discourse, with new analytical energy (O'Connor, 2007). It may also mean that more 'carers' define themselves as 'doing care' and access support services for themselves and the person they support (George, 2001; Molyneaux *et al.*, 2010). While it is not for the authors to 'promote' a definition of carer *per se*, it is difficult to imagine how carers' issues can be articulated or supported without a shift towards definitional acknowledgement of 'carer' identity (Ray *et al.*, 2009). Certainly, specific initiatives to encourage GPs to discuss caring issues with patients who live with, or support, a disabled relative have resulted in the roles and needs of hitherto hidden carers becoming recognised (Royal College of General Practitioners, 2011). Placing workers with a distinct remit to identify and support carers in primary care is also evidenced as effective (HM Government, 2008; Department of Health, 2010a).

The reluctance of some carers to align themselves with a universal 'carers' agenda' is a related issue. The fact that carers are not a single group because of their very different needs is well-established. Whilst this is clearly also the case for disabled people, one of the strengths of the disability movement is that, historically at least, the main group driving it forward constituted a coherent entity who were making a distinctive set of demands (Oliver, 1996). Despite their heterogeneity, for most carers there is a large area of shared terrain. A platform tends to be stronger if a single voice is being heard. The greater unification of carers through creative use of carers' collective experiences could increase the carers' movement's political momentum (Carers UK, 2012c). Robust research that includes carers and evidences both the effectiveness and cost effectiveness of support to carers will also greatly assist in the on-going promotion of carers' rights (Knapp, 2012).

There may be a case for according family care the same definitional and political status as 'child care'; namely, that caring is recognised as contributing to the public good and carers are accorded rights to automatic leave and an adequate income. The provision, for example, of (relatively) affordable and regulated childcare services has improved working mothers' status and income. Although some changes have been introduced to support working carers, extension of these rights would enhance their quality of life and well-being and reduce the poverty experienced by many long-term carers (Yeandle and Buckner, 2007; Carers UK, 2010).

Articulating what carer empowerment could look like is self-evidently important. Taking younger disabled people as an example of a group that has achieved a (relatively) empowered status, dimensions of success would include: consistent prominence for caring issues on the political and policy agenda; lower levels of stigmatisation and discrimination; rights to work, education, leisure and a decent income; greater choice and control over the nature of support services they, and the cared for person, receive; greater access to services; and services run by carers for carers. Equipping carers with the power of self-determination is pivotal. Carers being able to choose to walk away from their caring role would be a primary indicator of enhanced carer empowerment. Re-sculpting power relations between carers and welfare services is another. Evidence of a shift would include displacing the deficit-based language and bio-medical lens that currently characterises encounters between health and social care professionals and carers with the more nuanced knowledge and understandings that carers have of both their own needs and the needs of the person they support. Foucault (1977) suggests that disempowerment occurs as a result of the knowledge of those subject to power being subordinated to the knowledge of those who have power. This is one of the most profound ways in which carers remain marginalised, have few choices and receive limited support from welfare agencies.

Conclusion

Although there has been a paradigm shift in relation to conceptualising care and carers and in recognising carers' roles and needs, the extent to which this has contributed to their 'empowerment' is debateable. Further, whilst the term empowerment is widely *used*, the extent to which is it *useful* to, and for, carers remains a key question. This critical review makes it clear that taking forward the goal of carer empowerment is complex and involves addressing a range of intersecting conceptual, theoretical, political, legal and practice issues. That many carers continue to be significantly disadvantaged by caregiving, and that few are offered support from services suggests that whatever form empowerment takes it must ensure that these fundamental issues are the litmus test of progress. Putting carers in the driving seat of defining empowerment and achieving outcomes, including political status, is crucial, and the potential for a credible theoretical model to underpin and drive change is also important. As public sector cuts deepen and the 'tipping point of care' becomes visible over the horizon, anticipated as being in 2018, it is timely to stimulate debate about the empowerment of carers and explore '21st century solutions to a 21st century challenge' (Carers UK, 2010: 4) both in the UK and beyond.

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Notes

1 This refers to a mental health condition or illness including dementia or a learning disability.

2 This is the cost of replacement care provided by unpaid carers based an official estimate of the actual cost per hour of providing home care to an adult.

3 http://www.eurocarers.org.

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