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**Article:**

Arksey, Hilary and Glendinning, Caroline (2007) Choice in the context of informal care-giving. *Health and Social Care in the Community*. pp. 165-175. ISSN: 1365-2524

<https://doi.org/10.1111/j.1365-2524.2006.00671.x>

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## Choice in the Context of Informal Care-Giving

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This article was published in March 2007:

Arksey, H. and Glendinning, C. (2007) Choice in the context of informal care-giving, *Health and Social Care in the Community*, 15, 2, 165-75.

This is an author produced version of the article published. This paper has been peer-reviewed but does not include the final publisher proof-corrections or journal pagination. Acknowledgement to Blackwell Publishing and the journal, *Health and Social Care in the Community* for permitting this version to be displayed.

The definitive version is available at [www.blackwell-synergy.com](http://www.blackwell-synergy.com):  
<http://www.blackwell-synergy.com/doi/abs/10.1111/j.1365-2524.2006.00671.x>

DOI: 10.1111/j.1365-2524.2006.00671.x

## **Abstract**

Extending choice and control for social care service users in England is a central feature of several policy documents published during 2005 and 2006. However, these policy proposals have comparatively little to say about choice in relation to carers of disabled or sick relatives, friends or older people. This article reviews recent research in three areas in which carers are likely to face choices, to explore the realities of choice as experienced by carers. The three areas are receiving social services support; entry to long-term care; and combining work and care. The research evidence sheds light on the factors that influence carers' choices and shows that these are circumscribed by two sets of factors. One cluster of factors relates to the nature of the care-giving relationship; the second cluster consists of wider organisational factors. A number of reasons are suggested to explain the invisibility of choice for carers in current policy proposals for increasing choice. In particular, it is suggested that different conceptual models of the relationship between carers and social care service providers shape the extent to which carers can be offered choice and control on similar terms to service users.

Understanding these models helps to explain the relative invisibility of choice and control for carers in recent policy proposals. In particular, the exercise of choice by carers is likely to be highly problematic if it involves relinquishing some unpaid care-giving activities.

## **Keywords**

Informal carer; choice; decision making; policy.

## **Acknowledgements**

We would like to thank Michael Hirst and two anonymous referees for valuable comments on earlier versions of this paper. Part of the paper draws on a literature review, which was one component of a study funded by the Department for Work and Pensions and carried out by the Social Policy Research Unit at the University of York. Other members of the study team included Peter A. Kemp, Inna Kotchetkova and Rosemary Tozer. The views expressed are those of the authors and are not necessarily shared by the Department for Work and Pensions.

## **Introduction**

This paper discusses the problematic nature of choice, and the reality of the opportunities to exercise choice on the part of people who provide support and help for disabled or sick relatives, friends or older people (hereafter referred to as 'informal carers'). The context for the paper is set by a brief outline of several important policy documents published during 2005, all of which contain proposals to increase choice and control on the part of disabled adults, older people and other users of social and health care services in England. However these proposals have comparatively little to say about choice in relation to informal carers. After briefly considering the broader policy context of service modernisation and the rationale for increasing choice and control on the part of social care service users, the article reviews empirical research about carers and choice to shed light on the complexity and reality of choice for carers. This evidence is then synthesised to gain a better understanding of the factors that influence choice for carers. Finally, possible explanations are offered to account for the relative invisibility of choice for carers in recent English policy documents.

## **Choice and public service reform**

The current emphasis on choice for service users in England is not new; indeed, this was one of the underlying aims of the community care reforms set out in the 1989 White Paper *Caring for People* (Department of Health [DH], 1989) and embedded in the 1990 National Health Service (NHS) and Community Care Act. These reforms reflected a wider critique of the post-

war welfare state as being unresponsive to the individual needs of service users (Hadley and Hatch, 1981). However, within the four countries of the UK, England is now distinct in placing a heavier weight on consumerist approaches to choice in public services. The Scottish Executive, for example, emphasises social inclusion and equality and aims to develop a fairer society in which equal opportunities are available to all (Scottish Executive, 2003). The Welsh Assembly does value choice, but within the context of partnership and citizenship (Welsh Assembly Government, 2005). This approach is also in part a reflection of the different realities between England and Wales, and the fact that there are few if any large urban conurbations where it is relatively easy to provide choice in service delivery. Similarly, reasons of scale mean that the public sector quasi-markets currently being developed in England are also unlikely to be appropriate in Northern Ireland and are therefore likely to limit what can be realistically offered by way of consumer choice (Appleby, 2005).

The current Labour government's choice agenda for social care in England features prominently in a series of policy documents published in 2005. First, the Prime Minister's Strategy Unit published proposals for *Improving the Life Chances of Disabled People* (Cabinet Office, 2005). Subsequently, *Opportunity Age: Meeting the Challenges of Ageing in the 21<sup>st</sup> Century* set out a cross-government strategy for an ageing population (Department for Work and Pensions [DWP], 2005). Finally the Green Paper *Independence, Well-being and Choice: Our Vision for the Future of*

*Social Care for Adults in England* was published by the Department of Health (2005).

The government's strategy for improving the life chances of disabled people (Cabinet Office, 2005) is written from a social model of disability perspective, whereby social barriers and the environment are seen as disabling rather than individual medical conditions or impairments. The document proposes that disabled people should be supported to realise their full potential through practical measures in four areas: increased ability to live independently; family-focused support, childcare and early education to help families with young disabled children; effective planning and support for disabled young people during the transition from childhood to adulthood; and employment. To that end, disabled people should be supported to improve their employability and work skills; case managers should be available to help them find, and sustain, work.

*Opportunity Age* reviews progress on tackling the demographic challenges of an ageing society, and sets out proposals for future actions (DWP, 2005). The strategy aims to: enhance the employability of people aged 50 and over to help achieve higher employment rates; enable older people to play a full and active role in society; and develop public services for older people that promote well-being and independence. The proposals recognise the need to challenge cultural stereotypes about ageing, hence the emphasis on measures to combat age discrimination.

The Green Paper contains the government's vision for social care for adults in England for the next 10 to 15 years within the context of the challenges of an ageing population (DH, 2005). Specific proposals include providing better information about support, help and equipment; improved assessment practice; the expansion of a wider range of services, including more domiciliary care; better use of universal services (education, health, libraries, leisure facilities and transport); and a greater focus on preventative services.

These three documents share a common central objective; to transform future service provision by extending choice and control. Individuals are conceptualised as active consumers of public services, able to exercise enhanced choice over how their needs should be met and thus experience greater control over their own lives. An important mechanism for achieving increased choice emphasised in all three publications is the continued expansion of direct payments, in which individuals receive a cash payment to manage and to organise their own care arrangements in lieu of services. To address the obstacles that some people experience when using direct payments, the alternative of 'individual budgets' is proposed (Hasler, 2003; CSCI, 2004). Individual budgets draw together and make transparent the resources, from a number of different funding streams, to which an individual is entitled. The budget may be held by the local authority on behalf of the service user; transferred to a third party or service provider organisation as an individual account; or paid as cash in the form of a direct payment. This transparency and flexibility may give

individuals greater control over the resources available to them, and thus over the range and mix of services that best meet their needs and preferences.

### *Choice for whom*

Whilst the current policy proposals emphasise choice for users of welfare services, they have far less to say about choice in relation to informal carers. Indeed, informal carers - who provide by far the greatest volume of social care and support - are relatively invisible in comparison to disabled, ill or elderly people. This might be expected in the case of the Strategy Unit's report on improving the life chances of disabled people, as it adopts the social model of disability (Cabinet Office, 2005).

However, the other two documents also make little mention of carers; where they do, this tends to be from a purely instrumental perspective. For example, the adult social care Green Paper identifies scope for drawing on the resources of the wider community in extending the range of available support; an important element of those wider resources is the contribution of carers (DH, 2005). Passing reference is made to providing the 'right levels of support' (DH, 2005, para 5.2) for carers through the assessment process, including opportunities to access training and support in the caring role to help improve the quality of care provided. The document simultaneously promotes this sort of training as a potential route into paid employment once caring ceases, and it is suggested that

informal carers should be incorporated into local health and social care workforce development strategies (DH, 2005, para 5.3).

Given the prevalence of informal care-giving amongst older working age adults (the 2001 Census showed that 45 per cent of carers in the UK were aged between 45 and 64 [National Statistics Online, 2006]), *Opportunity Age* advocates improving support for informal carers in paid work. The importance of flexible employment practices to enable people to combine caring responsibilities with work is emphasised (DWP, 2005). So far as the new policy initiative of individual budgets is concerned, it is not clear from any of the policy documents whether they will be available to carers in their own right, nor how the choices of carers and older or disabled people will be negotiated and balanced.

The limited amount of attention that carers have received in recent policy initiatives raises a number of problematic questions: what choices do carers have; how do carers make choices and what factors are important to them; are carers' choices restricted; how are choices negotiated and agreed between carers and those they support? This paper attempts to address some of these issues by focusing on the realities of choice for carers. Although it is important, the nature and extent of the choices carers (and older and disabled people) make about taking on a caring role in the first place is not a present concern. Caring takes place in the context of an on-going relationship and earlier literature suggests there are strong notions of duty, obligation and expectations in taking on a caring

role (Qureshi and Walker, 1989; Parker, 1993; Twigg and Atkin, 1994). This is an area where new research is urgently needed, in the context of shifting relationships and responsibilities between families and the state.

The next section looks at some of the main issues in the current debate about extending choice, to set the context for empirical evidence about carers and choice.

### **What choice means and involves**

It is beyond the scope of the paper to give a detailed discussion of the literature on choice; what follows is therefore limited to a broad brush picture of some of the main issues.

#### *Potential advantages and disadvantages of choice*

There are strong arguments for paying close attention to choice and its role in sustaining independence and quality of life among users of social care. The capacity to exercise choice and control over daily life is an outcome of social care services that is commonly desired by service users (Vernon and Qureshi, 2000; Morris, 2006); is central to concepts of independence (e.g. Parry *et al.*, 2004); and is arguably important for mental well-being (Boyle, 2005). The ability to exercise choice and control over daily activities – and, therefore over the type, timing and volume of help required to perform those activities – is therefore a ‘good-in-itself’ (Giddens, 2003, cited in Lent and Arend, 2004), because the freedom offered by greater choice has the potential to result in increased

satisfaction both personally and with service provision. Whether this is borne out in reality, however, is contested. Schwarz (2004) argues that whilst excessive choice can lead to decisions that produce better outcomes, at the same time exercising choice can cause anxiety, stress and regret. From this point of view, choice is not good for psychological and emotional well-being and can indeed be problematic rather than beneficial.

Within a paradigm of quasi-markets, choice may be an effective mechanism for improving service standards and prompting the introduction of new services that better meet users' needs (Lent and Arend, 2004; Mayo, 2005). However, because the exercise of choice is commonly associated with market-type mechanisms, the opportunities to exercise choice may be inequitably distributed and the outcomes of those choices may lead to even greater inequalities (Lent and Arend, 2004; Fotaki *et al.*, 2005). Thus, people who have or can access resources such as wealth, knowledge and information, personal skills in dealing with professionals, or personal familiarity with decision making professionals are likely to be advantaged when making choices and so secure better outcomes than those who are 'resource poor'. Commentators (for example Needham, 2003; Schwarz, 2004; Clarke *et al.*, 2005) have criticised the consumerist approach to welfare services, pointing out that theories and practices that have developed in the context of the private consumption of goods and services are not necessarily applicable either to the collectively-funded public sector, or to welfare goods and services.

### *Preconditions of choice*

The exercise of choice depends on some important preconditions. One such precondition is accessible information about available service options. Without up-to-date, accurate information, individuals are unable to make well-informed decisions in favour of one alternative rather than another (Lent and Arend, 2004; Fotaki *et al*, 2005).

Secondly, Dowding (1992) points out that for choice to be meaningful, at least two positive alternatives are required. This means being able to choose between *a* and *b* (for example between day care or a sitting service), rather than a negative choice which would involve choosing between alternatives *a* or not-*a* (i.e. day care or not-day care). Choices can be increased by adding more alternatives to the 'choice set' or menu of services available – options *a*, *b*, *c*, *d* and so on. However, adding alternatives brings benefits only if they comprise options that people value and would choose.

Diversity of service provision is necessary to accommodate people with different requirements, needs and aspirations, but a menu of welfare services is not sufficient in itself unless those services also have the ability and the spare capacity to respond to users' choices. This can be a problem with a publicly-funded or provided choice set. The 1990 NHS and Community Care Act made consultation with service users a legislative duty for local authorities. Since then a number of important initiatives have been introduced specifically designed to ensure that people who use

services and their carers participate in service development. For example, the National Strategy for Carers proposed that policy makers involved in service planning should work in active partnership with carers and their organisations to help ensure that services are responsive to the needs of carers, and those they support (DH, 1999).

In practice, however, there are constraints on meaningful public involvement in service provision. One restriction is that social services departments work within a context of limited financial and other resources (Waterson, 1999; Lewis, 2001). Because social care is subject to tight budgetary controls, supply and demand may have to be rationed. Rationing strategies to limit supply, and by extension choice, include denial through excluding particular forms of help from the menu of available services, restricted access and eligibility rules; delay through waiting lists; and dilution by giving people less than they may want (Klein *et al.*, 1996; Hardy *et al.*, 1999; Arksey, 2002).

A second reason for limitations on choice relates to the behaviours of social services departments in purchasing services on behalf of their users. Thus choice may be restricted to the limited range of providers or types of services that the local authority purchases from providers. Moreover, in such situations, choice is only possible if it is offered by care managers or others mediating between individual users and potential providers; but a recent Audit Commission (2006) study found that less

than 20 per cent of a sample of councils routinely offered service users a choice of domiciliary care service providers.

What types of choices are available to users of social care and other support services? Myers and MacDonald (1996: 106-7) draw on empirical data to suggest that at the point of service delivery, three different levels of choice may be available:

- No opportunity to choose: users and carers are advised what services they can have, with only the negative power of refusal (if deemed able to give informed consent).
- Opportunity to choose from a limited range of available or pre-determined options.
- Opportunity to develop their own package, with the worker acting as broker, or user and carer having delegated authority to make decisions and access to resources.

There are parallels with Dowding's (1992) analysis. Level one reflects his example of choice between alternatives *a* and not-*a*, and level two reflects a *choice set* comprising at least two positive options. Level three reflects the levels of user control characteristic of direct payments or the new individual budgets scheme.

These theoretical approaches to choice have implicitly been developed around the situations of service users themselves (older or disabled people) and their dealings with publicly funded, formally organised welfare

services. However, as noted above, family and friends currently supply a much greater volume of support than do formal services. Yet the extent to which these debates about choice and social care reflect the situation and experiences of informal carers is far from clear. This question was examined by appraising empirical research.

### **Research evidence about choice for carers**

We sought evidence through a scoping review of primary research about choice and carers. As noted earlier, the focus of the review was on choice **within** the care-giving role rather than about taking on a care-giving role. The search strategy for the review combined three different sets of terms. One set involved words intended to identify people with caring-giving responsibilities (e.g. carer, care-giver, relative); the second comprised terms representing people receiving help and support (e.g. care recipient, disabled person, older person, service user); and the third set of terms described the process or outcomes of interest (e.g. choice, decision-making, self-determination).

Thirteen electronic databases were searched, chosen to include literature from the fields of both social and health care. Databases included: ASSIA; IBSS; Social Care Online; ISI Web of Knowledge; Medline; HMIC; Sociological Abstracts; INGENTA; ZETOC; and the National Research Register. Geographical coverage was not restricted, and articles published in English since 1985 were included. Scrutinising the literature on informal care published in the last 20 years aimed to focus on the

contemporary social and policy contexts of choice and care-giving and, in particular, covered the period since 1993 when major changes to the funding, organisation and allocation of community care services came into effect.

This process identified over 150 abstracts, all of which were considered. Potentially relevant references reporting empirical studies were then obtained. The references of all the retrieved studies were checked for citations that had not appeared in the initial reference set. Most of the retrieved research reports focused on choice and decision-making in relation to social care services in general; use of respite care; and entry to long-term residential or nursing home care. In many cases, the main focus of attention was the person receiving support; very few empirical studies specifically examined choice for carers. In order to extend the scope of the paper, it was therefore decided to draw on another recently completed literature review that focussed on empirical research on carers' choices about combining work and care (full details of the methods of this latter review can be found in Arksey *et al.* 2005).

### *Social services support*

As noted earlier, current policies state a commitment to supporting carers in their care-giving role (DH, 1999). Thus carers may be helped by services aimed specifically at them (for instance, short breaks or carer support groups); or by services aimed primarily at the person needing support (such as home help or day care) but from which carers also

benefit (Twigg, 1992; Pickard, 2004a, b). However, the literature indicates that carers' opportunities to exercise choice over services appear to be closely circumscribed by factors outside their control. These factors include the limited budgets of statutory services; tight eligibility criteria; a restricted range of service options; and the limited availability of agencies and paid care staff to provide the care required (Parker, 1993; Twigg and Atkin, 1994; Hardy *et al.*, 1999; Wenger *et al.*, 2002; Ware *et al.*, 2003).

Social services practitioners' approaches to carers can also constrain their choices. While carrying out assessments of carers' needs, social services staff may establish what carers are willing to provide before explaining what help is available; alternatively, they might simply tell them what service(s) they can have (Ellis, 1993). Social workers may restrict carers' choices to a limited range of services, and/or operate unofficial rationing procedures (Twigg and Atkin, 1994; Arksey, 2002). Carers may also restrict their choices because of a perception that statutory agencies have limited resources available for community care services (Hardy *et al.*, 1999; Arksey, 2002).

It is well known that the financial costs of caring can be considerable and that carers tend to have low incomes (Glendinning, 1992; Carers National Association, 2000; Howard, 2001). Means-tested charges for social services therefore also influence carers' decisions about accepting formal help. Studies show that carers refuse or stop services because they (or

the person they are supporting) cannot afford them (Macgregor and Hill, 2003; Arksey *et al.*, 2005).

More subjective factors can also influence carers' decisions about using services. For instance, individual carers have their own understandings of the activities they think it legitimate to accept help with; of the types of help they think are useful; and of the acceptability, value and benefit of a particular service for the person they are supporting. Some carers may choose to undertake personal care tasks (such as bathing or hair washing) themselves, even if this puts additional pressure on them, rather than accept help from formal services (Twigg and Atkin, 1994; Arksey *et al.*, 2005). Such choices reflect the private nature of these tasks and carers' perceptions of the unacceptability to the person being supported of this sort of intimate care from an 'outsider'. On the other hand, some carers who are supporting a very close relative prefer personal care to be provided by professionals, leaving them free to provide moral and emotional support (Ellis, 1993).

Gender can also affect choices over the provision of personal care. Male carers tend to find cross-gender caring which is intimate in nature more problematic than women; consequently, men are more likely to draw boundaries around what they will or will not do for fear of feeling awkward and embarrassed (Twigg and Atkin, 1994). Gender differences also apply to choices about the use of domiciliary services. Female spouse carers may choose to reject services such as meals on wheels or home help,

viewing them as an implicit criticism of their competence to run a home (Parker, 1993). In contrast, male spouse carers are more likely to accept help with household chores, possibly because it substitutes for domestic labour previously provided by their wives.

Carers' opportunities to exercise choice over formal services can also be restricted because of the explicit objections of the care recipient. Older people are reported to be particularly likely to want only a close relative to look after them; refusing services can also reflect the care recipient's insistence on maintaining 'normality', denying that anything is wrong or that external help is necessary (Twigg, 1998; Mooney *et al.*, 2002; Wenger *et al.*, 2002; Arksey *et al.*, 2005).

'Respite' care is regarded as central to policies to support carers (DH, 1999; Royal Commission on Long-Term Care, 1999). However, it can also generate serious conflicts of interest between carers and care recipients who in many cases dislike the notion of respite. Older people fear that respite may be a precursor to permanent residential care (Allen *et al.*, 1992). Younger disabled people and people with mental health problems complain that respite facilities are not age-appropriate; are inflexible and of poor quality; and do not offer interesting or stimulating activities (Parker, 1993; Twigg and Atkin, 1994; Arksey *et al.*, 2005). Consequently, they may refuse a place at day care, for example, and effectively embargo this potential source of help to their carer, irrespective of benefits to the latter. Similarly carers of older people may actively

choose not to use overnight respite services away from home because of concerns that the care recipient may become distressed or be adversely affected by the stay (Levin *et al.*, 1989; Hirsch *et al.*, 1993; Larkin and Hopcroft, 1993).

Spouse carers can face particular dilemmas. Even though they might need a break from care-giving responsibilities, normative assumptions by social workers about intruding into spouse relations may lead them not to offer carers respite breaks (Twiggs and Atkin, 1994). Even if they do, carers might well refuse. Carers' own self-imposed or internalised constraints arising from the feelings of obligation and duty associated with a close relationship; apparent disloyalty; and guilt at 'sending their partner away' can make it difficult for spouse carers to accept respite care.

Partner carers often want to be with the person they look after rather than separated from them. This is understandable: being apart and building up a separate life can threaten close relationships. Parker (1993), in a study of spouse carers, suggests that the dynamics around respite care and short term breaks may be gendered, with women less likely than men to put their own interests or needs before those of their spouses.

Information is pivotal to exercising choice (see above). However, a finding repeatedly emphasised in the research literature is that carers are ill-informed about services, individual providers and what they can offer (Twiggs and Atkin, 1994; Ware *et al.*, 2003). Instead, carers often rely on

family and friends for information about what services are available, which can further undermine their capacity to make choices.

### *Entry to long-term care*

The majority of carers want the person they are looking after to remain at home for as long as possible (Nolan *et al.*, 1996a). However, if carers feel they are no longer able to cope, and if (increased) community care is either unavailable or unacceptable, then residential or nursing home care may be the only alternative (Minichiello, 1987; Penrod and Dellasega, 1998; Davies and Nolan, 2003). In such circumstances, carers rarely experience a move to long-term care as desirable or a positive choice (Minichiello, 1987; Nolan *et al.*, 1996a; Penrod and Dellasega, 2000).

Identifying who makes the decision about entry to residential care is not straightforward (Williams, 2005). However, the literature about moving to a care home indicates that carers play a key role in both the initial decision to seek long-term care, and in selecting a home (Allen *et al.*, 1992; Penrod and Dellasega, 1998). However, such choices do not have the positive, empowering implications or connotations suggested by current policies. On the contrary, when making decisions about the need for long-term care, carers are reported to feel guilt, sadness, failure and - for spouse carers - a betrayal of marital vows (Dellasega and Nolan, 1997; Tilse, 2000). It is within this emotionally-charged context that carers make choices - choices that moreover are shaped by other people's opinions (Davies and Nolan, 2003). People needing support exert some influence,

although this is often limited because of cognitive frailty (Minichiello, 1987; Tilse, 2000; Davies and Nolan, 2003; Allen *et al.*, 1992). If they resist placement, carers can experience increased guilt feelings, especially if they feel a strong obligation to honour their relative's preferences (Bell, 1996; Nakashima *et al.*, 2004). Likewise, other family members may be reluctant to see their relative placed in long term care and may also respond negatively (Penrod and Dellasega, 1998). However, this is not always the case and there is also contrasting evidence of strong family support for carers' placement decisions (Bell, 1996).

The opinions of health and social care professionals also impact on carers' placement choices. The initial decision about care-home entry is often made at a time of crisis such as during a period of hospitalisation. Medical practitioners and social workers can be particularly persuasive, expressing the view that admission to a care home is the only realistic solution (Naleppa, 1996; Penrod and Dellasega, 1998; Davies and Nolan, 2003). This can make the process more palatable for carers, as it helps legitimate the decision they have to make.

Implementing the placement decision is frequently the responsibility of a main carer (Bell, 1996; Nolan *et al.*, 1996b). This involves looking at homes, completing paper work and arranging finances to cover the cost of care. The notion of choice suggests that ideally a long term care facility is selected from a range of options that are matched against a list of preferred criteria (Nolan *et al.*, 1996b). In reality, choice can be restricted

by the facilities available, especially in rural areas where there may be few homes within a reasonable travelling distance of the family (Bell, 1996; Penrod and Dellasega, 1998). Furthermore, decisions about admission to care may be urgent because of pressure to vacate a hospital bed. In these circumstances, carers are likely to take the first available placement and aim to transfer their relative to a more desirable location later (Penrod and Dellasega, 1998). Cost and financial barriers (i.e. shortfalls between the public funding available and the actual fees) can also prevent the selection of what might appear to be the most appropriate home (Davies and Nolan, 2003).

Choice about admission to long-term care also depends on timely, useful, reliable and appropriate information about care homes. However, the evidence suggests that carers have very limited information about the type of homes available, relevant quality indicators, guidance on how to compare homes and financial responsibilities (Allen *et al.*, 1992; Dellasega and Nolan, 1997; Davies and Nolan, 2003). Instead, they may be given little more than a list of homes. Carers' choices are further limited because they have few criteria upon which to make an informed decision about which particular home to select.

### *Combining work and care*

Paid employment is important to carers for a number of reasons: financial independence; helping to meet the direct financial costs of caring; offering an identity outside the carer role; maintaining social networks and

friendships; and a source of satisfaction and self-esteem (DH, 1999). The research literature indicates that many carers want to both work and care. Even though it can be difficult, the majority of carers do manage to combine the two activities (Parker, 1990; Glendinning, 1992; Joshi, 1995).

Carers' choices about work and care tend to become narrower as care-giving responsibilities intensify. Once carers are providing more than 20 hours of help each week, it becomes increasingly difficult for them to remain in paid work (McLaughlin, 1991; PRTC, 1995; Joshi, 1995; Arksey *et al.*, 2005). However, feelings of obligation and duty prompt many carers to continue their caring responsibilities (Arksey *et al.*, 2005), and alter their working patterns to make the two activities more compatible. Adjustments might include changing to less a demanding job, moving from full-time to part-time work, making use of flexible starting and finishing times, working from home or job sharing (Caring Costs Alliance, 1996; Kagan *et al.*, 1998; Arksey, 2002; Spiess and Schneider, 2003). Again, the nature of such decisions appears at odds with the positive alternatives that Dowding (1992) identified as necessary for meaningful choice.

Furthermore, carers' choices are likely to be limited by available formal services such as day care or respite care. The timing and reliability of statutory services is often experienced as problematic; inflexible services with rigid starting and finishing times do not accommodate paid work arrangements (Seddon *et al.*, 2004; Arksey *et al.*, 2005). Unreliable and/or expensive transport arrangements, inadequate levels of day care,

or the lack of affordable and suitable after-school and holiday care for disabled children can mean that carers are forced to transfer to part-time hours or not work at all (Lewis *et al.*, 1999; Seddon, 1999; Arksey *et al.*, 2005).

As noted above, many people with additional support needs are reluctant to accept formal services. Their resistance to alternative arrangements that substitute for the carer's presence can be a strong influence on carers' decisions to work part-time or not to work at all (Arksey *et al.*, 2005). Negative attitudes may be heightened amongst older people, who may not approve of women working. For example, Mooney *et al.* (2002) found that traditional beliefs that women should occupy caring roles in the family rather than take part in the labour market were prevalent amongst older people who received care from their daughters(-in-law). Disapproval of carers' paid work has the potential to make carers' lives yet more stressful and may contribute to an eventual enforced choice of not working.

### **Discussion: What does choice mean in the context of informal care-giving?**

The literature reviewed above highlights the problematic nature of choice for informal carers. The evidence shows that choice is not an individualised activity, but instead one that takes place in a wider social arena. Two sets of factors are influential, both of which act to circumscribe carers' opportunities to exercise choice. One is the nature of

the relationship within which care is given and received, which is often based on kinship ties and characterised by a history of reciprocity, closeness, obligation and respect for the other person's preferences. The second set comprises wider organisational factors, in particular eligibility criteria, the limited availability of services, the lack of information, financial charges and the approach taken by professionals. The evidence also reveals that some of the key choices that carers make, for example in relation to utilising respite care or entry to long-term care, are negative rather than positive; thus, it is unlikely that carers will perceive them as meaningful or empowering.

Dowding's (1992) model of extending choice through increasing the number of alternatives in a choice set has the potential to address the heterogeneity of carers, and the interdependence and potential for conflict that is inherent in the carer-care recipient dyad. In principle, the greater the diversity of provision, the greater the chances of carers and people receiving care to obtain help tailored to both their individual and joint priorities and preferences.

However, exercising choice depends on the availability of good quality information and sufficient time to make complex decisions. Moreover, some people may be better placed than others to access information, negotiate appropriate timescales and thus take advantage of opportunities for choice. Moreover, choice also risks leading to increased inequalities, especially for groups that are already disadvantaged, for example in terms

of ethnicity, social class or gender (Lend and Arend, 2004; Fotaki *et al.*, 2005).

The evidence from our review suggests that both the concept and practice of choice is highly problematic for informal carers. Does this help understanding of the relative invisibility of carers in both the discourse and the specific proposals contained in the three policy documents discussed at the start of this paper? Arguably, a number of factors contribute to the explanation. First, there is a widespread tendency in both policy and practice to overlook the complex dynamics of care-giving relationships and conflate the needs and opinions of carers and the people they support into a single (implicitly harmonious) unit; or alternatively to fudge the issue of whose needs should be addressed (Myers and Macdonald, 1996; Scourfield, 2005). A second reason is the unresolved tensions between the disability and carers' movements and their respective influences over discourse, policy and practice (Parker and Clarke, 2002). Thus, disability rights activists argue that policies focused on supporting carers perpetuate the dependency of disabled people, older people and users of mental health services (Morris, 1993; Shakespeare, 2000).

How these tensions are reflected in policy and practice is illuminated by Twigg and Atkin's (1994) typology of four different models of carer-service provider relationships. Whilst the models were derived from, and applied to, research on front-line health and social care practitioners, they are equally applicable to policy (Pickard, 2001). Twigg and Atkin (1994) argue

that practitioners respond to carers in one of four ways. According to Twigg and Atkin, the dominant model is that of carer as a *resource*, taken for granted and perceived purely in terms of their ability to provide support for a disabled or older person. In the carer as a *co-worker* model, the person receiving support remains the main focus of attention, but there is some instrumental recognition of the carer as a partner working alongside formal carers. The well-being of the carer is of concern, but only to ensure the continuation of caring. The third model regards carers as *co-clients*, entitled to support in their own right; here, the carer's interests and well-being are valued outcomes in themselves. Finally, in the *superseded carer* model, the informal care-giving relationship is transcended by measures that maximise the disabled or older person's (and the carer's) independence and potentially dispenses with the need for informal care. According to Twigg and Atkin (1994), these models help to explain variations in practice by shedding light on the different degrees to which carers are seen as a 'free' resource or a central focus of social care investment, services and practice. UK government policy, as reflected in the 2005 proposals, appears to continue to regard carers instrumentally, as resources or co-workers, but with some concern for carers' well-being in order to sustain their care-giving capacity (Pickard, 2001).

Twigg and Atkin's models can be seen as a hierarchy in which different levels of choice are available to informal carers. At the lowest level, carers who are regarded as free resources have few opportunities. As they move up the different levels to co-worker, co-client and finally to the superseded

carer pinnacle, carers' opportunities for choice increase accordingly. So, too, do the prospects for choice on the part of people with additional support needs, who may no longer have to depend on the unpaid labour of close relatives in order to remain living in their own homes (Parker and Clarke, 2002).

This is not to deny the desires of many partners, parents and children to give support to, and receive it from, their closest and most cherished relatives and friends. However, as long as the government continues to view carers as a free resource, the reality of the choice agenda for carers is highly problematic - especially in relation to choices that are likely to impact on their unpaid care-giving roles.

Pickard (2001) makes the case for a more comprehensive approach to policy for carers, whereby the interests of both carers and those receiving care are considered together. This would mean that the common and separate choices and interests of both carers and the people cared for are not neglected. This is reflected in the approach of the Scottish Executive, whose support for carers is underpinned by a wider commitment to social inclusion and equity (Scottish Executive, 2003). The Executive's policy encompasses the principle that carers should be recognised and treated as key partners in providing care, reflecting their knowledge and expertise about the person they care for. Our paper endorses these approaches. By incorporating support for both carers and care recipients, policy measures have the potential to facilitate increased choice for both groups.

This approach might have the additional advantage of encouraging stronger relationships between the carers' movement and the disabled people's movement.

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