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Dimensions of Choice:
A narrative review of cash-for-care schemes

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Abstract

This working paper presents the results of a narrative review of the international literature on ‘cash-for-care’ schemes whereby users purchase care rather than receive in-kind services. The paper looks at the primary research evidence in order to examine four questions that are of central importance to social care policy: what can be chosen, what are the barriers and what are the facilitators to exercising choice, and what are the outcomes of choice? Based on the findings of the review, we present some ‘preconditions for choice’, that is, arrangements and facilities that need to be in place in order for cash-for-care users to be able to exercise effective choice over their care package. Finally, we identify some important methodological weaknesses in the evidence base on the outcomes of cash-for-care payments.

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Introduction

Welfare state provision of social care for older and disabled people, where it has existed at all, has traditionally involved the provision of services in kind, often delivered by public or non-profit agencies. Since the 1990s, however, there has been increasing interest in many advanced welfare states in the use of 'cash-for-care' schemes as an alternative to the delivery of home care services. Such schemes take a variety of forms (Ungerson, 1997, 2003; Benjamin, 2001) but typically involve the provision of cash payments, or near cash payments such as vouchers or personal budgets, to enable recipients to purchase their own care instead of receiving in-kind help in their homes (Timonen *et al*., 2006).

Interestingly, experimentation with cash-for-care schemes is not confined to liberal welfare regimes (such as Canada and the USA) that have traditionally been more market-oriented in their approach to benefits and services. They have also been introduced in conservative welfare states (e.g. such as Austria and Germany), social democratic nations (e.g. Finland), and in southern European countries (such as Italy). While some of the countries that have introduced such schemes have little public provision of home care services (e.g. Italy and Ireland), others have extensive provision of in-kind services for older and disabled people (e.g. Sweden). As Keigher (1999) points out, cash-for-care schemes are an idea whose time appears to have come.

The forces that lie behind the introduction of cash-for-care payments are diverse and to some extent vary from one country to another (Timonen *et al*., 2006). Perhaps the most important driver has been a desire to provide increased choice for social care users. This rationale derives from several sources. First, there has been growing demand for greater user control and empowerment from the Independent Living Movement and other groups representing disabled people and (at least in the USA) older people (Benjamin, 2001; Keigher, 1999; Morris, 2006). Traditional service delivery provides little opportunity for disabled people to take control of their lives and make decisions, even though most home care services are 'low tech, non-medical and do not require extensive training or oversight' (Kodner, 2003: 2).

Second, it is argued that the delivery of in-kind services has been producer rather than consumer-focused – paying more attention to the needs of those who provide home care than those who receive it – as well as being bureaucratic, inflexible and paternalistic. As Clarke and others have pointed out, this critique is not dissimilar to neo-liberal arguments in favour of vouchers instead of in-kind services in relation to the welfare state more generally (Clarke, 2005, 2006). Indeed, in some countries (such as Finland) cash-for-care schemes have been introduced precisely in order to stimulate private provision of care services and a home care market (Timonen *et al*., 2006).

In addition to increasing choice, cash-for-care schemes are seen as a way of containing the costs of long-term care, particularly in countries such as Italy, Ireland and the USA, where community services are relatively under-developed. Increasing female labour market participation potentially challenges the ability of society to provide non-institutional care for the growing numbers of care-dependent older people (Keefe and Fancey, 1997; Timonen *et al*., 2006; Vabo, 2006; Ungerson and Yeandle, 2007). For some policymakers, cash-for-care payments offer the prospect of enabling people to purchase the care that is necessary to enable them to remain in their home rather than have to move into more expensive, institutional care.

At the same time, cash-for-care schemes are seen as being cheaper than in-kind service delivery because they are thought to involve less bureaucracy and outsource the 'transaction costs' associated with organising care to the recipient (Doty *et al.*, 1996; Schore *et al*., 2007). Moreover, in some countries payments are below the true cost of care on the assumption that the money will be used to pay relatives below the amount that would have to be paid for personal assistants (PAs) in the care market place (Wiener, 2006).

Another rationale behind experimentation with cash-for-care payments, at least in the USA, is the belief that, in the face of a shortage of frontline care workers, they help expand the supply of workers by facilitating the employment of relatives or friends (Kodner, 2003; Schore *et al*., 2007; Ungerson and Yeandle, 2007b).

Aims

Thus cash-for-care schemes have been introduced for a variety of reasons, but a central motive has been the desire to increase choice for disabled people who need long-term care (Ungerson and Yeandle, 2007b). In fact, 'choice' is becoming an increasingly important feature of public service reform more generally (Clarke *et al*., 2006; Perri 6, 2003; Rostgaard, 2006).

This paper presents the findings of a narrative review of the literature about the nature of choice in relation to cash-for-care schemes. In undertaking this task, we focus on four topics that are of particular relevance to current policy and practice: (1) the aspects of care on which cash-for-care schemes may allow recipients to make choices; (2) the factors that restrict the exercise of choice; (3) the facilitators of choice; and (4) the outcomes of choice. After outlining our methods, we survey each of these four topics in turn. Drawing on that review, we outline a number of 'preconditions of choice' in relation to cash-for-care schemes, before presenting some more general conclusions.

Although there have been a number of review papers on cash-for-care payments (e.g. Pijl, no date; Tilly and Wiener, 2001; Ungerson, 1997), this working paper is

distinctive in several respects. First, as described below, the literature search was conducted in a systematic and transparent way. Second, the coverage is international in scope (albeit limited to the English language) and not confined to only one or to a small number of countries. Third, it brings together a diverse evidence base from a wide range of studies. Fourth, it avoids taking an 'advocacy' approach in which it is taken for granted that cash-for-care is necessarily beneficial for all users. Fifth, it addresses four important questions that are of critical importance to social care policy in this area. And, finally, it identifies some important methodological weaknesses in the literature on cash-for-care payments.

Methods

There is an extensive theoretical and policy literature on cash-for-care schemes and their relationship to different welfare state models (see for example Da Roit *et al*., 2007; Timonen, 2007). However, our aim was to identify *empirical* evidence on the experiences of, and outcomes for, people using these schemes. Specifically, we sought evidence on:

- The range of choices allowed.
- Factors restricting the exercise of choice.
- Factors facilitating choice.
- The outcomes of choice in cash-for-care schemes.

In order to examine these questions, we conducted a narrative review of empirical research published in English since 1995. A review strategy was devised to access publications to be considered for inclusion in the review. The focus of the review is on the perspective of social care *users* rather than family carers (see Arksey and Glendinning, 2007), policymakers or care workers (see Ungerson, 1997, 2004; Ungerson and Yeandle, 2007). The literature was restricted to articles documenting research undertaken in the advanced welfare states of Western and Northern Europe, Australia, New Zealand, Canada and the USA. Research that was focused only on people with mental health problems or learning difficulties (as opposed to people with complex needs including either mental health problems or learning difficulties) was excluded from the review.

The literature search strategy involved a combination of electronic database searches, website and citation searches, and contacting leading researchers in the field. The electronic databases that were searched were chosen to represent literature from a range of discipline areas and also to provide evidence from published/unpublished literature, and on-going research projects (see Box 1).

Box 1 Electronic databases searched for evidence review

- CSA Illumina (ASSIA; Social Service Abstracts; Sociological Abstracts)
- ERLWebSpirs (Social Policy and Practice; SIGLE)
- OVID Web Gateway (Health Management Information Consortium [HMIC]; International Bibliography of the Social Sciences)
- ISI Web of Knowledge (Social Science Citation Index)

Box 2 shows the three sets of search terms that were identified for the review. 'Advanced' searches were conducted, aimed at retrieving research reports that combined one term from each of the three lists. In addition, potentially relevant references were obtained from the retrieved publications and by contacting researchers in the field.

Box 2 Search terms used for the literature search

Aim for a combination of one term from each of the three bullet point lists:

- Disabled or handicapped or chronically ill or special needs or learning difficulties or older people or elderly or service user or cared-for person or care recipient or carer or care giver (*first list includes terms intended to identify or describe client group)*

AND

- Choice or preference or personalisation or direct payments or personalised budget or self-directed support or individualisation or person-centred or individualised (*second list includes terms that aim to identify or describe the process of exercising choice or the medium through which choice may be exercised*)

AND

- Social care or social services or social welfare or support services or domiciliary care or domestic services or care home or day care or welfare services or public services or residential care or home care (*third list describes settings where choice may take place*)

Truncate words as appropriate. Search on: title, abstract and key words

Together, the searches generated 780 references following the removal of duplicate records. The abstracts were all read independently by members of the research team; this triple screening was intended to ensure consistency, and avoid errors and bias, amongst the reviewers. Discrepancies were resolved through discussion. Some 148 articles were considered to be potentially relevant to the topic area. Full-text documents were obtained to confirm relevance and to evaluate the robustness of the evidence reported.

Studies were checked for relevance and quality. Quality control was undertaken using a tool developed by Croucher *et al*. (2003). This quality appraisal tool helped determine whether studies met five criteria focusing on: the clarity of the research question(s); the appropriateness of the study design the adequacy of the sampling strategy; the robustness of the data collection; and the rigour of the analysis. The screening process was undertaken using EndNote, a reference manager software program.

A database in Microsoft Access was specially developed as a management tool for the data extraction. This particular software package was chosen because it is relatively easy to manipulate, and has the facility to undertake 'search and retrieve' procedures. Data from the articles included in the final review was extracted using the following fields, where information was available: the quality appraisal criteria identified above; client group; type of payment or 'voucher'; areas where can recipients can exercise choice; barriers to exercising choice; facilitators to exercising choice; outcomes of exercising choice; additional information; reviewer's comments; associated articles.[1]

Findings

1. What can be chosen?

Social care provision, where it has existed at all, has traditionally taken the form of services delivered by public, private or voluntary organisations. In contrast, as their name suggests, cash-for-care schemes generally involve the provision of cash, or quasi-cash payments such as vouchers, that enable users to purchase their own care. Whereas social care users typically had no say over the services that were provided to them, cash-for-care payments are intended to enable the user to choose and organise their own care package (Carlson *et al*., 2007).

Austria and Italy appear to be relatively exceptional in providing cash-for-care schemes that are unregulated (Gori and Da Roit, 2007; Ungerson, 2004; Pijl, nd).

[1] Because of space constraints it is not possible to list all of the possible citations for every finding presented in this paper.

Indeed, in Italy payments are often regarded by recipients as an income supplement. In effect, these payments are simply unrestricted cash transfers paid to people who are in need of social care services. Consequently, they may not necessarily be used to pay for social care, but may be used for other purposes, such as general household expenses (Gori and Da Roit, 2007).

More usually, cash-for-care schemes place restrictions on what can be purchased by users (see Table 1). Hence in countries where such restrictions exist, cash-for-care schemes provide *tied* cash payments or vouchers. However, the extent of these restrictions varies between and (in federal nations such as the USA) within countries. Payments may be restricted to the purchase of care services or may allow users to purchase equipment and non-care services. In some schemes, care services may only be purchased from authorised agencies, some may allow users to employ their own PAs, and some allow them to pay close relatives including partners, children or parents. Thus, one important aspect of choice is what may be purchased with cash-for-care payments (Doty *et al*., 1996; Keigher, 1999; Pearson, 2000; Clark *et al*., 2004).

In the USA, use of Medicaid Personal Care Services (PCS) is restricted to personal care that has been assessed as required and is included in the user's care plan (Keigher, 1999). Likewise, in France the payment may be used to purchase only things that are included in the user's care plan. In Sweden, the money may only be used to buy personal assistance, while in Flanders it may not be used to pay for medical expenses or education and employment services. In the Netherlands, cash-for-care payments are very largely restricted to the purchase of care, but there is a small amount of discretion to spend the money on other things. In England, the money can be used for employing PAs or home carers, buying services from a home care agency or buying other services which the user has been assessed as needing.

One of the most important potential benefits of cash-for-care payments is that they enable users to choose their own care staff, either by directly employing a PA or using workers recruited through an agency. Countries vary in the extent to which cash-for-care scheme users have the choice of whether to employ family members instead of agency workers or strangers. Not all cash-for-care schemes allow users to employ close relatives as PAs. For example, a study of five European Union countries (Ungerson, 2004) reported that in France cash-for-care users could only employ non-relatives, but in Austria, Italy and the Netherlands there was no restriction on the employment of close relatives.

Table 1 Restrictions on choice in the use of cash-for-care payments

Country	*Rules for use of allowance at home*	*Payment to relatives*
Austria	No rules	Yes
England	Equivalent of care services assessed as needed	Normally, non-resident family members only
Flanders	May not be used for medical expenses, education or employment services	Yes, provided there is an employment contract
France	In accordance with care plan	Family members other than partner
Germany	No rules	Yes
Italy	No rules	Yes
Netherlands	98.5% must be used for care	Yes, but relative is required to have an employment contract
Sweden	Personal assistance only	Yes, but care recipients may not employ partner
USA	In accordance with care plan	Varies by state

Sources: Breda *et al*. (2006), Keigher (1999), Gori and Da Roit (2007), Pijl (nd), Ungerson (2004), Timonen *et al*. (2006), Lundsgaard (2005), Pilj and Ramakers (2007).

In England, unless there are exceptional circumstances, the direct payments scheme does not allow recipients to use the money to employ partners, close relatives or anyone who lives in the same household as the disabled or older person, unless that person is a live-in employee. Meanwhile, in the USA, whether or not Medicaid PCS recipients are allowed to employ relatives varies from one state to another (Doty *et al*., 1996). In Flanders (Belgium), the Personal Assistance Budget scheme allows both relatives and non-relatives to be employed. Where the care user is a disabled child, one parent may be the budget holder on the user's behalf while the other parent can be the paid carer (Breda *et al*., 2006). When the Dutch personal budget scheme was introduced it did not allow users to employ family members, but this restriction was removed in 1997 after pressure from recipients and family carers (Kremer, 2006). However, partners may only be employed if the user provides them with an employment contract (Lundsgaard, 2005; Pilj and Ramakers, 2007).

2. Barriers to exercising choice

The provision of cash-for-care payments instead of traditional services requires a major change in the outlook of social service agencies (where they are involved in providing services), represents a fundamental transformation in service delivery, and transfers responsibility for organising social care onto users and their carers. It would hardly be surprising, therefore, to find that some barriers exist to the take-up of cash-

for-care payments among some service users. Although the literature on cash-for-care is predominantly concerned with the benefits that such payments bring to users and their carers, it does nonetheless highlight potential or actual barriers to the take-up of such schemes (CSCI, 2004).

Several studies report resistance from social care agencies to the idea of cash-for-care payments, at least in the initial stages of programme implementation. Consumer-directed care is perceived as a challenge to traditional service delivery mechanisms and to professional expertise. It can also be seen as a potential threat to jobs and can lead to resistance from trade unions and professionals (Dawson, 2000; Riddell *et al*., 2005). As a result, social service agencies with a limited commitment to user involvement and the ethos of independent living, or that have a culture of conservatism, are relatively less likely to actively promote and engage with cash-for-care schemes (Hasler, 2003, 2004; Pearson, 2006; Priestley *et al*., 2006). Limited levels of involvement can also reflect organisational inflexibility over the rules about the use of cash-for-care payments (Freedman and Boyer, 1999; Lundsgaard, 2005; Priestley *et al*., 2006). However, these restrictions do not apply in countries such as Germany and Austria that have universal access to cash-for-care schemes (Tilly *et al*., 2000).

A related barrier discussed in the national and international literature relates to the role of care managers acting as ‘gatekeepers’ and, in particular, concerns about subjectivity in interpreting eligibility criteria about a user’s ability to give consent, and in assessing capacity to manage (Clark and Spafford, 2001; Leece, 2003). Consequently, practitioners may be selective in terms of the clients to whom they offer cash payments, which in England and elsewhere can impact particularly on opportunities for people with cognitive impairments, including persons with mental health problems, dementia or learning difficulties (Clark *et al*., 2004; Priestley *et al*., 2006; Tilly and Weiner, 2001). A number of surveys conducted in the USA have found that there is a greater interest among younger disabled people than among older people in participating in cash-for-care schemes instead of traditional service delivery (Mahony *et al*., 1998; Mahony *et al*., 2004; Benjamin and Mattias, 2001). In addition, a quasi-experimental study in the USA found that, holding other factors constant, clients in a consumer managed care model were significantly more likely to be adults with disabilities, while clients in the more traditional service delivery model were more likely to be older people (McWilliam *et al*., 2004).

If individuals lack up-to-date, accurate information, then they are not in a position to make well-informed decisions about whether to opt for traditional services or cash-for-care payments (Lent and Arend, 2004). Similarly, without information people cannot easily gain access to cash-for-care schemes (Kestenbaum, 2001; Poole, 2006). Social care professionals play a pivotal role in determining whether or not potential cash payments recipients are provided with accessible, up-to-date information. However, there is considerable research indicating that key front-line

staff themselves have limited understanding, knowledge and awareness of cash payments (Clark *et al*., 2004; Priestley *et al*., 2006; Fernandez *et al*., 2007). As a result, social care practitioners may lack knowledge, expertise and confidence in offering cash-for-care payments.

The practical difficulties associated with managing cash-for-care payments have been shown to present barriers to the take-up of such schemes in European countries and elsewhere. For example, the record keeping requirements of social services or government agencies are sometimes felt to be overly bureaucratic and burdensome (Tilly *et al*., 2000; Kremer, 2006; Pijl and Ramakers, 2006). Indeed, many cash-for-care recipients may need considerable support to help them organise their own care arrangements, and subsequently deal with the practical management and monitoring requirements of cash payments, (Glasby and Littlechild, 2002; Clark *et al*., 2004).

If recipients use the money to employ a PA, they have to take on all the practical and administrative tasks associated with being an employer (Glasby and Littlechild, 2002; Flynn, 2005). However, studies in France (Martin and Le Bihan, 2006) and the Netherlands (Pijl and Ramakers, 2006) have reported that recipients did not feel like they were employers, even though they had a PA working for them. In order to avoid the paperwork and administrative duties associated with becoming an employer, as well as not having to worry about unreliability or arranging sickness or holiday cover, some people choose to use agency services rather than recruit privately (Kestenbaum, 2001). In the Netherlands, a third of personal budget holders have outsourced the bureaucratic tasks associated with the scheme, such as paying PAs and dealing with tax and social insurance contributions (Kremer, 2006).

Difficulties relating to the recruitment of PAs can hinder the exercise of choice. There can be problems in recruiting PAs with the right skills, characteristics or qualities to ‘match’ the disabled or older person (Glendinning *et al*., 2000; Witcher *et al*., 2000; Kremer, 2006; Poole, 2006). Recruitment difficulties can be exacerbated for people that have only a small number of hours of employment to offer (Clark *et al*., 2004) or who live in rural or remote areas (Spall *et al*., 2005; Freedman and Boyer, 1999).

Several studies from a range of countries report that some cash-for-care recipients choose to employ several PAs in order to avoid paying social insurance contributions. For example, in the Netherlands, these contributions are not payable for employees working no more than two days a week. In consequence, most personal budget holders have chosen to employ more than one PA and only one in 20 has employed a full-time PA (Timonen *et al*., 2006). The low rates of pay that cash-for-care payment users are able to offer can also make it more difficult to recruit suitable PAs (Kremer, 2006). That is an important reason why in countries such as Austria and Italy many PAs are migrant workers, especially women, recruited from

neighbouring countries and from Eastern Europe where rates of pay are typically much lower (Gori and Da Roit, 2006; Osterle and Hammer, 2006).

In order to exercise choice, there needs to be a social care market generating a supply of care workers or service providers. As noted in the Introduction, in some countries an explicit objective of cash-for-care schemes has been precisely to induce the development of a home care market. For example, in Finland, an important aim of home care service vouchers is to stimulate the provision of services by private and not-for-profit providers as an alternative to municipal provision (Timonen *et al*., 2006). By contrast, in Scotland there has been ideological resistance to the use of direct payments as a mode of service provision (Pearson, 2006), which is linked to concerns over the marketisation of social care and broader anti-privatisation campaigns across public services. In practice, a social care market is lacking or relatively undeveloped in many countries (Keigher, 1999; Timonen *et al*., 2006; Spall *et al*., 2005; Lundsgaard, 2005). Hence Kremer's (2006: 391) conclusion, that Dutch personal budget holders 'are waiting for a market that has not come yet', could be applied to many other countries as well.

Lack of suitably trained or qualified PAs can also be a barrier for some users, a problem that can be especially difficult for people with complex needs (Keigher, 1999). As well, the low pay and poor terms and conditions offered to some PAs can result in high staff turnover (Keigher, 1999). The net result of these recruitment difficulties is that, in some cases, there is a lack of real choice for some users (Tilly and Wiener, 2001; Freedman and Boyer, 1999). Conversely, the requirement in some U.S. states, such as Texas, that Personal Care Service programme users must recruit PAs who are employees of certified home care agencies poses a barrier to family members or friends being paid to provide care (Doty *et al*., 1996). An additional problem is that some users may be difficult to get on with, or exhibit challenging behaviour, which can make it hard to recruit and retain PAs to work for them (Keigher, 1999).

Community care services are often carefully regulated, but this is generally not the case for cash-for-care payments. Lack of regulation can lead to concerns about the quality of care received by users (Carlin and Lenehan, 2006). However, the extent to which the quality of services purchased by cash-for-care payments should be regulated is contested. First, an implicit assumption underlying cash-for-care programmes is that formal quality assurance mechanisms are not needed because recipients can fire assistants that provide an unsatisfactory service (Tilly *et al*., 2000). Second, some researchers have questioned whether such regulation is necessary and argued that it is paternalistic and patronising to disabled people, as they are quite capable of assessing the quality of service that they are receiving (Doty *et al*., 1996). In contrast, some practitioners have expressed concern about the quality of care for people with cognitive impairments, especially because of their perceived vulnerability to abuse (Tilly and Wiener, 2001).

3. Facilitators to exercising choice

What can be done to try to ameliorate the above barriers? And what does the literature say about the factors that have the potential to facilitate individuals' ability to exercise choice through the use of cash-for-care schemes?

Given the problems documented above about users' lack of knowledge, it is not surprising that research studies commonly highlight the importance of publicity and information about cash-for-care initiatives (Clark *et al*., 2004; Ridley and Jones, 2003). To that end, social services practitioners who are not only well-informed, but also communicate that information to potential recipients and share their aspirations for independent living, are important in helping people to maximise their opportunities for choice through cash-for-care schemes (Dawson, 2000; Clark *et al*., 2004; Yoshida *et al*., 2004).

There is a wealth of evidence from a range of countries endorsing the crucial role of support systems and advocacy organisations for recipients of cash-for-care payments (Dawson, 2000; Yoshida *et al*., 2004; Riddell *et al*., 2005). Although they can vary hugely in form and scope, generally speaking support services provide information and advice (Witcher *et al*., 2000). In addition, they may offer practical help in relation to some or all of the following tasks: recruiting PAs; drawing up contracts of employment; operating a payroll; managing the financial and administrative tasks demanded by the cash-for-care scheme provider; supporting recipients to be good employers (Yoshida *et al*., 2004). It appears that older people might need more intensive and on-going support than younger disabled people. Peer support is recognised as an effective way to share experiences and information about direct payments, but older people tend to be less keen than other user groups in being involved in peer support groups (Clark, 2006). In the Netherlands, an organisation was established for budget holders and has 15,000 members (Kremer, 2006).

Family carers and networks of friends and contacts have been shown to be important in assisting with the recruitment and employment of PAs; similarly, carers and relatives can assist recipients to organise and manage viable care packages (Dawson, 2000; Yoshida *et al*., 2004). For people with significant impairments, cash-for-care schemes require the involvement of other people, such as family carers or advocacy workers, to manage the budget and their PA (Doty *et al*., 1996). However, carers and other family members themselves need information about cash-for-care schemes and related support services in order for them to exercise this role (Freedman and Boyer, 1999). Timonen *et al*. (2006) concluded that the Home Care Grant in Ireland seemed to work best for older people with a family carer who could take responsibility for the employment of the PA and also meet the care needs not covered by the grant.

A Canadian study found that the factors that facilitated the successful implementation of a cash-for-care scheme for disabled people included a clear vision by the community, a core group of leaders able to act as advocates for the scheme, the existence supporters inside and outside the community, and support services to tackle barriers to the successful implementation of the scheme. Thus, schemes may operate best when embedded within the community and provided with resources over and above the money allocated to users (Yoshida *et al*., 2004).

4. Outcomes of choice

Almost all studies report that cash-for-care schemes bring positive outcomes to those who use them. In line with the ethos of the Independent Living Movement, an important goal of many such schemes is to increase recipients' ability to make choices. In that respect, the research evidence suggests that cash-for-care schemes are highly successful. The majority of respondents in studies of cash payments report a greater sense of choice and control over their day-to-day lives.

There is also a wealth of evidence highlighting the psychological benefits for recipients of exercising choice through cash-for-care schemes. These can include feeling more confident, optimistic and positive, as well as increased levels of independence and being motivated to explore new openings or opportunities in ways that might not have seemed possible before (Doty *et al*., 1996; Ungerson, 2004; Breda *et al*., 2006; Yoshida *et al*., 2004).

A common benefit evidenced in cash-for-care schemes in different countries is that individuals can arrange the assistance they buy to fit their particular needs and circumstances. Hence, users can decide, for example, the timing of visits from PAs, the type of support they require, and how it should be delivered. They can also make requirements about such matters as the setting and maintaining boundaries regarding personal privacy (Benjamin *et al*., 2000; Foster *et al*., 2003; Clark *et al*., 2004). This has enabled the timing of assistance and the manner in which it is given to be tailored to users' personal preferences and lifestyles. This contrasts with traditional agency provided services, which are normally provided in accordance with the decisions of the agency, the imperatives of which (such as cost-efficiency) may well be different from those of recipients.

Some cash-for-care schemes allow recipients to purchase services that might not otherwise be offered to them by traditional service agencies (Freedman and Boyer, 1999). Such schemes can also provide the opportunity for recipients to ask their PA to undertake tasks that formal service providers will not do or that are not specified in their contract with the social services authority. For example, Benjamin *et al*. (2000) found that PAs employed by cash-for-care recipients in California's in-Home Supportive Services programme (IHSS) were more likely to perform non-authorized

tasks and work extra, unpaid hours than workers employed by traditional service provider agencies. If the cash payment has the flexibility to enable PAs to get involved in the health-related aspects of a recipient's personal care, that further extends the areas over which they can exercise choice and control (Glendinning *et al*., 2000).

Cash-for-care schemes also enable users to decide who they want to work for them. Thus, in many schemes they can choose to employ people they know and trust, should they wish to do so, or employ someone they do not know if that suits them better (Breda *et al*., 2006). Benjamin *et al*. (2000) found in their Californian IHSS study that people hired as PAs were more likely to match the recipients ethnically and linguistically in a consumer-directed service model than in a traditional agency model. Cash-for-care recipients often employ people they know (Tilly and Wiener, 2001), in some cases because they find that 'having intimate care, such as help with bathing and dressing, performed by a person of one's choosing is much more satisfactory than having it performed by a stranger' (Foster *et al*., 2003: 171-72).

Recipients of cash-for-care schemes appear to experience a higher level of satisfaction with their PA than people receiving traditional agency provided services (Benjamin *et al*., 2000; Mahoney *et al*., 2006). A study of the Arkansas Cash and Counselling demonstration project in the USA, for example, found that recipients were much less likely than the control group receiving traditional agency provided services, to report that their paid caregivers performed poorly and more likely to say they performed exceptionally well. Compared with users of traditional service delivery, fewer Cash and Counseling recipients reported that their paid caregiver failed to complete tasks, sometimes failed to visit as scheduled, or had been rude or disrespectful (Foster *et al*., 2003).

Users of cash-for-care schemes often appreciate the fact that they can now compensate their carer for work previously undertaken on an unpaid basis (Ungerson, 2004). People who employ PAs who were previously friends are in a position to reciprocate and give something back to those individuals who have provided informal care in the past (Stainton and Boyce, 2004). This can enhance their sense of self-esteem (Ungerson, 2004). Users can benefit in terms of continuity of staff, and strong friendships that can be increasingly important as people become more housebound (Dawson, 2000).

One potential advantage of employing a PA compared with receiving help from an unpaid carer is that relationships are thereby based on a contract of employment, roles and duties are clear to both parties, and the emotional aspect of the relationship is reduced, especially when compared with informal care (Ungerson, 2004). As Ungerson (1997) has shown, introducing the cash nexus into care work alters, often in quite subtle ways, the relationship between the disabled or older person and their carer – although not always in ways that are mutually beneficial (Ungerson, 2004;

Poole, 2006). Interestingly, one study in England found no evidence that older people were empowered as a direct result of receiving direct payments if they had a carer who was closely involved in managing services, thus raising questions about the extent to which carers follow their own preferences in deciding how to use the cash (Clark and Spafford, 2001).

The research evidence on quality of care received by cash-for-care recipients is limited, but generally suggests that it is no worse than that received by recipients of traditional agency services. For example, the evaluation of the US Cash and Counseling demonstration project found that, of 11 measures of health problems or adverse events, none of the outcomes for programme recipients were worse than for recipients of traditional Medicaid services. The study concluded that 'Consumers under Cash and Counseling appeared to receive care at least as good as that provided by agencies' (Carlson *et al*., 2007).

Although research evidence on the impact of cash-for-care on health outcomes is limited, US findings indicate that such schemes produce comparable outcomes relative to traditional service delivery (Foster *et al*., 2003; Carlson *et al*., 2007; Mahoney *et al*., 2006). Moreover, the evidence suggests that cash-for-care scheme users are no more at risk of abuse or neglect from workers than clients of services provided by agencies (Foster *et al*., 2003; Mattias and Benjamin, 2003). Further research evidence on health outcomes is needed before more definitive conclusions can be drawn on this crucial aspect of outcomes.

While the majority of cash-for-care recipients in the US Cash and Counseling demonstration project were satisfied, a substantial minority left the programme. The main reasons why people gave up were because the payment was not regarded as large enough, they had difficultly coping with being an employer, or they decided that they preferred agency services (Schore *et al*., 2007). An Australian study found the possibility of choice did not address the lack of services in rural or remote areas, it increased the cost of care to the user but decreased the quality of the care they received, and was accompanied by perceived cutbacks in public service delivery and longer waiting times (Spall *et al*., 2005). These negative outcomes have not generally been found other studies of cash-for-care schemes and may reflect the particular context within which the Australian scheme was introduced.

An important objective or anticipated outcome of cash-for-care schemes in some countries has been budget savings (Timonen *et al*., 2006; Keigher, 1999). Some studies report that cash-for-care payments enabled recipients to live in their own home rather than long term institutional care (Witcher *et al.*, 2000; Clark *et al*., 2004). However, there are few studies of the costs of cash-for-care schemes compared with in-kind agency services or institutional care. Moreover the effect of cash-for-care payments on cost containment is likely to vary according to the design details of such schemes. An evaluation of the US Cash and Counseling demonstration project, for

example, found that it actually increased costs compared with expenditures under the traditional Medicaid scheme (Dale and Brown, 2007).

Preconditions for choice

This review of the evidence base on cash-for-care schemes provides insights into the preconditions of choice, that is, the arrangements and facilities that would need to be in place in order for cash-for-care payments to enable users to exercise ‘real’ choice over their care package, can be identified. We have identified five such preconditions:

1. Potential cash-for-care users need to be aware of the existence of such schemes, eligibility criteria and how to access them. This in turn requires policy makers and local social service agencies to implement active publicity drives to draw them to the attention of potential users and their carers.

2. Social service agencies need to ensure that adequate advice, advocacy and support services are available. Without such support, some potential users, such as very frail older people, may not easily be able cope with the tasks that are associated with managing their own care.

3. In order for choice to be real rather than nominal, users should be allowed to decide for themselves whether to choose conventional in-kind service delivery or cash-for-care payments, or a mix of the two. For this to happen, there needs to be commitment to an ‘ethic of choice’ among policymakers and social services authorities.

4. The cash-for-care payment would need to be sufficient to enable the user to purchase a suitable care package in the social care market. If it is insufficient, only those users who can afford to make up the difference, or who have carers who are able to provide care at below the market rate, will be able to choose cash-for-care payments instead of in-kind services.

5. There needs to be a functioning market of care providers, from which users may choose their PA and required services. The marketplace in turn relates to the financial adequacy precondition. Unless the user can afford to pay the going rate for PAs, they may have no choice but to rely on an under-paid relative.

Conclusions

The overwhelming message from the literature is that cash-for-care payments offer social care users the scope to exercise some choice over the assistance that they receive and by whom it is provided. In general, compared with traditional service provision, the outcomes of this choice include a care package that better suits their needs and preferences and which therefore provides them with a higher level of satisfaction, enhanced feelings of control and self-esteem, greater independence, and the ability to participate more fully in normal, every day activities.

However, the degree of choice that users may exercise varies considerably between countries and jurisdictions (states, provinces, local authorities) within countries. In some countries, such as Italy, the cash payments are not regulated and can be spent on anything the user wishes; they are in effect unrestricted cash transfers. More usually, cash-for-care payments are provided with more or less restrictions over what can be purchased and who can be hired. To some extent, these restrictions reflect policymakers' perceived need to ensure accountability and value for money in the use of public funds as well as the objectives of their cash-for-care schemes. But it remains an open question as to whether some of these restrictions are truly necessary or consistent with what one might call an 'ethic of choice' in relation to cash-for-care payments. Thus, while cash-for-care schemes do offer choice, there are often important limits in practice on the extent to which choices can be made by disabled and older people.

It is equally clear from the research that there are a variety of barriers that may prevent social care users from taking part in cash-for-care schemes or making the best use of such payments. These barriers range from lack of information about these schemes, through the record-keeping requirements of social service authorities, to the hassles that being an employer of a PA may entail. Nevertheless, it is apparent from the research that there are ways in which many if not all of these barriers may be overcome or minimised, provided there is the will to do so.

Although the outcomes of choice appear to be very largely positive, the research evidence on cash-for-care payments is limited in several important respects. First, it is notable that most of the publications on cash-for-care payments concentrate on disabled adults or older people. Relatively few empirical studies examine cash-for-care schemes in relation to other client groups, for example parents of disabled children. Second, the literature focuses almost exclusively on cash-for-care payments that are publicly funded in full or in part and gives little attention to care services that are wholly privately funded (but see Keigher, 1999).

Third, the existing literature has relatively little to say about which types of social care user may find cash-for-care payments very difficult or impossible to manage. While physically disabled people and older people with little or no cognitive impairment may

easily be able to manage such payments, users with dementia or similar conditions may not necessarily be able to cope without the help of carers. In practice, in cash-for-care schemes run by local authorities, judgements about suitability are generally made by social care staff. But it may be helpful for policymakers, if not for practitioners, to have research evidence to guide policy decisions about the scope of cash-for-care schemes. At a general level, it may be helpful to know whether there are some health conditions that make cash-for-care payments not typically feasible.

It is also worth noting some significant methodological limitations in much of the research on this topic, especially in relation to the *outcomes* of cash-for-care payments:

1. The majority of the research studies undertaken so far are based on studies of cash payment recipients only. As a result, they do not make comparisons between the outcomes experienced by cash-for-care scheme recipients and those experienced by users of traditional agency-provided services.

2. Many of these studies suffer from potential 'selection effects', that is, they involve people who have opted for such payments. By contrast, there have been relatively few studies that have involved random assignment of users into 'treatment' (cash-for-care schemes) and 'control' (traditional service delivery) programmes.

3. Outside of the USA, the research on cash-for-care schemes is dominated by qualitative studies. This qualitative evidence needs to be complemented by more quantitative survey data, since this can identify the impact of particular characteristics that help to make such schemes a success while controlling for other factors.

4. While almost all studies have focused on the perceptions and experiences of recipients – which of course are absolutely critical to evaluation of such schemes – relatively few studies have examined more objective measures – such as activities of daily living – using validated instruments. There is also little systematic evidence on the cost of cash-for-care payments compared with traditional service delivery.

5. Most studies are cross-sectional rather than longitudinal. As a result, the research has relatively little to say about how traditional service delivery and cash-for-care schemes compare in enabling recipients to cope with changing circumstances or declining functional ability (Benjamin *et al*., 2000).

Thus, while cash-for-care schemes are an idea whose time has come (Keigher, 1999), more robust research evidence is required before there is a full understanding

of the extent to which cash-for-care payments can enhance choice compared with conventional in-kind service delivery.

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