# The Costs and Benefits of Formal Personalised Care

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# The Costs and Benefits of Formal Personalised Care

# Abstract

For more than two decades, local authorities across the UK have been developing and implementing schemes and support programmes under a range of titles. These include Direct Payments, Cash for Care, Consumer-directed Care, and Self Directed Support, which have often been categorised as being part the personalisation agenda. The essence of this is that governments across the UK, and indeed globally, wish to shift the manner in which services are delivered to those who have disabilities, requiring social care, and other support, thus allowing them to participate in daily life in a manner which ostensibly moves financial control into the hands of individual. Here we set this concept of self directed support in the context of a focus on the social model of disability and citizenship, community participation, and individual and collective empowerment more widely. We make particular reference to the capabilities approach in terms of how well it feeds into the perception and implementation of SDS. We do this first in Scotland, and then internationally, which leads to an analysis of the challenges relating to the implementation of such programmes in Scotland, and the UK, before setting this evidence in the wider international context. The review then draws conclusions about the gaps in the overall field of literature in relation to what makes ‘good’ self directed support, before offering an explanation of how the current project serves to fill those gaps, and setting out the methodology and rationale for the project.

# Introduction

*“Self-Directed Support is a tool which disabled people can use to support their inclusion as a valued member of our society, with roles and responsibilities to help with functioning of their community. SDS is part of the journey to reach Independent Living.”*

Miro Griffiths

For more than two decades, local authorities across the UK have been developing and implementing schemes and support programmes under a range of titles. These include Direct Payments, Cash for Care, Consumer-directed Care, and Self Directed Support (SDS), which have often been categorised as being part the personalisation agenda. The essence of this is that governments across the UK, and indeed globally, wish to shift the manner in which services are delivered to those who have disabilities, requiring social care, and other support, thus allowing them to participate in daily life in a manner which ostensibly moves financial control into the hands of individual. Defined in the Scottish Government's 2010 publication, 'Self Directed Support: A National Strategy for Scotland, SDS is "the support individuals and families have after making an informed choice on how their *Individual Budget* is used to meet the outcomes they have agreed. SDS means giving people choice and control" (Scottish Government, 2010: 7). Despite the apparent simplicity of this definition, there are practical and philosophical debates around the impact and meaning of this policy in Scotland. Indeed these debates extend beyond Scotland to the remainder of the United Kingdom and wider global context.

This review offers a discussion of this agenda in its historical context as it links to the spectrum of models of disability ranging from the medical, individual/personal tragedy models at one end towards the social model and capabilities approach at other. Further it discusses the links between these models and empowerment of those with disabilities.

# Models of disability

(Disability movement - Community Empowerment and Citizenship - Participation)

The terms 'individual/personal tragedy' and 'medical' models of disability are often used interchangeably when describing the 'Individual Model' of disability, and in essence, that is what is being discussed here. Under this model, disability is seen as predominantly an individual problem, which medical and other interventions should be used to alleviate, so that the individual can adapt and function in accordance with society's expectations (Drake, 1999: 10-12). Arguments put forward by academics such as Goffman and Scott, and the development surrounding disabled people promoting their wishes to live independently, resulted in academics such as Mike Oliver developing the ‘social model of disability’. Under this model, the aim was to improve the environment and societal attitudes regarding disabled people such that they were better able to function in society and barriers to their participation were ameliorated (Drake, 1999: 13)(see table below). For instance, it is not the responsibility of a disabled person, under this model, to ensure that the surrounding architecture and general environment is accessible to them, but rather, society more widely, in conjunction with those with disabilities, should adapt the physical and social environment to make access possible (Bickenbach, Chatterji, Badley, and Ustun, 1999: 1174).

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| --- | --- |
| ***The Individual Model*** | ***The Social Model*** |
| Personal tragedy theory | Social oppression theory |
| Personal problem | Social problem |
| Individual treatment | Social action |
| Medicalisation | Self-help |
| Professional dominance | Individual and collective responsibility |
| Expertise | Experience |
| Adjustment | Affirmation |
| Individual identity | Collective identity |
| Prejudice | Discrimination |
| Attitudes | Behaviour |
| Care | Rights |
| Control | Choice |
| Policy | Politics |
| Individual adaptation | Social change |

(Oliver, 2009: 45)

It is often suggested that the original description set out by the social model precludes any real discussion of the issue of impairment and its impact on individuals, therefore, academics who might be described as second wave writers in this area, attempted to bring the issue of impairment back in. In other words, to expand the debate around the social model so that impairment would no longer be 'off the table'. (Goodley, 2001: 208; Abberley, 1996: 62-63; Oliver, 1996; Crow, 1996). Researchers and policymakers must remain cognisant of the fact that often, the demarcation between disability and impairment is complex and subjective, and cannot easily be extracted from each other (Shakespeare, 2014: 21-22). Another complication is that not only can disability and impairment not easily be separated, but the term disabled and disability be can be something which is fluid (Barnartt, 2010: 1-3).

By the 1990s the social model manner of thinking around disability was beginning to be clear with enactments such as the Disability Discrimination Act, 1996. Social model thinking was also present at the international level - in 1993, the UN published the Standard Rules on the Equalisation of Opportunity for People with Disabilities (Barnes and Mercer, 2004: 4-5; Barnes, 2012: 12-29). However supporters have consistently noted that the social model still exists in a world where the medical model continues to dominate the discussion due to the constant medical advances (Thomas, 2002a: 64; Thomas, 2002: 40; Lee, 2002: 148; Oliver and Barnes, 2012: 84-85).

It has been noted this resistance to bringing forth the social model has not only been present within the medical profession but also among academics whose role it was to study and describe disability (Shakespeare and Watson, 1997: 294, Oliver and Barnes, 2012: 87). Johnston suggests researchers need representativeness to achieve best results in a clinical setting, however she does not diminish the impact of social and environmental factors in terms of its impact on impairment and disability, and suggests 'WHO' models could integrate all these factors but this integration would be dependent on some core assumptions about which goals or purposes these models should serve (Johnston, 1997: 309).

The continued prominence of the medical model can partly be explained by a difference in thinking around particular issues such as independence, and the 'them and us' view which this can create (Bricher, 2000: 783; Ghosh, 2012: 10-12). There is a continued strong presence of medical categories within the ICF and this continued dominance of the medical model exists across western societies (see also: Areheart, 2008; Humpaige, 2007: 217).

Albrecht was critical of the ability of the social model to effect any real change based on the assistance required to allow persons with disability to be better able to function, and the emergence of ‘the disability business’. He suggests that because western economies have moved toward an economic structure predominantly based on provision of services for commercial gain, this has led to the ‘production of disability'. The greater the numbers of people who use such services in this manner, then the greater the expansion of disability related commercial enterprise (Barnes, 1996: 45). Arguably a balance needs to be struck between the right of individuals to support, and a requirement for society to promote self help, and it is only when this balance is struck that society stands any chance of achieving the social model of disability. The removing of social barriers to help make disabled people better able to function in society can only work if those people are encouraged where possible to help themselves because, if they are not encouraged to help themselves a new barrier forms (Oliver, 2009a: 49 gives a defence of the social model against its critics).

Shakespeare is of the view that functionality for disabled people and the context of the society in which they live need to be considered together in order to gain a full understanding of disability, disabled people, and their position in society. Shakespeare asserts that one possible option for creating a model which combines both these issues would be to use the International Classification of Functioning, Disability and Health (ICF) (Shakespeare, 2006: 78-79; Sapey, 2010: 2). Other models seeking to bring together the medical, environmental and individual factors and move on from the medical/personal tragedy approach, include the 'capabilities framework' or capabilities approach (Burchardt, 2004; Mitra, 2006), and an affirmation model of disability (Swain and French, 2000; Swain and French, 2004; Cameron, 2014). Connected to the idea around moving toward affirmation models of disability is the idea of empowerment, and the personalisation agenda which ostensibly suggests that people with disabilities should be given a voice in terms of how services are organised, and that these services should be provided in such a way as they fit around disabled people's lives allowing them to participate fully in all aspects of daily living and care (Mackay, 2010: 192-193; Millar, 2010: 284). Notably however, despite this more recent focus on empowerment of individuals with disabilities, and their right to have control over their lives and the services they use (Barczyk & Lincove, 2010: 211-212), many writers have questioned what this control and empowerment really means in practical terms (Mladinov, 2012; Elder-Woodward, 2014). See also, Perri 6, (2003), for a discussion of the limitations of choice in the British Public Policy context, including community care.

# Personalisation agenda

SDS has been linked strongly with the personalisation agenda across the UK, but has also been subject to criticism in this context, as the definition of personalisation and co-production that in principle should embody SDS, have been seen as not being fully implemented, in the sense that this personalisation has been 'shallow' where the process focuses on small scale adaptations to large scale, standardised services. This contrasts with 'deep', personalisation which sees individuals take responsibility for both the use of and the development of services from grass roots level (Elder-Woodward, d'Aboville, Duncan-Glancy, 2015; Elder-Woodward, 2016).

**I**t is clear that SDS in principle would provide a useful and workable route for people with disabilities to live independently, however, it is clear that in order for such processes to work fully as intended, then there requires to be a fully functioning partnership between service users and the council and other bodies providing the services. This would require a shift in focus, away from empowering people to become consumers in a market context, rather the focus needs to be on person centred planning, and doing this in such a way that it is not perceived as simply an increase in bureaucracy (Slasberg, Beresford, Schofield, 2012: 174-175). In part, this perception of SDS as an increase in bureaucracy by health and social work professionals, emanated from a sense that, certainly in the early stages, professionals felt that they lacked the information about how SDS would work, a perception shared also by service users. Although some of these issues around lack of information may have been improved over time, concerns around practitioners reluctance to offer full budgetary control to individuals seems to have continued to exist (Harkes, Brown and Horsborough, 2012: 97-98). In part, this may emanate from the concerns described by Pearson (2004: 8-10), that the control over individual budgets moving away from local authorities toward individuals, giving them the ability to use private and third sector organisations, may consequently result in a commensurate reduction in local authority funding. SDS as a process is one which can be complex for particular groups who face specific challenges, therefore, in some areas the uptake of SDS among these groups, for example clients with dementia can be unnaturally low, caused in part by the increased bureaucracy involved in meeting their specific needs. However, where the information is set out in an accessible format, and the professionals are provided with the necessary training and knowledge of the condition, and the support that these individuals and their carers require, then the process can function well (Moore and Jones, 2011).

There is also an apparent sense in which the Scottish implementation of Direct Payments has been curtailed by an anti-market sentiment, which has seen a reduced uptake in direct payments and a lack of clarity around what qualifies as being 'covered' by the Direct Payment (Pearson, 2000: 471-474). The SDS policy instituted across the various regions of the UK, has also been subject to questions over the actual meaning of the control and independence it offers those using the process. Does 'control' simply mean that an individual has access to money to set up their own care package, and local authorities no longer provide traditional day care centre packages or collective services for those with disabilities, as they have characterised such services as removing peoples' freedom of choice? Or does 'control' really mean that people have control over their budget but collective services are still an option, and SDS is not seen as a route to protection from responsibility for budget cuts (Roulstone and Morgan, 2009)? Kendall and Cameron, (2013), further argue that we must clarify what we mean by choice and control, and caution against the move to direct payments simply being seen as an opportunity to transfer control. They also strongly point out that the move away from a 'forced collectivism' toward 'forced individualism' could in fact, rather than producing increased independence and choice, perversely produce restricted choice and an increased isolation, instead of the increased participation that many advocating SDS seek.

SDS was intended to produce a context of meaningful co-production between service users and those in social care and health, but in truth it is difficult to say that this process has produced the transformative change that was intended, as many local authorities have not yet completed the process of actively providing individuals with choice in terms of the care options on offer (Pearson, Watson and Manji, 2017: 668-669). Given that SDS has been instituted in a context where there were also other large scale service reorganisations being implemented concurrently, meant that SDS started off as a priority and subsequently became subsumed within other service changes, which meant that it was not consistently fully implemented across Scotland. The health and social care partnerships have been run in different ways across Scotland, and some have functioned more effectively than others, although in some instances health professionals have found it difficult to meaningfully participate in the partnership arrangements. Consequently, the implementation of SDS that requires health support has been difficult to produce consistently. This allied to a context of on-going austerity has meant that SDS in some regions was perceived as a way to survive cuts in budgets, rather than as a route to individuals having control over their care. Therefore the sense that SDS has not so far achieved transformative change is unsurprising (Pearson et al. 2017: 669-671). Arguably, some of the difficulties around meaningful co-production and transformative change in service provision and delivery, can be exacerbated by some of the problems that have been seen to be present in service user participation schemes in the past, such as a sense among carers and service users that they will not really be listened to, so there is no real point in participating, and that staff have limited resources to really make full use of the potential of service user participation (Carey, 2009: 184).

Concerns around the managing of the financial aspects of Direct Payments and SDS can make the implementation of such processes, and the assessments around client contribution problematic. Arguably, the ensuring of flexible assessment processes, and guidance about the degree of contribution and other financial information, would make the uptake of this type of support being increased more likely, as would comprehensive, clear, easily accessible from a single source about the service in general (Duncan-Turnbull, 2010: 256-257). Many of the concerns around information and financial support could be overcome through the involvement of service user and carers organisations in the development of and provision of independent information about the services that are available (Harkes, Brown and Horsborough, 2012: 98). Notably, this sense that disability and carers organisations have a key role to play in the advocacy for and increasing the uptake of direct payments and indeed Self Directed Support is not a new one. Charlotte Pearson, more than a decade ago was highlighting the important role played by disability organisations in advocating the expansion and increased uptake of direct payments in areas of Scotland (Pearson, 2004).

Slasberg and Beresford, (2015: 481-483), argue that, even if one allays the concerns of service users, carers and professionals around SDS, there remains a difficulty surrounding eligibility criteria. They posit that the strategic outcome of the SDS process cannot be achieved, because the process still functions in a context whereby need is decided on the basis of meeting the minimum eligibility criteria, rather than on the specifics of individual circumstances and sufficiency of resource to meet actual need. They also advocate that the flexibility of response in terms of commissioning of services needs to improve in order for SDS processes to be more fully taken up (see also Slasberg and Beresford, 2017).

# Self-directed supported in the wider international context

There have been long-standing concerns within developed welfare states as to how to manage welfare and care policies in such a way which caps the rising demand for resources, leading to a shifting of responsibilities across public sectors (for example from health to social care, and from national to localised provision), and across sectors (for example from state to private or third sector provision, or from state to family [or, indeed, family to state]). At the same time a variety of international, national and local political, social and economic factors have led to changes in the governance of welfare, including increasing commodification of services and deprofessionalisation of practitioners (Newman, 2005). Rising demand for support and services has also come not just from demographic changes but also from increasingly politicized ‘user’ movements (such a disability rights organisations in the UK and the Netherlands, and older people’s organisations in the USA) who have rejected both family and informal care as exploitative (for both carers and cared-for) and state care as increasingly fragmented, unresponsive and dehumanising – indeed, rejecting the rhetoric of ‘care’ altogether and demanding social rights, empowerment and control over the type and level of support received instead (Morris, 2004). Increasing regulation of services in response to ‘consumer’ demand has only partially succeeded in responding effectively to these changes: new models of service delivery are being actively sought in response to these complex political, social and economic changes (Ungerson and Yeandle, 2007).

These pressures have led to the development of personalisation schemes across a range of developed welfare states. Although these vary considerably in their intentions, scope and the way they function, they are essentially mechanisms whereby a disabled or older person receives a cash benefit in order to purchase help or services themselves, in lieu of receiving services or support directly. They can be seen as a way of ‘commodifying’ care (Ungerson, 1997) and several different models have emerged: tightly controlled personal care budgets allowing direct employment of formal care workers; care allowances paid directly to disabled and older people but not directly governed; income maintenance approaches (whereby allowances are paid directly to carers to acknowledge or compensate for the loss earned income, usually only available to low-income carers); and directly paying informal carers to replace publicly funded formal care. In some forms, particularly those paid directly to disabled and older people, their popularity amongst disabled and older people is well-documented: they have been hailed as an important victory for social rights by campaigners in the UK, because of the way in which they have allowed disabled and older people to exert choice and control over the type of assistance and support they receive (Rummery, 2006), and the way in which it they have enabled disabled people to combine different types of support (health and social care, formal and informal) in ways which have led to greater independence and social participation, without the ‘burden of gratitude’ experienced by people receiving informal care from family members or voluntary or paid workers not directly employed by the disabled or older person themselves (Galvin, 2004).

An international comparative review of such schemes was undertaken, focussing particularly on the structure and governance issues, and on how well they balanced the needs of service users and carers.

# Examples of personalised care policies

There are many ways of comparatively classifying welfare regimes, but the most commonly used are those developed from Esping-Andersen’s ‘Three Worlds of Welfare’ thesis (Esping-Anderson, 1990), which divided welfare states into ‘liberal’ (in which means-tested assistance and modest universal or insurance transfers take place, and the free market is seen as the best way for distributing resources, with the state supporting it – such as UK and USA), ‘conservative’ (in which state-led social policy development reflected invested interests that are neither purely social democratic nor market driven, such as the Netherlands, Italy, France and Austria), and ‘universal’ (where a commitment to universalism and decommodification involves the state working outside the market, such as the Nordic welfare states). Bettio and Plantenga (2004) have extended and nuanced this analysis with respect to European care regimes and found five typologies: countries that rely on the family for all care (Italy, Greece, Spain); countries that rely on informal care (but more so for childcare than adult care) (UK, Netherlands); countries with state facilitated private care (Austria, Germany); countries with highly developed formal care (France); and those with moderate to high levels of formal care (Denmark, Finland, Sweden).

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| Country | Welfare typology | Percentage of people over 65 receiving formal help at home\* |
| UK | Liberal1 informal care2 | 5.5 |
| Netherlands | Conservative1 informal care2 | 12 |
| Italy | Conservative1 family care2 | 2.8 |
| France | Conservative1 formal care2 | 6.1 |
| Austria | Conservative1 public/private care | 24 |
| USA | Liberal1 | 16 |

Fig 1, \*source Casey et al (2003) 1 Esping Andersen (1990) 2 Bettio and Plantenga (2004)

It is perhaps worth noting at this point that no case study examples of cash-for-care schemes have been included from either Esping-Andersen’s ‘universal’ nor Bettio and Platenga’s ‘moderate/high informal care’ regimes, as schemes in these countries have either been relatively underdeveloped, or have not followed the marketised route of enabling direct employment of carers.

## United Kingdom

In the United Kingdom a system of direct payments was introduced in 1996 which replaced previous ad-hoc schemes. Disabled and older people are now able to apply for payments in lieu of directly provided services (the level of which are set according to a needs assessment) and these payments are usually used to directly employ formal care workers, or purchase care from not-for-profit care agencies. It is not possible to directly pay family members, as, unlike other schemes, it is intended to replace formal rather than informal care and support, and there is relatively low takeup amongst older people. A regulatory system is in place, although there is little formal employment protection for directly-employed workers, and lack of formal assistance in recruitment of care workers is a problem for both users and employees. It is implemented locally, with the result that there is considerable regional variation in criteria, eligibility and access, although policy developments are in place to support more systematic take-up and to enable users to purchase a wider range of services (at present the scheme is limited to ‘social’ care) (Rummery, 2006).

## The Netherlands

The Netherlands has seen the introduction in 1991 of a personal care allowance scheme that was extended in 1995 to become part of the national long-term care insurance scheme (Pijl and Ramakers, 2007), allowing recipients to chose to receive direct payments in lieu of directly provided services. This scheme is relatively strictly regulated, providing a degree of protection for directly-employed care workers and making it impossible to directly pay workers on the ‘black’ or unregulated market. However, it can be used to purchase care from family members and thus enables recipients to combine formal and informal care arrangements flexibly. It is also relatively generously funded, leading to political concerns about rising demand, although, in common with other cash-for-care schemes it is still cheaper than directly providing state-funded services (Weekers and Pijl, 1998).

## Italy

Italy has historically seen very little development of formal residential or community based care services, explained in part by very decentralised state provision of services generally (leading to substantial regional variations), and a reliance on family and informal care (Gori, 2003), accompanied by a reluctance to develop formal, central-state driven responses to the rising demand for long-term care and support (Pavolini and Ranci, 2006). The ‘Indennita di accompagnamento’ is a non-means tested benefit available to disabled and older people who are certified as ‘dependent’. It is not tempered according to need, and no restrictions are placed upon its use. This comparative lack of regulation means that it is most often used to employ to employ care workers, often on the black (unregulated) labour market (Ranci, 2007; Gori and Da Roit, 2007). Local means-tested care allowances, which are subject to local variations in terms of eligibility and access, are also available, and are also used primarily to purchase care from individual workers and family members, reinforcing gendered divisions of labour – or sometimes as a supplement to the family income and not paid out directly for care (Gori and Da Roit, 2007).

## France

France is usually viewed as a ‘familialist’ welfare state, with insurance-based health and social care payments couple with a strong ethos of family-based care (Martin and Le Bihan, 2007). In 1997 the ‘Prestation Specifique Dependance’ (PSD) was introduced, which was replaced in 2002 by the ‘Allocation Personnalisee a l’Autonomie’ (APA). This is a payment made directly to older people (which can be supplemented by other means-tested benefits) which enables them to directly purchase their own care, either from a professional or a relative (but not from a spouse). It is most commonly used to purchase services from formal, not-for-profit social care organisations, rather than directly employing individuals. It has been argued that this formalised element to the payment is an important part of France’s strategy of protecting the employment rights of care workers, as well as reinforcing gendered divisions of low paid formal and informal labour (Martin, 2000). The more formalised APA system has led to more employment protection for professional carers (Bresse, 2004), but it has not altered the gendered division of formal and informal care (Le Bihan and Martin, 2000).

## Austria

Austria has traditionally been viewed as a strong social-democratic state with an emphasis on a gendered division of labour and the ‘male breadwinner’ model of welfare provision, resulting in low levels of provision of formal care services (Bettio and Plantenga, 2004). In 1993 the long term care allowance (‘Pflegegeld’) system was introduced, a tax-financed non-means tested benefit paid directly to the disabled or older person (Oesterle et al, 2001). It is generally used to purchase care from either organisations, individuals, or to reimburse family members (Hammer and Oesterle, 2003). They have tended to be used to fund informal care or migrant/’grey’ labour market workers (often from neighbouring accession states), reinforcing traditions of lowpaid workers (often women) with very little employment protection whilst also reinforcing gendered divisions of labour within the familial sphere (Kreimer and Schiffbaenker 2005; Oesterle et al 2001).

## USA

A high degree of policy decentralisation has led to considerable federal-level variation in American social care provision. Since 1981 Medicaid programmes in the USA have been allowed a greater discretion in providing services and support for older and disabled people, leading to a proliferation of ‘consumer-choice’ programmes allowing people to directly hire their own care workers, particularly through schemes such as the Cash and Counseling Demonstration pilots in Arkansas, Florida and New Jersey (Mahoney et al, 2000). These schemes usually allow disabled and older people to directly employ workers with whom they have an ongoing relationship (through kinship or long-term care relationships), and have proved popular and successful, with the result that such ‘private market solutions’ are becoming part of mainstream social care policy (Keigher, 2007).

## Governance and personalised schemes

Two issues pertinent to the governance of personalised schemes emerge from an analysis of the six schemes under discussion. Firstly, there is the issue of national versus regional/local governance. Where schemes have been developed which allow for a degree of localised discretion in their implementation (eg UK, USA and, to a certain degree Italy) there is considerable scope for inequalities and inequities inherent in the system to have a gendered impact: (for example in the different types of employment protection available to workers, and the differential impact commodifying care can have on family relationships). Secondly, there is the issue of the governance of the schemes themselves: how they are operated, how users are made to account for the ways in which they spend money, and the level of policing and surveillance that gives the state over individual’s lives. Some schemes (eg UK, the Netherlands, France) are highly regulated, which, one the one hand, offers a degree of protection both to potentially vulnerable users and workers (and, particularly in the case of France, offers valuable employment protection to potentially exploited groups of care workers who are overwhelmingly women), but which, on the other hand also gives the state a Lifecourse and social divisions

In some respects, the introduction of a marketised, consumerist mechanism such as cash-for-care schemes into an area that was previously the domain of either the private, familial sphere or the public, statutory sphere is likely to create and exacerbate social divisions already apparent between different social groups. For example, the evidence on takeup of such schemes in the UK suggests that it is generally articulate, younger, well-educated disabled people who are disproportionately represented amongst those who chose to use them (Spandler, 2004). Take-up amongst older people, ethnic minorities and learning disabled adults remains comparatively low. These findings echo concerns across other areas of welfare provision that consumerist-driven reforms will tend to favour those best-placed to benefit from the market by exercising choice, voice and exit (6, 2003). In other words, the gulf between middle class and poorer disabled and older people is likely to be made greater by the introduction of cash-for-care schemes, as is the gulf between middle class and poorer carers, with the former being more able to exercise choice about the level and type of care work they undertake than the latter. As discussed above, cash-for-care schemes are also likely to lead to a widening gulf between carers working in regulated, professionalised and protected formal care employment and those working in private, unregulated employment, whether this be for a family member, direct employer or through the grey/black labour market. They are likely to further disenfranchise low-skilled, poorly paid women in comparison to their wealthier, better-educated sisters and to widen social division within and across genders.

Furthermore, the impact of personalised schemes on power relationships within the family sphere across the lifecourse and across generations remains unexplored, but there are reasons to voice concern about several aspects. Firstly, in low-income families where the use of the cash payment is fairly unregulated (for example in Italy) it is likely, based on what we already know about the distribution and use of money in low-income households, that gender differentials will emerge, with women more likely to use the payments to purchase care and men being more likely to use the payments as part of the general household income (Vogler and Pahl, 1993), leading to a reinforcement of gendered power differences within families. Secondly, where personalised schemes are used to route money to informal family carers this can have the effect of creating, or reinforcing dependency relationships both intergenerationally (for example between learning disabled adult children and parent/carers; or between daughters/daughters-in-law and parents) and intragenerationally (for example between spouses). Finally, the use of unregulated and unsupervised cash-for-care payments, both to pay family carers and directly employ unskilled care workers, has the result of commodifying intimate and sometimes unarticulated relationships and expectations, with the possibility of exploitation and abuse of vulnerable parties on both sides (Ungerson, 2004). Money, after all, in a highly consumer-oriented capitalist society, is power, and the person controlling the money in a care relationship is in a position to be able to exert power and influence over the person who does not: and any relationship involving the exertion of power and control over another person is open to the possibility of the abuse of that power and control. Again, better-educated, better-skilled and better-paid women are likely to be in a better position to avoid the potential abuse and exploitation suffered by lower-education, lower-skilled and lower-paid women in these situations, leading to greater inequalities between different groups of women (and sometimes men).

## Wellbeing and citizenship

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

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

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

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