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Personalisation: where do carers fit?

Wendy Mitchell, Jenni Brooks and Caroline Glendinning

Introduction

Adult social care in England prioritises personalisation for service users of the support they receive (Department of Health (DH), 2005; DH, 2007). Personalisation is founded on arguments about promoting choice, control and empowerment of individual service users. Individuals are conceptualised as active consumers of public services, able to exercise enhanced choice over how their needs should be met thus experiencing greater control over their own lives. However, these arguments appear to ignore the realities of older and disabled people's lives, which are often embedded in networks of support from close kin and friends.

Carers, especially family carers, play important supporting roles in the lives of many older and disabled people. Amongst developed welfare states England is unusual, as carers have secured rights to assessments of their needs. Carers can also receive services (or cash grants) as well as an income replacement benefit (Carers Allowance) to support their care-giving roles (Carers (Recognition and Services) Act, 1995; Carers (Equal Opportunities) Act, 2004; HM Government, 2008). However, the arguments and assumptions underpinning personalisation – that this will promote choice, control and empowerment – appear to overlook the perspectives of carers. Arksey and Glendinning (2007), in a review of research evidence on choice and care-giving, drew attention to the relative invisibility of carers in a series of policy statements on personalisation in adult social care and concluded that choice remains highly problematic for carers. Indeed, choice-making is a complex process as people do not make choices in social isolation; choice-making frequently involves weighing up options with others, often carers (Mitchell, 2012). However, policy and practice both reflect a widespread tendency to overlook the complex dynamics of care-giving relationships and conflate the needs and aspirations of carers and the people they support into a single (implicitly harmonious) unit. The interdependencies that often exist between disabled and older people and the relatives and friends who support them (Fine and Glendinning, 2005; Kröger, 2009) are also widely overlooked. Thus, the services and support provided to disabled or older people can have important benefits for carers too (Pickard, 2004). This impact can be both direct, where services for the disabled or older person, such as day or respite care, benefit carers by giving them a break; and indirect if, for example, carers derive satisfaction from knowing the person they support receives appropriate, good quality services.

Carers have received relatively little attention in the growing body of research on personalisation (Flynn, 2005; Moran *et al.*, 2012; Jones *et al.*, 2012). This marginalisation appears inconsistent with the public recognition and policy initiatives raising the profile of carers and their needs over the past 15 years (HM Government, 2008; Carers UK, 2010; DH, 2010). English policy and practice is further complicated by ongoing debates between the disability and carers' movements, particularly, questions about whether policies that support carers perpetuate disabled and older people's dependence (Shakespeare, 2000). This chapter explores the challenges and potential tensions adult social care faces arising from this dislocation between personalisation and carer policies and practice.

Background

As mentioned earlier, carers have legal rights. In 1995, carers gained entitlement to an assessment of their own needs (Carers (Recognition and Services) Act). This right was extended in 2000 (Disabled Children Act) to entitlement to a carer assessment even if the person they supported refused or was ineligible for local authority support. The 2004 Carers (Equal Opportunities) Act placed a statutory duty on local authorities to inform people (with regular and substantial care responsibilities) of their right to separate assessments, in which carers' aspirations for employment, learning and leisure should be considered. Since 2000, carers have also been able to receive cash direct payments in their own right. The revised Carers Strategy included a commitment that everyone using adult social care, including carers, should be able to receive a personal budget (PB) (HM Government, 2008). However, in 2009-10 only four per cent of carers reported having been assessed (Princes Royal Trust for Carers and Crossroads Care, 2010) and by March 2012 only 51,191 carers reported receipt of a PB.

Research into the impacts of direct payments has found carers faced additional responsibilities, such as, recruiting and employing paid care workers (Carers UK, 2008, Grootegoed *et al.*, 2010). However, these additional responsibilities could be offset by benefits for carers. For example, increasing independence for the disabled or older person could facilitate opportunities for carers to reduce their caring responsibilities. The national evaluation of the individual budget (IB) pilot projects in England compared carers of IB recipients with carers of people receiving conventional social care support (Glendinning *et al.*, 2008). Carers of IB recipients were often involved in managing the disabled or older person's IB and coordinating her/his support arrangements. These carers spent more time on care-related activities than carers of people using conventional services. Despite this, outcomes were better for carers of IB recipients, who also reported IB support planning processes as more holistic than traditional service user assessments. Hence, support planning could be an indicator of positive

outcomes for carers (Glendinning *et al.*, 2009; Moran *et al.*, 2012; Jones *et al.*, 2012) (see also Think Local Act Personal, 2013).

The evaluation of personal health budgets (PHBs) also found that carers providing assistance to individuals receiving PHBs were more likely to report better quality of life and perceived health compared to carers assisting an individual in the control group. Carers in the PHB group also generally reported less impact of care-giving on their health (Forder *et al.*, 2012). Furthermore, qualitative interviews with a small sample of carers of PHB holders found the potential for both direct and indirect benefits from PHBs for carers (Davidson *et al.*, 2012).

The IB evaluation also demonstrated how the introduction of personalisation occurred, at least initially, with little consideration of or coordination with local authority responsibilities towards carers. The IB evaluation found no explicit reference to how carers should be included in IBs and few local authority carer lead officers played an active role in the introduction of IBs (Moran *et al.*, 2012). Some localities had included only limited prompts or questions about carers' circumstances and needs in their new IB assessment processes. Variation was also apparent amongst the IB pilot sites in how help provided by family carers was treated in the disabled/older person's assessment and in calculating the level of the service user's IB. There were also inconsistencies in the roles practitioners expected carers to play in helping IB holders plan and manage their IB. These inconsistencies suggest that the failure to consider carers in the implementation of personal budgets is an important design flaw within personalisation.

Research commissioned by Carers UK has also identified considerable variability in how (self-) assessment forms for PBs consider carers' needs (Clements *et al.*, 2009). Local authorities have been reminded, as they implement personalisation, of their obligations to adhere to legislation and practice on supporting carers (SCIE, 2009; CSCI, 2008). The Law Commission (2008) has also recognised this disconnection between personalisation and carers' policies and has proposed that the legal framework for the provision of services to carers and its relationship to that of service users should be reviewed. The outcome of this review is reflected in the Care Bill 2013 which places carers' rights to public support on an equal footing to the rights of the person they support (Secretary of State for Health, 2013).

Official guidance (DH, 2010) recommends that service user assessments for personal budgets should routinely ask carers how much help they are willing and able to give. Separate assessments of carers' needs and those of service users should be coordinated, so that information from both assessments can be brought together to inform support planning. Indicative budgets for service users should take into account

the availability and level of support service users receive from family carers, but only *after* a carers' assessment has been conducted, so that the service user's PB reflects the carer's *actual* willingness and ability to provide support. Transparent and equitable approaches to allocating resources to support carers in their own right are recommended, with maximum choice and control for carers over how those resources are used. Support plans should address the needs of both service users and carers, with services and support to sustain the caring role (as far as the carer wishes) included in the PB of the service user. This guidance can be seen as an attempt to graft local authorities' statutory responsibilities to carers onto personalisation processes. However, it does not address some important underlying issues and leaves many questions unanswered. For example, whose needs should be taken into account? Who should resources be directed at? To what extent should carers and service users be treated as separate individual units? How best to optimise outcomes for both?

As increasing numbers of disabled and older people receive social care support in the form of PBs, it is important to examine how far carer and service user support processes are integrated or aligned, and how any tensions are acknowledged and managed in routine social care practice. This was the aim of the study reported later. For brevity, throughout this chapter the term 'personalisation processes' is used to refer to processes of assessment, determining resource allocation, planning support, and ongoing management and review of support arrangements.

The Study

The Carers and Personalisation study (2011-13) explored how far adult social care practice recognised and balanced the needs and wishes of service users and their carers.

The study involved:

- A survey of local policy/practice in two English regions (16 out of 29 councils completed the survey).
- In-depth investigation of practice in three of these 16 councils, through interviews with senior personalisation and carer lead managers (total six interviews) and nine focus groups (total 47 staff) involving qualified social workers and non-professional social care staff who conducted assessments from older people and learning disability teams.
- Individual interviews with carers and older and disabled people with cognitive or communication disabilities (14 carer and service user dyads).

The study focused on older and disabled people with cognitive or communication impairments, as their carers were likely to be heavily involved personalisation processes. Findings can also be found in Brooks *et al.* (submitted) and Mitchell *et al.* (submitted).

Carer Involvement in Service User Assessment

In this study, staff recognised the inappropriateness of focusing solely on service users' needs and aspirations and staff reported that carers of service users with cognitive or communication impairments were routinely involved in service user assessments. Carers and service users also emphasised the importance of carer involvement. Staff in learning disability teams felt they worked particularly closely with carers due to long-standing relationships with service users and their families. Carers themselves wanted to be involved, especially in social worker assessments so they could help service users understand questions and contribute detailed information.

'I think my role's just to make sure that, you know [son's name] sort of giving a reasonable rendition of what they're asking him ... I mean I'm there if he gets something slightly wrong or can't remember.'

(Carer of son with learning disabilities)

The majority of service users were happy about their carer's participation; few spoke to practitioners on their own, as they found talking to practitioners difficult.

'She [Mum] helped me with some questions ...'

(Service user with learning disabilities)

'... someone was there who understood me.'

(Older person service user)

Assessing Carers' Own Needs

The role assigned to carers during personalisation depends on practitioners' perceptions, for example, as Twigg and Atkin (1994) suggest, a support resource or a co-client with their own support needs. Focusing on carers as a resource, local authorities have duties, as part of service user assessments, to ask carers about the support they give and their willingness and ability to continue providing this (DH, 2010). In response to prompts on service user assessment forms, managers and staff confirmed that carers were routinely asked during service user assessments about their willingness and ability to continue caring and about any support they needed to do so. However, staff also reported using these prompts to ask carers about their own support needs, reflecting more of a co-client role. Some practitioners described these questions as 'mini' carer assessments nestled within service user assessments; others saw them

as part of a 'joint' assessment. However, other practitioners regarded carer questions within service user assessments as too narrow, overlooking the emotional impact of caring.

'I think a joint assessment you get the more practical things of what the carer does, I don't think you get so much about the emotional impact because I don't think they feel about to say that in front of their mother/father.'

(Care practitioner)

Service user assessment forms also had limited space to record carers' needs and this was an issue of concern for some practitioners. Assessment forms designed around tick boxes did not allow detailed recording of carers support needs.

'... the form pushes you more into thinking about how much the carer is doing rather than the impact it's having on the carer. And I think if you haven't always considered the carer, I don't think that form necessarily says you're to do that, not really.'

(Social worker)

Most carers recalled being asked whether they were willing and able to continue providing support, but could not remember being asked in detail about their own support needs, that is, as a co-client during service user assessments.

Reflecting the view of carers as co-clients (Twigg and Atkin, 1994), local authorities also have duties to inform carers of their right to a separate assessment of their own needs. Managers and staff reported that they informed carers of their rights to separate assessments but beyond this there was little consistency and separate assessments of carers support needs were far less common. Some practitioners were aware of the benefits of separate assessments for carers, acknowledging that they provided an opportunity for carers to discuss their own needs and the impact of caring in private. Some separate carer assessments were reported, but the timing of these varied and they could be conducted some time after the service user's assessment. There was also little agreement between managers and practitioners over whether the same practitioner should do both service user and carer assessments. Managers and staff reported that not all carers wanted a separate assessment, particularly if they had already contributed to the service user's assessment.

Having a separate assessment was recalled by some carers but not all could remember being offered one and others had declined the offer of a separate assessment because its relevance and purpose was unclear to them. Those carers who had had separate

assessments valued opportunities to discuss the emotional aspects of caring with practitioners

‘She [social worker] came to the house, she had a nice cup of tea and she did have a bit of a checklist but was more a really good informal chat ... and it was nice cos it was actually how that affects you.’

(Carer of son with learning disabilities)

However, such opportunities were reported as rare.

Carers and Resource Allocation

Practitioners reported that service users’ PBs were reduced to reflect help given by carers but there was little consistency or transparency in exactly how this was implemented. Most importantly, even when separate carer assessments were conducted, these were rarely linked to service user assessments so it was unclear how carers’ own views about providing care, its impact and their own support needs would inform the level of the service user’s PB.

Furthermore, practitioners’ awareness of resources to support carers themselves was limited. Support for carers tended to be in the form of short breaks and these were commonly included within service users’ PBs.

‘... almost always a good package of care and a good assessment of the service user does everything that the carer wants.’

(Social worker)

Very few carers were reported to receive PBs of their own, although occasional one-off payments to carers (for example, for a washing machine) were reported by practitioners. These were usually funded and delivered separately, directly to carers themselves. How to allocate support to carers was a topic of ongoing debate for managers, as they had mixed views about developing separate resource allocation systems for carers. This fragmentation of resources between service user and carer budgets proved difficult for carers to understand.

Support Planning

Practice guidance recommends that support planning should be led by service users, with carer involvement, and conducted *after* calculating an indicative service user PB (DH, 2010). Carer involvement in service user support planning is important because, as the IB evaluation (Glendinning *et al.*, 2009) concluded, this could be an indicator of positive outcomes for carers. However, practitioners in this study reported that it was

often common practice for support planning discussions to take place at the same time as service user assessments. Hence, there appeared little opportunity for any separate carer assessments to influence the level of service users' PBs or support plans. It was also unclear, given the infrequency of separate carer assessments, how any information from these separate assessments about changes in carer circumstances would be reflected in revisions to service user budgets and support plans. Despite these practice inconsistencies, staff still reported that carers participated in service user support planning because of their routine involvement in service user assessments and the opportunities this gave carers to discuss service users' support needs.

Reflecting the reported low frequency of separate carer assessments, it comes as little surprise that there was an absence of evidence of carers' having their own support plans that included employment, training or leisure activities. Carers themselves had low expectations of receiving such support.

Issues and Implications

Findings from the study demonstrate the constraints and pressures that routine social care practice faces in trying to balance and take account of the needs and wishes of carers during service user assessments. Taken together, routine practice generally did not:

- Link information from service user and carer assessments.
- Ensure information from separate carer assessments contributed to service user support planning.
- Ensure separate carer assessments were conducted before service user PB levels were adjusted to take account of help from carers.

These issues reflect the everyday practice problems practitioners' face. These are due to structural design problems within a system of personalisation that fails to adequately recognise the rights of carers. Moreover, the inclusion of resources for carers' short breaks within the PB of the person they support does not appear to optimise carers' opportunities for choice and control, because these resources are under the control of the service user. This does not give carers equal rights on a par to those they cared for. However, recognising that the lives of carers (especially family carers) and those they support are often interwoven and inter-dependent can mean that good support arrangements for service users may go some way to meeting the needs of carers.

How to overcome tensions created by the separation of legislation and practice guidance regarding service users and carers also remains unresolved. It is not clear how far this separation will be remedied by the Care Bill in England (Secretary of State

for Health, 2013) which aims to clarify, for example, responsibilities and to give carers similar rights and entitlements to service users. By strengthening carers' rights, the Bill may simply intensify the challenges frontline practitioners face. Yet, at the same time, the interdependence and personal preferences of older and disabled people and their carers cannot be overlooked. It is thus important to recognise this variability in relationships between service users' and carers and how this may affect how carers prefer to be assessed and have their support needs met. Some carers, for example spouse carers, may prefer to be treated as a single 'whole family' unit, whereas others, such as an adult child and his/her parent may want to be assessed and have their support needs met independently of each other. Standardised practice may not always be the most appropriate way to meet carer and service user individual needs. Although clearly no easy answers, working towards better coordinated service user and carer assessments and support plans continues to be important.

Despite this, it also remains important to recognise that it may not be possible to resolve the tensions inherent in the policies and practice of personalisation when these are based on wider assumptions of individualised consumerism and overlook the realities (as identified by Arksey and Glendinning, 2007, and Mitchell, 2012) of the diverse social contexts within which people receive (and give) care and make choices about that care.

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