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Personalisation, Personal Budgets and Family Carers. Whose Assessment? Whose Budget?

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Keywords

Carers, personalisation, personal budgets, adult care, assessment, direct payments, social work

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Abstract

Summary

The policy of personalisation in English adult social care prioritises choice and control by service users over the support they receive. Carers also have rights to assessments and support, but these rights have developed separately, so interdependencies between carers and service users may be overlooked. Moreover it may be difficult to reconcile these divergent policies in routine practice.

This paper reports findings from a study examining the roles played by carers in England in the processes of assessment, support planning and management of personal budgets for disabled and older people. The study was conducted between January 2011 and February 2013. It involved a survey of sixteen adult social care departments across two English regions, and interviews with personalisation and carers lead officers in three local authorities. The Framework approach was used to manage the data, and analysis was done thematically.

Findings

Practice was fragmented and inconsistent. Carers were reported to be involved in service users' assessments, and also asked about their willingness and ability to continue caring, but not necessarily about their own needs. Separate carers' assessments were reported to be usually offered, but take-up was low and lead officers' opinions about their value varied. Any help given by carers reduced the level of service users' personal budgets, but there was no evidence that carers' own needs (as identified in carers' assessments) were taken into account.

Applications

Greater clarity and consistency is needed, especially the linking of service users' and carers' assessments and finding appropriate ways to meet both. These changes will become increasingly urgent with the implementation of the 2014 Care Act.

Keywords

Carers, adult care, personalisation, direct payments, personal budgets, assessment, social work

Introduction

Over the past decade, policies and practices to promote personalisation in English adult social care have developed somewhat separately from those aimed at supporting family carers. Personalisation prioritises the aspirations and preferences of service users. However, England is unusual among many developed welfare states in that family carers have also secured rights to separate assessments of their needs. Currently, carers can receive services or cash grants, as well as an income replacement benefit (Carers Allowance) to support them in their care giving roles.

This separate development of personalised social care and carers' rights appears to overlook the substantial interdependencies that often exist between disabled and older people and the relatives and friends supporting them (Fine & Glendinning, 2005; Kröger, 2009).

This paper explores the official accounts of current practice, as reported by local authority personalisation and carers' lead officers, about how these tensions are managed in social care practice.

Personalisation in context

Personalisation is contested. Whilst the principle of personalising care is difficult to argue against, many have argued that its implementation, primarily through personal

budgets, has not achieved what it set out to (Beresford, 2012, Slasberg, Beresford & Schofield, 2013). Questions have been raised about the appropriateness of personal budgets to deliver personalised care to all groups (Glendinning, 2008), particularly older people (Lloyd, 2010, Moran et al 2012) and those with complex needs (Henwood and Hudson, 2009). Not all groups have access to either the social capital or the support necessary to make best use of the apparent opportunities afforded by personal budgets (Ferguson, 2007), and such opportunities may be severely limited by the lack of a developed market for care provision (Kremer, 2006, Baxter, Wilberforce & Glendinning, 2011, Wilberforce, Baxter & Glendinning, 2012).

However, Glasby (2014, p260-1) suggests that hostility to these reforms of social care may stem from a misunderstanding of key concepts, and notes that some critics compare potential negative impacts of personal budgets with 'an overly optimistic view of the current system' which does not take into account present inequalities.

Current practice in delivering personalised care

Current practice in delivering personalised social care in England usually involves an assessment of needs, in which the disabled or older person is actively encouraged to participate. A resource allocation system (RAS) is used to convert the assessment into a cash value or 'indicative personal budget' – a guide to the level of resources available to fund the required support. This should take into account any help given by family

carers. The disabled or older person then plans how to use these resources. The budget is finalised and the support plan approved by the local authority after scrutiny for risks.

The personal budget can be held as a direct payment by the disabled or older person or a third party (such as a carer or support organisation), or used by the local authority to purchase council-commissioned services on the individual's behalf (often called a managed personal budget). In 2011-12, 432,349 adults were estimated to be receiving personal budgets. This was over half of all adults receiving non-residential social care support, and an increase of 38 per cent over the previous year (Association of Directors of Adult Social Services (ADASS), 2012).

Incorporating carers' roles and needs Implications of personalisation policy for family carers are ambiguous. There may be an overreliance on family carers, who may lack support to either make choices for themselves or ensure choices for the people they support (Beresford, 2012). Tensions can also arise when the needs of carers are not the same as those of the person they support, particularly if the carer is managing a direct payment on behalf of that person (Laybourne et al., 2014).

Limited research of the impact of direct payments on carers of disabled and older people has found that carers can face additional responsibilities, including new responsibilities for recruiting and employing paid care workers (Rosenthal, Martin-Matthews & Keefe, 2007; Carers UK, 2008; Grootegoed, Knijn & da Roit, 2010, Larkin, 2014). The

national evaluation of the English individual budget (IB) pilot projects included a study of the impact of IBs on carers which found that carers were often involved in managing the service user's IB and providing ongoing coordination of her/his support arrangements. However, despite these increased responsibilities there were indications that carers' involvement in helping the disabled or older person plan how to use their IB was associated with positive carer outcomes, such as improvements in health and well-being (Glendinning et al., 2009; Moran et al., 2012; Jones et al., 2012), and could also enhance the relationship between the carer and service user (Larkin, 2014).

The 2004 Carers (Equal Opportunities) Act places a statutory duty on local authorities to inform people with regular and substantial care responsibilities of their right to a separate assessment of their own needs, including their aspirations relating to education, training, employment and leisure. This right to assessment is independent of the circumstances of the person they support, and carers can request an assessment even if the older or disabled person refuses one themselves or is ineligible for local authority support. Depending on the outcome of the assessment, carers may receive services or a one-off cash payment, usually to fund a break from care-giving. However, in 2009-10 only four per cent of carers reported having been assessed. Twelve percent of these reported getting a break (in their own home or away from home), and 16 per cent reported receiving a cash payment (Princess Royal Trust for Carers and Crossroads

Care, 2011). One-off cash payments are by far the most common form of support given to carers by local authorities (Carers Trust, 2012, Mitchell and Glendinning, 2014).

At the time this study was carried out, Department of Health (DH, 2010) guidance recommended that no assumptions should be made by practitioners about carers' willingness to continue providing support. Instead, carers should routinely be asked during service user assessments about the help they are willing and able to provide, and about any support they need to continue doing so. However, Clements, Bangs and Holzhausen (2009) identified considerable variability and shortcomings in how (self-) assessment forms for personal budgets consider carers' needs. In addition, Series and Clements (2013) found that some local authority processes/systems considerably reduced allocations for people living with family members, with no consideration of whether they were willing or able to provide support.

Both the Commission for Social Care Inspection (CSCI, 2008) and the Social Care Institute for Excellence (SCIE, 2009) have reminded local authorities of their obligations to carers as they implement personal budgets for service users. DH guidance also recommends that separate assessments of carers' needs are offered, as required by statute. All three sources argue that carer and service user assessments should be coordinated, so that information from both assessments can be brought together to inform support planning. Personal budgets should take into account the availability of support from family carers, *but only after a carer assessment has been conducted*

(authors' emphasis) so the budget takes full account of carers' actual willingness and ability to provide support. However, Seddon and Robinson's (2014) analysis of carer research over 20 years suggests that practitioners can be ambivalent towards carer assessments, feeling that they may not capture the complexities of the caring relationship and carers' needs, and may raise carers' expectations when budget cuts mean support may not be funded. This can mean that separate carers' assessments may not be carried out at all.

DH guidance also recommended a transparent and equitable system for allocating resources to carers in their own right, with maximum choice and control for carers over how these resources are used. Support plans should address the needs of both the disabled or older person and the carer, and services and support to sustain the caring role should be included in the personal budget and support plan of the disabled or older person. While this latter recommendation may ensure an integrated approach, it may not necessarily be appropriate where disabled people and carers live apart or wish to maintain a degree of financial independence from each other.

As increasing numbers of disabled and older people receive social care support in the form of personal budgets, it is important to examine how far these different processes are integrated, and how any tensions are acknowledged and managed in routine social care practice. This was the aim of the study reported here.

The next section describes the study design and methods. Following this, findings are presented from a survey of local authorities and interviews with a small sub-sample of personalisation and carer lead officers. Finally, the practice implications of the findings are discussed.

For brevity, throughout this paper the term ‘personalisation processes’ is used to refer to the process of assessment, determining resource allocation, planning support and ongoing management and review of support arrangements.

Method

Study design

The study, conducted between January 2011 and February 2013, aimed to:

- Describe social care practice in relation to carers’ roles in personalisation processes.
- Examine how far these processes appear to recognise and balance the needs and wishes of service users and their carers.
- Explore what roles service users and carers want carers to play in personalisation processes.

We focused particularly on service users with cognitive or communication impairments, as they are likely to rely heavily on carers to communicate their needs and preferences, both during assessment and support planning and subsequently in the delivery of

personalised support. We were also interested in differences in practice between older people's and learning disability teams. The research was granted ethical approval from the Social Care Research Ethics Committee, and all participants provided written consent.

The study had four stages:

- A survey of English local authorities' formal policies
- In a sub-sample of these:
    - Face-to-face interviews with local authority officers with lead responsibility for personalisation and carers' issues;
    - Focus groups with frontline practitioners from older people's and learning disability teams;
    - Interviews with older people and younger learning disabled adults with cognitive or communication impairments and their carers.

This paper reports detailed findings from the first two stages – the survey of local authorities and interviews with lead officers. Findings from focus groups with practitioners, and from service user and carer interviews, are reported in detail elsewhere (Mitchell, Brooks & Glendinning, 2014, Glendinning, Mitchell and Brooks, 2014). A synthesis of the findings from the entire study is also available (Mitchell, Brooks & Glendinning, 2013).

Survey

The survey investigated formal local authority policies relating to carers' roles in personalisation, particularly for service users with communication or cognitive impairments. Of specific interest were the links (or lack of them) between these processes and practices relating to carers' assessments and support.

We developed the survey in consultation with a regional group of carers' lead officers, who advised on aspects of design and administration. Both this group and the ADASS carers' lead were consulted about the survey questions, and the final survey was piloted with other research staff to resolve technological glitches.

The aim of the survey was to obtain an overview of current English local authority policies and practices relating to personalisation and carers. It covered:

- Formal policy and practice guidance on the role of carers in service users' personalisation processes.
- The links (or not) between these processes and local authority practice for carers' assessments and support.
- Lead officers' own knowledge and understanding of how this policy and guidance was implemented, and any differences in implementation between different groups of service users (especially those with CCIs) and their carers.

Respondents were also asked to forward any relevant policy or practice guidance produced by their authority.

We sent the survey to all local authorities in two English regions. One region contained 14 local authorities, the other 15. Only two regions were surveyed because of the extensive follow-up work involved in securing an acceptable response rate. The regions were chosen following consultation with ADASS and included unitary, metropolitan and two tier local authorities, and diverse urban, rural and ethnic populations. There was no reason to believe the two regions were atypical.

The survey was directed to senior officers with lead responsibility for carers' support in each authority. It was distributed using online Survey Monkey software, and officers could complete it in one sitting or on multiple occasions. It was short and contained a mix of open and closed questions. Respondents were also asked to send relevant policy and practice guidance. Two weeks were given for completion - after this at least one written reminder and numerous telephone reminders were sent. Sixteen authorities completed the survey (twelve of these also sent additional documents), and four declined to participate. In the remaining nine authorities the researchers were unable to contact the relevant officer or reminders were ignored.

Interviews with personalisation and carers leads

Three local authorities were selected from those who completed the survey and who indicated that they were willing to participate in the subsequent stages of the study. Selection was also restricted to authorities indicating in the survey that they acknowledged, and had processes to address, both carers' own needs and carers' roles in personalisation processes for service users. The three authorities included unitary and two tier authorities, rural and urban areas, and those with high and low black and minority ethnic populations. Research governance approvals were obtained from each local authority.

Separate face-to-face interviews were conducted with the lead officer responsible for personalisation and the carers lead officer in each authority. The interview topic guide was informed by responses to the survey. It covered:

- Guidance, training and frontline practice in relation to personalisation processes.
- The roles carers were expected to play in these processes.
- Links between service user and carer assessments.
- How carers' assessments and support arrangements had been considered in the development of personalisation processes for disabled and older people.

The topic guide was piloted with carers and personalisation lead officers in another local authority not taking part in this stage of the study. Interviews lasted 60 to 90 minutes and were audio recorded and transcribed.

Data analysis

The Framework approach (Ritchie, Spencer & O'Connor, 2007) was used to manage both the survey and interview data. This enabled the summary and comparison of data and identification of similar themes across and between different groups of participants. It also enabled researchers to trace data back to individual respondents during the analysis.

For both the survey and the interviews, a coding framework was developed by one researcher then piloted by both. One researcher led on charting sections of the data, and samples of coded data were cross-checked by the other researcher to ensure consistency and aid validity.

Survey responses were entered into a framework together with relevant information from additional documents sent by local authorities. Interviews were transcribed, then summaries and selected quotations were entered into a separate framework. Researchers produced a separate 'central summary chart' containing data from both the survey and

interviews to allow comparison between officers in each local authority, and between all carers lead officers and all personalisation lead officers. This enabled the researchers to develop a more complete understanding of the processes in each local authority.

Findings

Data from the survey and the interviews with personalisation and carers lead officers in the three authorities are presented together. However, because the survey was deliberately kept short, data on some issues is only available from the lead officers' interviews.

The roles of carers in personalisation processes varied considerably between local authorities, with no observable differences between the two regions in the survey. Where local authorities did have written practice guidance, this mainly covered carers' involvement in assessments of disabled or older people, and carers' own assessments – activities in which local authorities have clear statutory duties. There was very little formal guidance, and no evidence of training for practitioners, on carers' roles in support planning, the ongoing management of personal budgets, or reviews of either service users' or carers' support needs.

Assessments

Both sets of lead officers in the interview sites considered holistic family assessments to be preferable, recognising that it could be difficult to separate carers' and service users' needs. These were described as 'joint assessments' and were reported to be the norm.

However, both survey and interview respondents explained that this practice actually involved documentation and processes that were primarily designed to assess service users' needs. Reflecting DH (2010, p.20) guidance, this documentation contained questions about help given by family carers, whether carers were willing and able to continue providing that help and any support carers themselves needed to continue doing this. However, only one example of service user documentation supplied to the researchers was found to include any additional questions about carers' own needs (beyond a prompt to offer a carers' assessment).

Lead officers recognised that this practice did not constitute a carers' assessment, and some interviewees acknowledged the importance of considering carers' needs separately, whether through a formal assessment or informal conversation:

> *'I actually think the ability to assess people together is a good thing, but I think that a component part of that needs to be having conversations with*

the individual and with the carer in terms of understanding what the impact is for themselves.'

(Carers Lead interview, Site 3)

Both the survey and interviews reported that separate assessments were routinely offered to carers, usually at the end of the service user's assessment. However, there were indications that carers could be reluctant to take up the offer because of the amount of time they had already spent in the service user's assessment:

'Carers focus all their attention and energy on getting the most and best service for their family member. It is only later, often much later, that carers return to the question of "Am I a carer? Is there something more that can be done for me?"'

(Survey, Region 1, LA 8)

Mixed opinions were expressed in both the survey and interviews about the need for, and value of, separate carers' assessments. These were considered valuable by some respondents because they provided an opportunity to meet carers' needs and generally raise the profile of carers in frontline practice. However, concerns were raised by a small minority of lead officers that, without a 'joint' assessment (i.e. involving the service user as well), some needs could be missed, or provision duplicated.

When separate carers' assessments were conducted, there was no consensus on whether they were, or should be, done by the same practitioner who conducted the service user's assessment. If the same practitioner conducted both assessments, it was considered easier to identify inconsistencies or differences of opinion between service users and carers about the support the carer provided and the extent to which they were willing and able to continue doing so. However, other respondents thought it was not always appropriate to have the same practitioner conduct both assessments, particularly if there was conflict in the family.

DH (2010) guidance recommends that when separate service user and carer assessments are conducted, information from both should be brought together and coordinated, whether they are conducted by the same worker or not. Opinion and practice varied, but there appeared to be no guidance or consistent practice around bringing information from service user and carer assessments together.

Resource allocation

Lead officer interviewees confirmed that in their authorities support provided by carers was taken into account and reduced the level of the disabled or older person's personal budget. However, there were differences in exactly how this reduction was calculated. In two authorities, service users were allocated points according to their level of need across the domains covered by the assessment (such as personal care and mobility).

Points were then deducted from the total to reflect the amount of help provided by the carer. Support needed by carers themselves as a result of their care responsibilities was not included in the service user's resource allocation.

The third authority was piloting a link between service users' and carers' assessments, so they informed each other:

> *'We have adjusted our RAS [resource allocation system] methodology in the customer's RAS to include points and therefore budget for breaks services (residential respite, sitting services and day care) [for the carer]. We have done this by changing the carer impact question at the end of the cared-for person's assessment to ensure that when a carer says they are meeting particular needs, and the budget is reduced throughout the assessment, some budget is re-inflated at the end of the assessment to reflect the degree to which the carer needs support to continue providing this support.'*
> (Survey, Region 1, LA12)

The re-inflated figure was displayed separately and intended to be used to purchase short breaks. In the subsequent interview, the personalisation lead for this authority clarified that funding for breaks was included in the service user's budget rather than being awarded to the carer. Support provided directly to carers for other needs (for example, funding for a training course) was provided separately following a carers'

assessment and application of a separate carers' RAS. The personalisation lead officer reported that in future all such support for carers would be delivered as a direct payment. Both lead officer interviewees in this authority thought this approach helped clarify what support was intended for the service user and what for the carer (although the total support for the carer was split between their own and service user's allocated resources).

Methods for deciding how to allocate support to carers were topics of ongoing debate in the other two authorities. However, interviewees in both considered it unlikely that they would develop a separate resource allocation system to convert carers' own needs into a specific cash value, as this would be too complicated. This view was also reflected in some survey authorities.

Carers' roles in support planning

Despite evidence from previous research (Glendinning et al., 2009) there appeared to be little guidance in any survey authority about carers' involvement in service user support planning. Documentation supplied to the researchers was brief, general, and did not go into detail about carers' roles. However, two of the three interview authorities were in the process of developing more detailed guidance.

There was general agreement among lead officer interviewees that, although support planning should focus primarily on the service user, in practice carers were usually involved, particularly when service users had cognitive or communication impairments and were unable to express themselves even with alternative communication methods.

> *'You certainly try to get [the views of the person with a learning disability] if you can, but it'll be the carer who'll probably tell you most of the history and experience.'*
>
> (Personalisation Lead interview, Site 1)

Indeed, it was considered highly desirable that carers should be involved in support planning, so that their needs were also taken into account in planning the service user's support and assumptions avoided about the level or duration of the help they were willing to give. Such assumptions could risk breakdown of the support plan. Hence, lead officers reported that carers were encouraged to consider their own needs as part of the service user's support planning process. These include needs for breaks, but also for social activities, employment or education, even though these may not have been formally identified through a separate carer assessment.

However, it was also recognised that service users and carers could disagree, or that carers might not always act in the best interests of the service user. It was therefore important to involve other people in support planning as well:

'I would want to see advocacy and I would want to see an independent perspective for that customer being built in, even if the carer knew everything about that person.'

(Carers Lead interview, Site 2)

Moreover, involving carers in support planning could bring to the fore difficult relationships and differing expectations, for example, when a learning disabled adult wanted to live independently, against their parent's wishes. Here, the support planning process needed to include negotiation with carers to produce satisfactory outcomes for both service users and carers.

Ongoing management of personal budgets

Where a personal budget is taken as a cash direct payment, carers may be involved in managing the budget, particularly if the service user has cognitive or communication impairments and cannot manage the budget themselves. DH (2010) guidance warns against assuming carers will be willing and able to take on managing a personal budget. None of the documentation supplied to the research team by survey authorities reflected this warning specifically.

Nevertheless, lead officer interviewees thought it likely that carers frequently took on managing service users' direct payments, particularly where the latter had learning disabilities. These carers were usually parents who already managed the service user's activities and money. Interviewees noted assumptions on the part of both practitioners and carers themselves that these roles would continue:

> *'What tends to happen is because they [the carer] want to carry on with a voice in terms of how that person is cared for… they're almost accepting it before the question's asked. They're already talking about what they're going to do with this budget... there's almost a presumption, yes, that they'll manage it rather than them not.'*
> (Personalisation Lead interview, Site 2)

Separate support for carers

In interviews, carers lead officers were asked about the help carers could receive. All three officers noted that elements of the service user's budget, particularly short breaks, could also benefit carers, and that appropriate support for the service user also had indirect benefits for carers. Additionally, lead officers in all three authorities reported that carers could be offered sitting services, short breaks and a carers' emergency card. In one authority referrals to the job centre were also mentioned, if carers wanted to obtain work.

All three authorities also offered one-off direct payments specifically for carers:

> *'It's a direct payment... And it's not about provision of a sitting service or a carer's break, it's about everything that would support the carer to have a life of their own.'*
>
> (Carers Lead interview, Site 1)

Such payments could be used for items such as gym membership, help with gardening or trips out. However, views about the purpose of separate carer direct payments varied, both within and between authorities. In one authority, these were intended both to benefit carers and help them continue in their caring role:

> *'We try to make it things where it's kind of a double whammy, so it supports the carer's sustainability and the impact, but also supports health and well-being.'*
>
> (Carers Lead interview, Site 1)

In this authority the carer lead officer was positive about carer direct payments saying that, because they could be used flexibly, carers would be more likely to take them up and also make best use of the money available. This was echoed by the carers lead in Site 3:

'It creates greater flexibility with a limited pot of money and they can access a greater range of services now, at a time and in a place that's more suitable to them. So that's why we've gone down that route.'

(Carers Lead interview, Site 3)

However, the carers lead in site 2 was more cautious about separate direct payments for carers:

'Personally I don't have a huge amount of faith in that kind of scheme, I don't believe it achieves massive outcomes for people... However, if we had a specific service that could be offered to somebody through a direct payment then we would do that. But on the whole it's the customer [service user] who receives the service.'

(Carers Lead interview, Site 2)

Reviews and changing circumstances

Local authorities may conduct both planned and unplanned reviews of service users' needs. Unplanned reviews can occur at any time if there is a significant change in the service user's circumstances. Survey responses indicated that, at least in some authorities, planned reviews were conducted around six weeks after the start of new personal budget-funded support arrangements, and annually after this. However, the

conduct of these reviews and how far they routinely included reviews of carers' needs and circumstances, varied between authorities. There was also confusion about some aspects of the review process.

Lead officer interviewees all thought that reviews of service users' support arrangements should include a review of carers' needs too. They believed this generally happened, particularly if carers had been involved in the service user's initial assessment and that assessment had generated information about help needed by the carer to continue providing care. However, interviewees pointed out that a separate carers' assessment should still be offered as well. If the carer had declined this offer at the time of the service user's original assessment, but subsequently asked for one (perhaps in order to access a short breaks service), then the service user's and carer's needs would be reviewed jointly at the time of the service user's assessment, providing there was no conflict in the family.

All three interview authorities had separate teams that conducted reviews, so reviews were generally undertaken by different practitioners from those who conducted initial assessments. An exception was reported in some learning disability teams, where service users were more likely to retain an allocated worker who was responsible for regular reviews and would also conduct any separate review of a carer's needs.

Lead officer interviewees acknowledged that carers' support needs could change and prompt the need for review at different times from the service user's planned review. However, lead offers were not clear of the process for conducting these unplanned reviews of carer needs.

Involving carers in the implementation of personal budgets

The survey revealed considerable variation in how far local authorities had integrated their responsibilities towards carers into the implementation of personal budgets. In some authorities, carers lead officers had been heavily involved from the outset. In others, carers' issues were only just beginning to be addressed several years after the introduction of personal budgets.

Consultation with carers or carer organisations also varied between survey authorities, from involving just one carer in the design of service user assessment documents, to regular consultation with a group of carers and service users about assessment and support planning tools. Indeed, some authorities viewed consultation as an ongoing process and had also involved carers in subsequent revisions to personal budget documentation. However, this involvement was restricted primarily to the design of assessment or support planning documentation; only one survey authority reported carer involvement in both.

The interviews revealed variations in opinions and practice about joint working between personalisation and carers leads. In two authorities, carers leads thought they had been appropriately involved. In one, this was attributed to a tradition of joint working. In the other, the carers lead also had a strategic management role within the authority, embedding carers' perspectives in many aspects of social care organisation and practice. In the third authority, implementing personal budgets had, until recently, taken place without consideration of carers' roles.

The involvement of carers' organisations also varied between the three interview authorities. In two, both personalisation and carers leads thought there had been insufficient involvement of carers' groups in the development of personalisation processes and practice, particularly in the early stages. In the third, both lead officers thought the involvement of carers' organisations had been timely and helpful:

> *'They, I think, have been more accepting of the changes that have been made in [local authority] because they've been involved.'*
>
> (Personalisation Lead interview, Site 2)

Discussion

Strengths and limitations

The survey covered only two English regions. However, given the substantial diversity of responses both within and between them, there is no reason to believe the regions themselves (or the authorities within them) were unrepresentative. There may be bias arising from the relatively low response rate to the survey – for example, it may be that survey respondents reported better developed practice than in non-responding authorities. Again, however, the diversity of responses suggests that responding authorities did not apparently share common features that made them significantly different from non-respondents. Furthermore, the survey captured processes and practices at a specific point in time, three years after the announcement of the roll-out of personal budgets to all adult social care service users. Further changes may have since taken place within what are fast-moving policy and practice environments.

The survey was completed in almost all cases by the carers lead officer, rather than the personalisation lead officer. There is therefore a risk that more detailed knowledge of front-line practice may have been missed, although the broad picture from the survey was not called into question in the subsequent interviews with the three personalisation lead officers. Both survey and interviews reported the 'official' views of senior officers, who may be unfamiliar with current frontline practice.

The three local authorities selected for the more in-depth stages of the study (of which the interviews with lead officers are reported here) were theoretically sampled. They were chosen because there were indications in the survey that they had policies or practices in place to address both carers' own needs, and the roles of carers in personalisation processes for service users. While the number of local authorities followed in depth is limited (and only six lead officers were interviewed in total), the authorities had different structural features and characteristics, and as with the survey, the range of policies, processes, practice and opinions both within and between authorities, strongly suggests these authorities were unlikely to share any potentially atypical characteristics.

A final limitation may arise from the focus of the study on practice with older and learning disabled people with cognitive or communication impairments. This focus was of interest because of the enhanced roles that their carers were likely to play; however, practice may differ with other groups.

Discussion

The findings reported here reflect the challenges faced by local authorities in reconciling divergent policy aims and priorities. On the one hand, personalisation represents a shift of power from professionals to service users, with a clear emphasis on service users having choice and control over their support arrangements. On the other

hand, since 1996 carers have achieved increasingly clear rights to assessments of their own needs. Moreover, the Care Act 2014 introduces new rights to both assessments and support for carers. These two parallel developments create points of tension which this study has highlighted.

This study confirms earlier research (Glendinning et al., 2009), that neither carer lead officers nor carer representatives were consistently involved in the development of personal budget processes. In some authorities, their absence may have exacerbated the practice challenges now apparent. DH guidance (2010) attempted to resolve these challenges; however the study found widespread divergence from this guidance. In particular, service user assessments that simply asked about carers' willingness and ability to continue caring were apparently widely regarded as 'joint' assessments. Although separate carer assessments were routinely offered, take-up was low and there was little evidence that any separate carer assessments were co-ordinated with service user assessments.

It was not the intention of this study to ascertain how far local authorities were, or were not, complying with DH practice guidance. However, the study has revealed a number of areas in which current guidance appears at odds with what was reported to be routine practice. The 2014 Care Act introduces a new, lower threshold for carers' assessments; carers will no longer need to request an assessment and a carer assessment will be required simply if there is an appearance of need. It will be important that the current

apparent tensions and discrepancies in practice are addressed and not taken forward following implementation of the 2014 Act.

Influence of carer support on service user budgets

There was little evidence that separate carer assessments were conducted before reductions in service users' personal budgets were calculated to take account of help provided by the carer. This is in contrast to current DH guidance (2010, p.20) which advises that service user and carer assessments 'should normally take place concurrently so that the carer's assessment can inform the community care assessment'. The 2014 Care Act stipulates that support provided by carers should be ignored when determining what eligible needs the service user has. Instead this should be taken into account during the subsequent development of the support plan, assessment and support planning being distinct stages. As Clements (2014, p13) notes, in principle assessment is currently distinct from support planning, but the 2014 Act makes this absolutely explicit. Treating assessment as a distinct stage will allow *both* service user and carer needs to be established *before* plans are put in place regarding how to meet those respective needs.

Assessing carers' needs

This study found a failure to routinely conduct separate carer assessments, particularly when service user assessments contained questions about the carer's willingness and ability to continue caring. These limited questions are not compatible with the

aspirations of the 2004 Carers (Equal Opportunities) Act. Lead officers reported that carers often did not feel the need for further, separate assessments of their own needs – however this is at odds with what carers themselves said when interviewed for this study (Glendinning et al., 2014), many of whom had accepted a separate assessment when offered.

The Care Act 2014 introduces changes to local authorities' duty to assess carers' needs. Carers will no longer be required to be providing regular and substantial care, nor to request an assessment - rather a carer assessment should be triggered by an appearance of need. The Act also emphasises a 'whole family' approach to care (Clements, 2014), and allows local authorities to combine service user and carer assessments where both parties agree (para 6.74). However, carer assessments (even where combined with service user assessments) must still ascertain whether the carer is willing and able to provide care; the impact of caring on carer wellbeing; and desired carer outcomes, including carers' aspirations for education, training and leisure activities – something this study found was often not currently done.

Integrating service user and carer support planning

This study found that, in accordance with DH (2010) guidance, carers were routinely involved in service user support planning. However, even when separate carer assessments were conducted, there was no evidence that they were co-ordinated with

service users' assessments or used to inform support plans or budget levels. This lack of coordination also reduced opportunities to develop integrated support plans that addressed carers' own needs as well as those of service users.

Practice in conducting and coordinating carer and service user reviews appeared particularly poorly co-ordinated, particularly when changing circumstances prompted unplanned reviews. Thus carer and service users' needs could be reviewed at different times, with any changes to the service user's support plan not reflected in changes in support for carers. The 2014 Care Act requires both carers and service users to have a support plan; this may prompt better coordination between support plans and reviews.

Support for carers

Support for carers themselves was fragmented, with funding for short breaks generally included in service users' personal budgets and additional funding or services provided directly to some carers. Although not evidenced by this study, this fragmentation may be confusing for carers. It also certainly reduced opportunities for carers to design and direct their own support because some of it was, in theory, controlled by the service user. Moreover, little progress had been made in the study authorities in developing a separate RAS for carers and there was little agreement on whether this was either feasible or desirable.

The 2014 Act retains the assumption that service users, 'with support if necessary, will play a strong leadership role in planning' their own support (DH, 2014, para 10.2). Clements (2014, p23) notes that the guidance does consider the potential complexities that may arise if service user and carer budgets are pooled, or if a carer's needs are to be met by providing support to the service user. In such circumstances, local authorities 'should consider how to align personal budgets where they are meeting the needs of both the carer and the adult needing care concurrently' (DH, 2014, para 11.38). This should be set out clearly in the service user's support plan, and also in a separate support plan for the carer (DH, 2014, para 10.87, Clements, 2014, p18),

Implications for social work practice

The study has identified a number of areas in which current front-line practice may not be compatible with official guidance. Some of these inconsistencies may be addressed by the implementation of the 2014 Care Act, which places carers' rights to assessment on the same legal footing as those of disabled and older people. Carers will no longer need to request an assessment, nor demonstrate that they are providing regular and substantial care in order to have an assessment; this should be undertaken simply on the appearance of need on the part of the carer. Local authorities will also be required to consider whether carers and those they support might benefit from preventive services, information, advice or other community services, especially if they are not eligible for

practical support, services or personal budgets for carers. The findings of this research have several implications for social work practice in the light of the new legislation.

- Assessment of both service user and carer should be completed before support planning is done for either. This should ensure that the needs of both are taken into account when planning.

- Carers and service users may be assessed together, but it is not enough to just ask carers about their willingness and ability to continue providing care – carer wellbeing and aspirations for activities outside the caring role must also be ascertained. Separate carers' assessments must still be offered, a copy of the carer's assessed needs given to the carer, and support for carers and service users integrated.

- Support for carers may be provided in the form of services or support to the service user – but this must be stated clearly in separate support plans provided to the service user and carer.

Concluding remarks

The Care Act 2014, due to be implemented from 2015, will clarify legislative responsibilities that local authorities have acquired piecemeal over half a century, and give carers similar rights and entitlements as those of service users. This study has

identified a number of areas where greater clarity and consistency may be needed to ensure such rights can be realised in practice.

Research Ethics

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