Carers' Roles in Personal Budgets: Tensions and Dilemmas in Frontline Practice

Wendy Mitchell*, Jenni Brooks, Caroline Glendinning

Social Policy Research Unit (SPRU)

University of York

York, YO10 5DD

UK

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Abstract

Adult social care in England emphasises the service and support personal preferences of disabled and older people. Personal budgets play a central role in this development. Carers in England have also secured rights to assessment and support in their care-giving roles. However, these policies have developed largely separately, with little consideration of the interdependencies between disabled and older people and their carers. There is limited evidence detailing current practice. This paper explores current practice, particularly, how far social care practitioners recognise and balance the needs and interests of service users and carers, especially those with cognitive and/or communication impairments. The paper reports findings from nine qualitative focus groups (47 participants) conducted in 2012 with practitioners involved in service user personalisation and carer assessments from older people and learning disability teams across three English authorities. Findings indicate inconsistencies in practice. Although practitioners felt they sought to involve carers, practices varied between authorities, teams and colleagues in the same team. Clear and timely links between processes for service users and carers were absent. Practice was discussed most frequently around service user assessments; other stages of personalisation appeared ad-hoc. Areas of confusion and tension are identified. Future policy and practice developments and challenges are also considered.

Keywords

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Practice

Introduction

Personalisation is at the heart of English adult social care policy and practice

(Department of Health (DH), 2001; DH, 2005; DH, 2007; DH, 2010) aiming to prioritise

the aspirations and preferences of service users. Commonly used terms, such as

consumer directed support, self-directed care, person-centred planning and co-

production all aim to enhance service users' voice in, and influence over, the services

they receive (Leadbeater, 2004; Needham, 2011).

In England, family carers who provide regular and substantial amounts of care have

also secured rights to assessments of their needs and may also receive services (or

cash grants) to support them in their care-giving roles (Carers (Recognition and

Services) Act, 1995; Carers (Equal Opportunities) Act, 2004; HM Government, 2008;

DH, 2010). However, these separate policy and practice developments appear to

overlook the interdependencies that often exist between disabled and older people and

the relatives and friends supporting them (Fine and Glendinning, 2005; Kröger, 2009).

The services and support provided to disabled or older people can have important

benefits for carers too (Think Local Act Personal (TLAP), 2013). These impacts can be

direct, where services for the disabled or older person, such as day or respite care, can

benefit carers by giving them a break. They can also be indirect if, for example, carers

derive satisfaction from knowing the person they support receives appropriate, good

quality services. Conversely, older and disabled people eligible for publicly-funded support usually have the level of support they receive reduced if they also receive help from a carer.

There are both potential tensions as well as synergies between the needs and interests of disabled and older people and those of family carers. Hence, whilst recognising the interdependent relationships between carers and service users, carers as individuals with their own needs should not be forgotten. Despite this, carers have received relatively little attention within research on personalisation (Flynn, 2005; Glendinning et al., 2008; Moran et al., 2012a; Jones et al., 2012b; Newbronner et al., 2011). This marginalisation appears inconsistent with the widespread public recognition and policy initiatives that have raised the profile of carers and their needs over the past 15 years (HM Government, 2008; Carers UK, 2010; DH, 2010; Larkin and Dickinson, 2011).

This paper reports research exploring how frontline practitioners recognise and attempt to balance the needs and interests of older and disabled people and their carers who provide regular and substantial amounts of care, within the current personalisation paradigm.

Practice and research contexts
Current English adult social care practice usually involves assessment of an individual's support needs, in which the disabled or older person is encouraged to play an active role. Support needs which are currently being met by a family carer may be recorded in

the assessment, but are usually discounted when it comes to estimating the services and/or funding allocated to the individual, so long as the carer is willing and able to continue providing that level of support.

The assessment is used to estimate an 'indicative' personal budget - a guide to the level of resources available to fund the individual's support. The disabled or older person then plans how to use those resources and the budget is finalised and support plans approved by the local authority. By 2011-12, 432,349 working age adults and older people were estimated to be receiving personal budgets across England, an increase of 38 per cent over the previous year. In total, over half of those receiving community (that is, non-residential) support received this in the form of a personal budget (ADASS, 2012).

Carers also have legal rights (Carers (Recognition and Services) Act, 1995; Carers and Disabled Children Act, 2000; Carers (Equal Opportunities) Act, 2004; HM Government, 2008, 2010; DH, 2010) to an assessment of their own needs, including those relating to education, employment and training. These rights are independent of the person they support. Depending on the outcome of the assessment, carers may receive a cash personal budget, or funding for a break from care-giving. In 2009-10 only four per cent of carers reported having been assessed (Princes Royal Trust for Carers and Crossroads Care 2010; see also Seddon *et al.*, 2007). By March 2012, 51,191 carers reported receipt of a personal budget, with just under half as a one-off cash payment (ADASS, 2012).

Research into the impacts of direct payments (service users given cash payments instead of services in kind) 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). Consistent with earlier studies, the former group of carers was often involved in managing the disabled or older person's IB and in co-ordinating her/his support arrangements and so spent more time on care-related activities than carers of people using conventional services. However, outcomes (such as carers quality of life, health and well-being) were better for carers of IB recipients than for carers of people receiving conventional support (Glendinning et al., 2009; Moran et al., 2012a; Jones et al., 2012b) (see also TLAP, 2013).

The introduction of personal budgets appears to have occurred, at least initially, with little consideration of the possible alignment with local authority responsibilities towards carers. The study of the impact of IBs on carers (Glendinning et al., 2009) found few local authority carer lead officers had played an active role in the introduction of IBs. There were inconsistencies between the 13 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 IB. There were also discrepancies in relationships between the assessment

and resource allocation processes of IBs for disabled and older adults and those used for carers; and inconsistencies in the roles carers were expected to play in helping IB-holders plan and manage their IB. Potential practice differences experienced by carers of older people and carers of people with learning disabilities were identified, suggesting further exploration was needed.

Research commissioned by Carers UK has also identified considerable variability in how (self-) assessment forms for personal budgets consider carers' needs (Clements *et al.*, 2009). 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 adhere to legislation and practice on supporting carers as they implement personalisation.

Official guidance (DH, 2010) recommends that service user assessments should routinely ask carers how much help they are willing and able to give. It also advocates that support needs currently met by family carers should be recognised and recorded in service user assessments. Alongside this, carers have rights to a full, separate assessment of their own needs.

Assessments of carers' needs and those of service users should be co-ordinated so that information from both assessments can be brought together to inform support planning. Indicative budgets should take into account the availability of support from family carers, but only after a carers' assessment has been conducted, so that the

budget reflects the carer's actual willingness and ability to provide support. However, how far carer's own needs should be taken into account in estimating a service user's indicative budget (as long as they carer is 'willing and able' to continue providing that support) is unclear. Furthermore, service user assessments should also consider any support or services carers may themselves need in order to continue caring. 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 user and carer, with services and support to sustain the caring role (as far as the carer wishes) included in the service users' personal budget.

The Study

This paper reports practitioner findings drawn from a wider study of English adult social care practice regarding carers' roles in the assessment, planning, management and review of personal budgets. (In the remainder of the paper 'personalisation processes' refers to the processes of assessment; planning how a personal budget is used and managed; and subsequent reviews of support arrangements). The wider study focused on service users with cognitive or communication impairments and their carers, particularly, carers of older people and those with learning disabilities. The IB pilot project evaluation (Glendinning et al., 2009) suggested possible differences in practice between carers of older people and carers of people with learning disabilities and hence, the need to further explore the role of these differences. Carers with cognitive or communication impairments were also viewed as likely to be particularly involved in

supporting service users to express their needs and aspirations and in planning support. The tensions for practitioners in identifying and responding to the separate needs of service users and carers, while at the same time acknowledging - and perhaps relying for effective communication on carers - their interdependence are therefore likely to be particularly acute. The study explored how far practitioners recognised and balanced service users' and carers' needs, given this interdependence, in personalisation processes. Carers and service users' personal experiences and evaluations of practitioners practice during personalisation processes were also explored.

The study had three stages. First, a survey of local authority policy and practice in two English regions; second, interviews with senior managers and focus groups with frontline practitioners in three local authorities; and finally, interviews with service users and carer dyads. The study was approved by the Social Care Research Ethics Committee and research governance approval was gained from the three in-depth study sites. This paper reports evidence from stage two of the wider study, the focus groups with frontline practitioners. It focuses on the everyday practice of staff working with service users and carers and how they balanced the interests of service users and carers within the broader policy context of personalisation. (Findings from stages one and two of the study are reported separately.)

Fieldwork

Three English authorities were selected as in-depth study sites from those completing the stage one survey. These three authorities were a metropolitan county, a two-tier

rural authority and a unitary authority. In each authority, practitioners in older people's and learning disability teams with experience of working with service users with cognitive or communication impairments were invited to participate in focus group discussions. Older people and learning disability team leaders identified and sent project information to all relevant staff in each authority. Contact details of staff willing to participate were then passed onto the researchers by these team leaders.

Nine focus groups were conducted, involving 47 qualified social workers and non-professional social care staff who conducted assessments and/or reviews (see Table 1).

Insert Table 1 here

Focus groups were conducted in workplace locations. They lasted between 90 and 120 minutes and with participants' permission were audio recorded. Two researchers facilitated each group. A semi-structured topic guide encouraged participants to discuss their practice in recognising the separate, but related, needs of service users and carers; relevant training undertaken; and use of any formal guidance about managing the interests of service users and carers. Additional issues relating to service users with cognitive or communication impairments and their carers were also explored.

Data analysis

The focus groups were transcribed and analysed using the Framework Approach (Ritchie and Spencer, 2004). Framework is a qualitative data analysis method where researchers engage in a process of data summarization, theme identification and comparison across cases and themes.

Data was initially summarised and compared; common themes across the authorities were then identified and any differences between practitioners working with older people and people with learning disabilities noted. Researchers familiarised themselves with the transcripts, then developed a charting framework from the topic guide and any clear emerging themes. Both researchers piloted the framework and agreed adjustments. Data was then placed into charts (one for each authority) by one researcher and a sample of charts was cross-checked by the other researcher to facilitate consistency and validity. Summary charts were developed, one summarising the focus groups by authority, the other by team (older person or learning disability). Conclusions were drawn and verified, including tracing data back to source.

Results

General comments

Differences in practice were apparent between the three authorities and between teams of practitioners working with older people and learning disabled people. However, these differences were not authority-specific; different practices and approaches were

apparent within authorities, between teams and within teams.

For example, workers in learning disability teams noted differences between their own practice and colleagues in older people's teams. Staff in learning disability teams thought that they were able to work more closely with service users and carers due to the longevity of their relationships with some service users and carers. This longevity was felt to help facilitate greater sensitivity to service user and carer dynamics and readiness to listen to both parties. Staff in older people's services concurred that learning disability colleagues were likely to have worked with service users and carers over a longer period of time.

Despite these differences, it was agreed by all focus group participants that their authorities recognised the importance of involving carers in service user personalisation processes.

Assessments

Involving carers in service user assessments

Practitioners working with both groups of service users reported that carers' presence and participation in service user assessments was usual practice. Carers' needs were reported to be 'taken into account' during service users' assessments, through specific questions which carers answered in relation to their caring role and feelings about this. For example, practitioners reported asking carers about their willingness and ability to continue caring during the assessment meeting. These questions were often prompted

by the service user assessment form. One worker described the questions in the service user assessment as 'a mini assessment tool' for carers (Social Services Officer, LA2, LD FG1). However, others questioned the adequacy of service user assessments to identify carers' needs.

"the form pushes you more into that way of thinking, about how much is the carer 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."

(Care Assessor, LA1, OP FG2)

Limited space on service user assessment forms to record carers' views of their own support needs was noted in two authorities, so the level of detail could be very restricted. Some staff sought to address this by using other spaces on service user assessment forms, for example using sections headed 'community' or 'additional information' to record carers' views and needs.

The wording on service user assessment forms could also hamper identification of carers' needs. For example, 'task orientated' questions focused on practical caring activities rather than emotional and social aspects of caring. The limitations of relying on service user assessments for carers to discuss their own needs and wishes were recognised.

"I think a joint assessment you get the, 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 able to say that in front of their

mother/father."

<div align="right">(Care Assessor, LA1, OP FG2)</div>

Practitioners tried to compensate for this by displaying sensitivity to carers during such 'joint' assessments.

"By the time we've sat there for an hour and a half, maybe two hours,

we're well aware of the carer's needs. You can, their body language,

their stresses, and they will just, they will just feed it to you, they will just

offload it to you at the time."

<div align="right">(Care Assessor, LA3, OP FG1)</div>

Practitioners were also aware of their role helping carers to express their own needs during service user assessments or express their feelings towards the person they cared for.

"I think when you're talking to the service user and the carer, it becomes

evident sometimes, or with more questioning, what someone can

continue to do. And sometimes I find carers probably don't actually want

to say it, but you've got to try and help them to say it to the [service

user]."

Carer assessments

Practitioners reported that they routinely informed carers of their right to a separate assessment, usually at the end of the service user's assessment. However, there appeared little consistency within authorities or teams over when separate carer assessments were conducted. Some were done at the same time as the service user assessment, others on a separate occasion, which could be up to a month later. Where there were delays between service user and carer assessments, it was unclear how information from a carer assessment was linked to the service user assessment and how this might contribute to determining the service user's personal budget.

Practice also varied around who should conduct carer assessments. Some practitioners, from both older people and learning disability teams, thought it best the same practitioner conducted both assessments. Practitioners could then draw on their knowledge of each person and be more sensitive to the dynamics of service user/carer relationships.

> *"I know they do have carers, people specifically for carers' assessments*
> *in other authorities, but I think if you're involved in the case, you know the*
> *relationships and the family dynamics, which sometimes you wouldn't*
> *know if you were just going in to do a carer assessment, and you may*

miss something... You know those family dynamics, and I think it gives

you a better insight into the pressures of that particular carer."

<div align="right">(Care Assessor, LA1, OP FG2)</div>

Others believed that a different carers' assessor could encourage carers to articulate their own support needs and wishes, especially if tensions between service users and carers existed.

Although practitioners reported complying with the legal duty to inform carers of their right to a separate carer assessment, they differed in opinion about the value of these. Carer assessments were considered to have real benefits when they were a passport to services, such as respite or emergency care. However, staff in one authority believed carers' assessments could raise carers' expectations inappropriately, because even if carers' own needs were assessed, the support they could offer was frequently limited.

"I mean the carer's assessment itself, I think it's a bit misleading.

Perhaps they want to go on courses, they want to have the opportunity to

learn, to do the best for themselves and the service user, but then [in] the

end, what can we offer?"

<div align="right">(Social Worker, LA2, OP FG2)</div>

Whether carers themselves wanted a separate assessment was also debated. Staff working with both older people and those with learning disabilities questioned whether

carers actually wanted or felt separate assessments were necessary. Some carers were reported to feel that their needs had been addressed within the service user assessment, while others viewed separate carer assessments as repetitive and time consuming.

"It's not very often that a carer's there and involved in quite a detailed assessment [of the service user's needs], and then wants another assessment in their own right."

(Social Worker, LA2, OP FG2)

Other practitioners emphasised the emotional importance of separate assessments for carers, providing time and space for carers' to consider their own personal needs.

"I think the thing about carers' assessments that's often forgotten is it actually allows the carer the opportunity to have that time to speak about their needs, whereas if they're part and parcel of somebody else's assessment, they don't often get that opportunity to identify their own needs. It's somebody else's needs that they can talk about, but not actually their own and what's important to them. And I think sometimes they just need that time for somebody to listen to them in their own right, and that's as important"

(Care Assessor, LA3, OP FG1)

Support planning

Earlier research (Glendinning et al., 2009; Moran et al., 2012a; Jones et al., 2012b) suggested that being involved in planning support to be purchased with a personal budget may be an indicator of positive outcomes for carers.

However, practitioners in all three authorities frequently viewed support planning primarily as a continuation of the service user's assessment, rather than a separate process conducted at a later date and informed by knowledge of the likely size of the personal budget. Practitioners reported that both needs <u>and</u> potential support arrangements were discussed during service users' assessments. Practitioners in all three authorities described how they usually wrote up support plans after the service user assessment meeting and sent these back to the service user and carer to check. Indeed, practitioner involvement in support planning was considered necessary, in order to word plans 'appropriately' so that they would be approved by personal budget panels. Many practitioners also used the terms 'care plan' and 'support plan' interchangeably, suggesting that there was often little difference between previous care planning and support planning associated with personal budgets.

> *"The support plan is no different from the assessment. It's the same*
> *information; it's just going on a separate piece of paper. What's the*
> *person's [service user's] needs and how are we going to meet their*
> *needs is what the whole process is about so I don't make a big issue*
> *about the two things being distinct because I don't think that's helpful."*

Although practitioners described how support plans focused on service users' needs, staff in all three authorities reported that carers were also involved in support planning discussions, as these frequently took place during service users' assessments. Moreover, involving carers was considered important; 'a good service user support plan was a good support plan for the carer', as their needs were often interwoven, especially when the service user and carer lived together. For example, short breaks or daytime activities for service users also provided carers with breaks from carer giving. This view was voiced most frequently by staff working in learning disability teams.

> SW1: *"… almost always a good package of care and a good assessment of the service user does everything that the carer wants."*
>
> SW2: *"I think just a break is very often what they [carers] need."*
>
> (Social Workers, LA3, LD FG1)

A number of practitioners pointed out that a good support plan for service users also had indirect benefits for carers, providing peace of mind that the service user would be well cared for or occupied during the day. Staff in both older people and learning disability teams also explained that if carers were not involved and their own needs not addressed through the service user support plan, there was increased likelihood of support arrangements breaking down.

"You can draw up the most wonderful plan and then you suddenly find

that the carer's shutting various things down because it doesn't work for

them, or it doesn't work for the family, you know, so you've got to include

them."

(Social Worker, LA2, LD FG2)

Practitioners across the three authorities described different practices around including

carers' own needs in service user support plans. As with service user assessments, in

two authorities, some practitioners felt their authority's support plan forms did not

provide enough space for them to record carers' support arrangements and so had to

find alternative spaces which could lead to variations in how much detail support for

carers was recorded.

"Sometimes I put family stuff under 'community'. To me it's a real glaring

error that there is no [space] in that support plan that actually lets you put

in carers' needs. And when you're squeezing it in, then you feel that [the

carer] must feel that it's not taken seriously, whereas I know I'm taking it

perfectly seriously."

(Social worker, LA3, LD FG1)

In the third authority, practitioners generally felt their authority's documents were

adequate. For example, as practitioners in one older people's team explained, if a

service user plan included short breaks for the service user, it should specify how this

would support the carer. The support plan would effectively be two plans in one, documenting both service user and carer support.

> *"…the carers get a support plan but it's on the service user's plan as*
> *well, so you know on there what they're getting. It's all incorporated."*
>
> (Care Assessor, LA1, OP FG2)

However, it was unclear how needs identified through separate carer assessments could be included in service users' support plans, given that the former generally took place separately and perhaps some weeks after the latter had been completed. It was also not clear whether, following a full carer's assessment and identification of any carer support needs, these would be recorded on the service user's support plan. Some staff reported that carer-specific support was not routinely recorded on service user support plans.

When asked about conflicts between service users and carers, staff in both older people and learning disability teams reported that conflicts were most likely to arise during assessment and support planning when decisions about service users' support were being made. Common sources of conflict concerned service users' abilities and support needs; managing risk; ensuring service user safety; promoting service user independence; and when/how carers took breaks from caring-giving. Staff reported that managing conflict between service users and carers was not easy, 'good' social work skills and practitioner sensitivity were valued rather than any specific training or skills

associated with personalisation.

Managing personal budgets

Personal budgets can be held by the local authority, managed by a third party, such as, a support organisation or carer, or allocated as a cash direct payment to the service user. Earlier research (Glendinning et al., 2009) suggested that carers taking on the management of a personal budget in the form of a direct payment may be reflected in an increase in time spent on care-related tasks.

Practitioners confirmed they were expected to mention direct payments as an option to all service users and carers, and routinely did this. Direct payments were generally discussed in service user assessment meetings so carers were frequently present. In fact, carers were often reported to be the person who chose whether the direct payment option was taken up. (This may reflect the study's two user groups and be different for practitioners working with other service users, such as, those with physically disabilities or mental health conditions).

Discussions with carers about direct payments centred on their administration. Separate conversations with carers, without the service user present, asking them if they felt able to manage the service user's direct payment, were not routinely conducted. The prevailing assumption reported was if the service user was unable to manage a direct payment, the carer would be asked to manage it for them.

"The carer would be the first point of call for me to, to ask them if they could manage the direct payment, before I would go anywhere else."

However, discretion over whether carers were encouraged to take on the management of a service users' direct payment was reported, particularly if practitioners believed there was a risk of financial mismanagement. Some practitioners also reported that carers did not want the responsibility and administration they felt accompanied direct payments.

Reviews

Practitioners reported that most service users had routine (annual) reviews unless changing circumstances prompted unplanned reviews. Staff in all three LAs reported that carers were generally present at service user reviews. This was expected, especially if the carer had been involved in the initial assessment. Practitioners reported that review meetings frequently replicated the service user's initial assessment and therefore asked about the carer's willingness and ability to continue providing care.

Carers' own needs may also change, and at different times from those of the person they support. However, separate carer reviews were less common. Even if a separate carer's assessment had been conducted, practitioners would often try to review service users' and carers' needs at the same time unless there was family conflict, carers wished to speak privately, or carers needs had changed at a different time/rate to the

service user's needs. However, practitioners acknowledged that, as with joint assessments, joint reviews also reduced carers' opportunities to discuss their own support needs in depth and in private.

Carers of service users with communication and cognitive impairments
Staff across all three authorities and teams acknowledged that, while they tried to treat all carers the same, they relied more on carers of service users with cognitive or communication impairments to provide information about the latter's needs and wishes.

> *"I think you set out to try and make the client [the] centre of the assessment. Then often, halfway through, you realise the client's not particularly able or some of it is unreliable information. It sometimes switches over unintentionally and sometimes the carer can take over."*
>
> (Care Assessor, LA2, OP FG1)

However, the danger of relying too heavily on carers to speak for service users was also recognised, especially the risk of carers presenting their own views as those of the service user, or carers prioritising their own views over those of service users.

> *"You've got to be a little bit careful how you interpret what's being said to you, and try and double check. I mean even if somebody can't talk to me, I would still have eye contact and I would be talking to them direct, even if it were their carer who were actually answering questions for them."*

To avoid over-reliance on carers' views, practitioners noted the importance of recognising and responding to service users' non-verbal communication. However, practitioners also recognised that involving service users was not easy; getting to know how each person communicated could take several visits.

Discussion

Personalisation raises challenges for routine social care practice as practitioners seek to develop a more facilitative and co-productive role of assisting individuals to identify their own support needs and commission services that meet these needs (Burton *et al.*, 2012; Carr, 2010). The role and importance of carers as 'experts' in relation to the person they support has also gained credence alongside recognition of carers' right to their own services and support (Carers (Recognition and Services) Act, 1995: Carers (Equal Opportunities) Act, 2004; HM Government, 2008, 2010; DH, 2010). These developments create some major challenges for frontline practice.

Study limitations

Data reported in this paper was derived from focus groups with samples of staff from older people's and learning disability teams in three English authorities. Participants were volunteers and so may not be representative in their views and practices. The carers these staff worked with were also likely to be more involved in service user personalisation. Nevertheless, despite this specific sample of practitioners, the absence

of any clear or consistent patterns amongst staff in their reported practice suggests this reflected wide ranging and diverse staff practice. The number of staff participating in each focus group also varied, this may have influenced their level of participation. The presence of colleagues may similarly have inhibited some participants' openness and honesty. However, participants expressed many different (and sometimes conflicting) opinions. The relatively small samples mean care needs to be taken in drawing wider conclusions. Nevertheless, the study's in-depth, qualitative insights provide important additions to our understanding of the challenges that practitioners currently face in respecting both the individuality of service user and carer needs, and their interdependence. These insights highlight some important practice issues which have broader relevance.

Findings overview

Although practitioners felt they sought to involve carers, practices varied between authorities, teams and colleagues in the same team. Clear and timely links between processes for service users and carers were frequently absent. The importance of professional judgment was recognised but practitioners also acknowledged that inconsistent practice could lead to inequitable treatment of carers with some carers' support needs recorded in more depth than others.

Carers were commonly involved in service user assessments. Practitioners generally fulfilled their statutory duty (DH, 2010) by recording, during service user assessments, whether a carer was willing and able to continue providing support. Service user

assessments with carers present were also felt to facilitate consideration of carer support needs, aided by specific questions and prompts on service user assessment forms. Ascertaining the level of support provided by carers and their willingness and ability to continue providing this was important as it had implications for the level of service users' personal budgets.

However, practitioners were less consistent in their views about whether the service user's assessment was an adequate tool to capture carers' needs. Some practitioners criticised service user assessment forms for lacking clear instructions on where and how to record carers' views. If carers' views were recorded elsewhere on the assessment form, there was a risk these might not be taken into account when calculating the service user's personal budget. Clearer questions on service user assessment forms about carers' views and needs, and space to record carers' answers, may be needed. However, recording carers' willingness and ability to provide support is not the same as recording carers' own needs and support preferences.

Research (Seddon *et al*., 2007) has documented the gap between carer assessment policy and practice, within the latter often ad-hoc and inconsistent. Practitioners in this study reported meeting their duty to offer carers their own assessment. However, some carers were reported not to want a further assessment of their own when they had already contributed to the assessment of the person they supported. When carer assessments were conducted and who conducted them varied across authorities, There was little evidence that they were co-ordinated with service user assessments.

According to these practitioners, if separate carer assessments were conducted, information from these was not routinely linked to service user assessments. This was because the carer's assessment could be conducted some time after the service user's assessment and support plan had been completed.

Support planning was a further area of inconsistent practice. Across all three authorities, practitioners felt that carers were involved in support planning discussions as they were usually involved in service user assessments during which support plans were discussed. Practitioners also recognised that the service user's support plan needed to be acceptable to the carer for it to be sustainable. However, it was not clear how any carer needs identified through a separate carer assessment, or carer support arrangements, including possibly, a separate carer's personal budget could be co-ordinated with the support arrangements of the service user. Despite this, although carers can get personal budgets in their own right, practitioners in these focus groups did not discuss carers personal budgets and had very limited knowledge of them.

Practice guidance (DH, 2010) advocates that carers' needs should be 'routinely reviewed' alongside those of service users. Practitioners reported that carers' needs were reviewed insofar as they were usually present at service user reviews. However, beyond this, practitioners reported little consistency over whether, how and when any separate carer reviews were conducted. This also meant that any changes in service user or carer support arrangements were unlikely to be reflected in the other's support plans. Practitioners reported that they would welcome clearer guidance on review

procedures for both service users and carers, especially the latter.

Conclusions

This study illustrates the tensions practitioners face trying to recognise and balance the needs and wishes of service users and carers in current personalisation processes. Carers and service users' lives are interwoven and inter-dependent, and good support arrangements for service users may go some way to meeting the needs of carers as well. However, other outcomes that carers may want in areas, such as, life-long learning, employment or leisure, are unlikely to be discussed in the course of a service user assessment. Indeed some of these desired outcomes may conflict with those of the person they support. Yet separate carer assessments were not routinely conducted and when they were, it was not clear how they were co-ordinated with those of service users, if at all.

Although practice guidance exists (DH, 2010) it is also important to recognise that standardised guidance may not always be the most appropriate or relevant to meet the needs of individual carers and service users. In this study practitioners frequently faced complex situations, such as balancing limited authority resources, budgets and staffing levels with requirements to meet carers identified needs and/or support expectations. Alongside this, staff discretion was also valued, particularly, practitioners' professional expertise and personal knowledge of individual carer preferences. How to balance these competing demands whilst also ensuring equitable but sensitive carer inclusion remained an ongoing challenge for practitioners.

How to overcome tensions created by the separation of legislative requirements and practice guidance regarding service users and carers also remains unresolved. It is not clear how far this separation will be remedied by the English Care and Support Bill (DH, 2013), which aims to give carers the same legal rights to assessments and support as the service users they support. Thus, it may no longer be sufficient simply to ask carers a few questions about whether they are willing and able to continue providing support to a service user as part of the latter's assessment. There may be stronger legal obligations on local authorities to conduct separate assessments of carers' own needs and desired outcomes. Yet, at the same time, the interdependency of older and disabled people and their carers cannot be overlooked. Carers will continue to derive indirect benefits from knowing that the service user has an appropriate, quality support plan. Some types of support, such as, daytime activities or respite care may also provide direct benefits to both. It will therefore continue to be important for service user and carer assessments and support plans to be better co-ordinated with each other. This may prove challenging, given the diversity of practice this paper has reported.

are those of the authors and not necessarily those of the NIHR School for Social Care

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Table

Table 1   Focus group participants: local authority and service area

Local Authority	Learning disability (LD) team	Older people (OP) team	Total participants
LA 1	FG1 - 4 participants FG2 – 3	FG1 - 8 participants FG2 – 7	22
LA 2	FG1 – 6	FG1 - 5 FG3 – 3	14
LA 3	FG1 - 6	FG1 – 5	11
Total participants	19	28	47