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Ambiguity in Practice? Carers' Roles in Personalised Social Care in England

Caroline Glendinning , Wendy Mitchell and Jenni Brooks

Abstract

Carers play an ambiguous role within the personalisation paradigm currently shaping adult social care practice in England. Although carers have rights to assessments and support in their own right, these rights sit uneasily alongside the practices of assessment, support planning and personal budget (PB) allocation for older and disabled people.

This paper reports how 14 dyads of older and learning disabled people with cognitive and/or communication impairments and their carers viewed the roles – desired and actual - played by carers in personal budgets. Interviews with disabled people and carers were conducted during 2012 as part of a wider study into carers' roles in assessment, support planning and managing personal budgets. The interviews complemented a survey of reported practice in two English regions; interviews with adult social care services senior managers; and focus groups with front-line care managers. Talking Mats© were used to support interviews with some service users. Interviews were transcribed and data analysed using the Framework approach.

The interviews indicated that carers played important roles in service users' assessments and support planning, but were less likely to report receiving assessments

or support of their own. While carers had the potential to benefit from PBs and support arrangements for service users, this did not reflect practice that aimed to enhance choice and control for carers. The paper draws on Twigg's typology of service conceptualisations of family carers and concludes that, despite the important social rights won by carers in England, current practice continues to regard carers primarily as a resource or a co-worker, rather than co-client.

Keywords: Carer, personalisation, assessment, personal budget, choice

What is known about this topic?

- Carers are entitled to assessments of their own needs and support in their own right.
- Personalisation aims to empower older and disabled people to exercise choice and control over their support arrangements.
- Carers may benefit from personal budgets for the people they support, especially if they are involved in planning how the budget is used.

What this paper adds

- Carers play important roles in assessments and planning how the personal budgets of the people they support are used.
- Carers are usually asked about the help they give and whether they are willing and able to continue.
- Carers are much less likely to have separate assessments of their own or receive support in their own right over which they can exercise choice and control.

Ambiguity in Practice? Carers' Roles in Personalised Social Care in England

Introduction

England is unusual compared to many developed welfare states, in that family and other unpaid carers have secured significant social rights. The 2004 Carers (Equal Opportunities) Act placed a legal 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 those relating to education, training, employment and leisure. These rights exist even if the person being supported refuses, or is ineligible for, local authority support. Depending on the outcome of assessment, carers may receive services or a cash grant in their own right. Government policy (DH 2010, HM Government 2010) is that carers should increasingly receive support in the form of a personal budget (PB) or cash direct payment (DP), which they can choose to use in ways that suit their individual circumstances and priorities. However, research conducted across England and Wales shows a considerable and enduring gap between policy and practice, with the latter both variable and inconsistent (Seddon *et al.* 2007).

Over the past decade, English social care policy and practice has also promoted the aspirations and empowerment of older and disabled people by enhancing their opportunities for choice and control. Personalisation and self-directed support are widely advocated as the means of achieving these goals. Thus, since 2007 English councils have been required to offer PBs to everyone eligible for adult social care (DH

2008). PBs involve: assessment of an individual's support needs, in which the individual is expected to play a full part; estimating the amount of help required, converted into monetary terms; planning how the budget will be used; and regular reviews thereafter. Significantly, PB levels are reduced to take account of help given by family carers (so long as they are willing and able to continue providing this). PBs can be allocated as cash DPs, held and managed by the disabled or older person or a third party such as a carer or support organisation; or held by the local authority and used to purchase council-commissioned services on the user's behalf. In 2012-13, 76 per cent of eligible adults were estimated to receive personalised care and support, with £3.3 billion allocated through PBs (ADASS 2013). Similar processes (entitled self-directed support) and options are in place in Scotland (Scottish Government 2010).

These latter developments have evolved separately from policies and practice promoting recognition and rights for carers. The evaluation of the individual budget (IB) pilot projects - precursors to the current configuration of PBs - found few local authority officers with lead responsibility for carer support had played active roles in planning their local IB pilot and some tensions existed between carer lead officers and IB implementation teams (Glendinning *et al.* 2009). At the same time, however, carers can derive benefits from budgets allocated to older and disabled people. The IB evaluation found IBs were associated with positive impacts on carers' quality of life, social care outcomes and psychological well-being (Glendinning *et al.* 2009). Similar benefits for carers were indicated by the national evaluation of personal health budgets (Forder *et al.* 2012, Davidson *et al.* 2012). These positive outcomes appear to outweigh the additional responsibilities often experienced by carers of older and

disabled people using cash PBs, which can include recruiting and employing paid care workers (Rosenthal *et al.* 2007, Carers UK 2008, Grootegoed *et al.* 2010).

Teasing out the complex relationships between providing support for service users and support for carers and the respective outcomes of that support is helped by Twigg's (1989) typology of carer-service provider relationships. Twigg argued that carers are most commonly treated as a resource, perceived solely in terms of their ability to provide support for a disabled or older person. This approach is implicit in current practice, whereby service users' PB levels are reduced to take account of support from family carers. A second role identified by Twigg is that of co-worker; here the older or disabled person remains the main focus of attention but there is instrumental recognition of carers' roles. This is exemplified by current practice guidance (DH 2010), which requires that carers are asked in the course of service user assessments whether they are willing and able to continue providing care and what help they need to do so. A third role for carers is that of co-client; here carers' interests and well-being are valued outcomes in their own right. Local authority duties to offer carers assessments of their own, and carers' rights to these regardless of the wishes of the person they support, reflect this approach.

Linked to this typology is a difficult practice issue – how best to assess the needs of, and deliver support to, older and disabled people and care-giving relatives and friends, in the context of the often close and interdependent relationships between them (Fine & Glendinning 2005, Kröger 2009). This interdependency suggests that attention should perhaps be given to identifying and addressing both shared needs, and whether

these could be met through a common service or intervention, as well as the separate needs of disabled or older people and their carers. How should professional practice take account of the fact that carers may benefit from appropriate support arrangements for an older/disabled person (and, possibly, vice versa)? This paper explores these issues from the perspectives of carers and, to a lesser extent, the people they support, by reporting their experiences of assessment, resource allocation, support planning and managing PBs.

The study

Evidence reported in this paper forms part of a study of carers' roles in the allocation and use of PBs in England. (Hereafter, 'personalisation processes' refer to assessment, planning how a PB is used and subsequently managed). The study aimed to: describe current practice relating to carers' roles in the assessment, support planning and management of personal budgets; examine how far practice recognises and balances the respective interests and perspectives of service users and carers; and explore the views of service users and their carers on the role that each wish carers to play in personalisation processes. It focused on older and learning disabled people with cognitive or communication impairments and their carers, as the latter were thought likely to be heavily involved in supporting service users to plan and manage their support; at the same time, social care practice was likely to differ between the two groups of service users.

The study, conducted between January 2011 and December 2012, comprised:

- Online survey of 16 adult social care departments in two English regions, about formal policies regarding carers' roles in assessments, support planning and managing personalised support.
- Following analysis of the survey data, three councils were selected for in depth study because their guidance to front-line practitioners gave explicit recognition to carer roles. In these in depth study councils, semi-structured interviews were conducted with personalisation and carer lead officers about details of local policies; and focus groups with practitioners about frontline experiences of carers' roles in assessments, support planning and managing personalised support.
- Separate interviews with dyads of older and learning disabled people with cognitive/communication impairments.

The study received Social Care Research Ethics Committee approval and Research Governance approval in the three in-depth study sites.

Other findings are reported in Mitchell *et al* (accepted, forthcoming) and Brooks *et al* (submitted). This paper reports findings from the service user and carer interviews, which aimed to explore both their separate experiences and the dynamics between them (Eiskiovits & Koren 2010, Kendall *et al.*, 2009, Morris 2001).

In the three councils selected for in depth study, frontline staff were asked to send invitations to dyads of carers and service users where: the service user had a cognitive or communication impairment but capacity to consent to participate; lived in the

community; and had been assessed for a PB within the past year. Once identified, both service users and carers had to agree to participate. Recruitment was later extended to voluntary organisations working with carers and service users, initially in the three study councils and then more widely. Recruitment through other organisations was protracted; neither statutory nor voluntary organisations' records enabled them easily to identify people meeting the study inclusion criteria. Although it was hoped to recruit more users and carers (and equal numbers of older and learning disabled people), it was only possible to recruit 14 dyads within the study timetable. Ten included a learning disabled adult and four included an older person (Table 1). Carers of learning disabled people were predominantly their parents (particularly mothers), while older people were cared for by spouses; all the latter, but not all the former group, shared the same households as the person they cared for. These different care-giving relationships, and their longer-term histories, may have impacted on carers' identities and on both their own and service users' perceptions of carers' roles, but no systematic differences were apparent in interviewees' responses to the interview questions.

Interviews were conducted in Spring/Summer 2012. A semi-structured topic guide for carers was developed from past literature and findings from earlier stages of the study, to explore carers' experiences of PB processes and any assessments of their own. The service user topic guide was shorter, with clear, direct questions and accompanied by Talking Mats®. These have been used extensively in research with people with dementia and learning disabilities (Murphy 1998, Murphy *et al.* 2005, Murphy & Oliver 2012). Talking Mat® symbols were linked to topic guide questions; participants could

answer a question verbally and simultaneously point to a symbol/symbols. Pilot interviews with two carer and service user dyads were conducted and topic guides amended accordingly.

Interviews were mainly conducted in participants' homes; two service users were interviewed at day centres. To assist confidentiality and prevent interviewer bias (Eisikovits & Koren 2010), one researcher interviewed the service user and another interviewed the carer. Two service users were interviewed with another supporter present for reassurance. Written consent was gained before each interview. If service users were unable to write, verbal or physically indicated consent was obtained alongside permission from another person who signed on their behalf. All interviews were audio-recorded and lasted 60 to 120 minutes (carers) and 10 to 30 minutes (service users).

Interviews were transcribed and analysed using the Framework approach (Ritchie & Spencer 2004) to data management. Data were initially summarised and compared; common themes across carers and service users were identified and any differences between carers of older people and people with learning disabilities noted.

Researchers then developed separate service user and carer charting frameworks; these were necessary as service user data were less detailed than carer data. Both researchers piloted the frameworks and agreed adjustments. Data were then placed into charts (one for carers and one for service users) by one researcher and a sample cross-checked by the other researcher to ensure consistency. A central chart was produced by placing the dyads together; this facilitated comparisons between dyads,

both the individual narratives and the combined dyad view (Eisikovits & Koren 2010). However, comparisons were bounded as service user data were narrower and shallower than that of carers.

Findings

Interviews were conducted with four older people and their carers and with 11 learning disabled adults and their carers (one carer supported two learning disabled adults) (Table 1).

Table 1 about here

PBs involve a series of stages - assessment, support planning, ongoing management of PBs and review (DH 2010). However, participants did not report clear discernible stages; for example, most found it hard to distinguish their different meetings with social workers. The findings are therefore organised around themes rather than a process.

Carers' roles in PB assessments

Carers wanted to be involved and consulted in assessments and discussions about PBs for the person they supported; service users confirmed they wanted carers involved. Carers reported they were almost always present at meetings between service users and social workers: some reported that they were invited by service users to attend; for others, it was assumed by the service user, social worker and carer themselves that the carer would be present. This assumption was not problematic for carers.

The most common reported pattern was for social workers to talk to the service user first (with the carer present); then ask the carer to clarify the service user's support needs; and finally discuss support options with both service user and carer. Carers felt they played important roles in supporting service users, by reassuring and interpreting information and providing additional information for practitioners. Carers thought both service users and practitioners valued their involvement:

'[Social worker] was really good talking to him but verbally she didn't get a lot back but I was able to kind of speak for him, you know, I was able to represent his views.'

[Carer of young man with learning disability 14]

Service users confirmed they valued carers' involvement and regarded their carer as a resource they could rely on to help answer questions and absorb information from practitioners:

Researcher: *'So does [carer] sometimes listen and then tell you things in a more simple way?'*

SU: *'Yes that's right ... she's helpful then.'*

[Older man with learning disability and dementia 12]

'I've got dementia you know? And so of course, I forget a lot of things and so therefore he [carer] puts me right.'

[Older woman with dementia 4]

Service users also reported deriving reassurance from having a carer present who was trusted and familiar with their needs:

'They [Mum and step-father] helped me with some questions Someone was there who understood me.'

[Young man with learning disabilities 5]

Researcher: *'And when Mum does the talking, do you think that's helpful or unhelpful?'*

SU: *'Helpful'*

Researcher: *'Why do you think it's helpful?'*

SU: *'Er, I'm quite shy to talk'*

Researcher: *'Why is that helpful to you?'*

SU: *'I'd feel a lot shyer'*

[Young man with learning disabilities 14]

Not all service users relied so heavily on their carers. Two young adults lived away from the family home and reported their parents were somewhat less involved; a third anticipated this developing in future:

'It's just that if something happens to her [Mum], then I need to speak up.'

[Young man with learning disabilities 9]

None of the older service users wanted less involvement by their carers.

Most service users reported their carer did most of the talking in assessments and other meetings, but this was not problematic for them. Nor did any service users have unmet wishes to talk to social workers alone. They explained they felt shy or had difficulty expressing themselves and explaining their support needs; one explained he did not always *'know the right words.'* [Older man with learning disability and dementia 12.

Carers' accounts of their roles tended to reflect the perceived capacity of service users to understand and participate meaningfully in assessment discussions. Carers of people with learning disabilities reported encouraging and assisting service users to speak for themselves and express their own wishes, by asking direct, simple questions or refusing to answer questions on their behalf if they thought the service user was able to respond:

'No, I won't talk for them [daughters]. I'll ask them, sometimes I'll rephrase a question ... so that they can understand and then eventually I'll get an answer and then pass the answer on.'

[Mother of two learning disabled adults 8]

Nevertheless, carers recognised that information given by service users was often inaccurate or incomplete:

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

[Step-father of young man with learning disabilities 5]

For these reasons, carers also did not think it was important for service users to be assessed alone.

Carers' own needs – resource, co-worker or co-client?

Reflecting a co-worker model, during service user assessments practitioners are required to ask carers whether they are 'willing and able' to continue providing support and about any help they may need to do so. Most carers reported they had been asked this. However, some carers reported feeling uncomfortable being asked about their 'willingness' to continue providing care in front of the service user. Others did not want to discuss their own needs during service users' assessments, preferring to focus on the latter's needs:

'Can't say that I ever raised anything really because, I mean, I don't think about it from my perspective, I always think about it from [son's] perspective because I think, I always think that's, that's what they're coming for, for [son] and not for me.'

[Step-father of young man with learning disabilities 5]

However, not all carers could remember being asked about their own care-related needs during service user assessments. Reflecting carers as a 'resource', others reported that social workers assumed they would be 'willing' and 'able' to continue providing care:

'I think there was a degree of expectation that you, you know, given the sort of facilities we have and the lifestyle that we have that we are happy to continue doing that [caring] and that we don't actually require any other support because we're fully capable of providing that support ourselves without any outside help.'

[Mother of young man with learning disabilities 6]

Consequently some carers reported feeling obliged and/or under pressure to say they would continue providing the same level of care. For example, one carer felt the social worker assumed she was 'superwoman' and could cope. Carers also referred to the nature of the relationship with the person they supported - how being, for example, a mother or spouse could engender assumptions of obligation to provide care. However, these experiences were not universal; two carers reported they had been able to say during the service user's assessment that they could not continue providing the same level of support.

However, simultaneously, social work staff are required to treat carers as co-clients by offering them separate assessments of their own needs. Separate assessments can provide opportunities for carers to express in private their feelings about providing

care and to discuss their own support needs. Eleven carers recalled having been offered an assessment and ten had taken the offer up, although some reported their assessment had been conducted several years ago. Some of these carers reported difficulty in disentangling the co-client role from that of resource:

'Yeah, we were asked about our needs ... I think what was important for us at that time was to focus on [daughter's] needs and what hers were, because we, for us if we can get, can get [daughter] sorted then our needs will follow. But the [social worker] left some paperwork for a carers' assessment ... and we will do that because we obviously have some needs ourselves ...'

[Carer of learning disabled adult 9]

A small minority of carers had declined the offer of a separate assessment as they felt they did not need one. Three could not remember being offered a separate assessment. Others were waiting to receive an assessment but were uncertain when or if this would take place as no timescale had been given. For the carers who recalled having separate assessments, these were generally 'one-off' events, not recent nor regularly reviewed and usually conducted solely so that the carer could receive a specific service such as a carer's emergency identification card.

Levels of satisfaction with the 'co-client' experiences of those that had had separate carer assessments varied. Some carers appreciated the opportunity for a relaxed, informal chat with a social worker:

'She came to the house, she had a nice cup of tea and she did have a bit of a checklist but it was more of a really good informal chat And it was nice 'cos it was 'Actually how does that affect you?''

[Mother of young man with learning disabilities 14]

For these carers emotional support, being listened to and regarded as a client in their own right were all valued aspects of the assessment experience. However, others had encountered rushed, impersonal carer assessments and had wanted more time and space to talk in private to social workers.

Even where separate carer assessments were conducted, there was little evidence from carers' reports that these had been brought together with information from service users' assessments, to inform plans for how PBs would be used.

Support planning: whose needs, whose plan?

Planning how to use a PB is recommended (DH 2010) to take place following assessment and an estimate of the budget level, with the active involvement of service users and carers. In this study, carers reported that support planning was generally social worker-led, with the social worker explaining what support was available. Most carers reported they were happy with this social worker lead role:

Carer: 'We did get like a booklet with all the questions that we'd answered and you know what the money was for and what [son] would get out of it'

Researcher: 'So who wrote this, the booklet that you've got then?'

Carer: 'Er, [social worker] did all the, you know, she obviously asked all the questions and she wrote in what was needed and things like that ... *I suppose that was good for me as all the paperwork would have totally baffled me to be honest.*'

[Carer of learning disabled adult 7]

Researcher: 'And so were you involved, did you feel involved in this [support planning] process?'

Carer: '.....I don't make decisions like that, so quickly so, I suppose I just sat back a little bit more and let them [social workers] make the decisions.'

Researcher: 'Were you happy with that?'

Carer: 'Yeah, it's not bothering me.'

[Husband of older woman with dementia 4]

Most carers were nevertheless able to identify some support needs of their own. For example, one mother of a learning disabled adult wanted services that would enable her to have time out with her husband:

'We've begged for over 10 years for myself and my husband to have a night off. As I said, it gets a bit much when you get to 60-plus and you have to ask for permission to go out for an hour with your husband.'

[Carer of young adult with learning disabilities 8]

However, a few carers found it difficult to identify any support needs of their own because of their interdependence with the service user:

'I'm quite happy as I am you know, I mean I cope, cope all right and the main thing is to me, I've got him home and At the end of the day, he's company for me and I'm company for him.'

[Wife of older man with dementia 3]

Services and support for carers can either be delivered directly to carers themselves (as co-clients), or indirectly through that provided for service users (co-workers). The most common support that carers in this study reported receiving was (one-off or regular) short breaks. Perhaps surprisingly, these were included in service users' PBs and support plans. Nevertheless appropriate short break arrangements could meet the needs of both carers and service users alike:

'Oh very happy ... it's like on a Tuesday I stipulated that he has four hours on a Tuesday and that is solely my time because while he's out with his PA [personal assistant], I know I can go out, I'm not going to be worried, you know ... I meet my friend, we go out and forget. So yeah, it's definitely been a godsend for me as well.'

[Mother of young man with learning disability 7]

Similarly, another carer explained that the personal assistant support paid for through her son's PB meant: *'him having a life, gives me a life.'* [Mother of young man with learning disability 14].

To ensure their own needs were met, carers acknowledged that they needed to be closely involved in planning the service user's support arrangements:

'... she [daughter] really enjoyed the [leisure] scheme but it didn't solve the issue that she couldn't start the scheme until 10 o'clock in the morning and I need to be at work for nine ... so I think as we've got more experience about what our needs are ... that then has made it [support planning] a much speedier and easier process.'

[Carer of learning disabled young adult 9]

Conversely, if the service user's short break arrangements were inappropriate or broke down, carers also lost their break:

'[Social workers] say I should have respite..... but that's something he [husband] won't do and if he won't do it, then I can't have the respite but now we've got him in this [new] place he seems to like it, so he might go again.'

[Wife of older man with dementia 2]

Much less frequently did carers report receiving separate support for themselves, especially support relating to leisure, education or training activities as outlined in the 2004 Carer Act. Even where carers did receive separate support of their own, it was not always clear how this was funded; one carer knew he received funding for his gym membership, but was unsure whether this formed part of his wife's PB.

When asked if they wanted more support, carers again illustrated the interrelationships between their own and service users' support needs, mainly by expressing desires for more short breaks and/or more hours of paid care for the service user. This was the same for carers of older people and those with learning disabilities. Carers also expressed needs for more emotional support, particularly having someone they could talk to, although this was not necessarily associated with separate carer assessments:

'It would be nice if I had someone that I could ring up, you know when things get drastic ... there are times in my life when I've been desperate for somebody just to say, "come on, calm down, sit down and we'll have a cup of tea.'"

[Mother of young woman with learning disabilities 8]

Differences of opinion?

Carers and service users reported few major disagreements about the carer's role or the support needs of the service user. Carers reported trying to avoid any disagreements by fully involving service users in all discussions with social care staff:

'I mean, he's [step-son] included, you know, we always ask him about it [his wishes] even down to holidays and things. So we do talk, you know, he's just included in everything.'

[Step-father of young man with learning disabilities 5]

Service users were also happy with how decisions were made and with carers' involvement in decision-making processes that affected them. Once again, carers were seen as a trusted resource, with the knowledge and ability to represent the service user's needs and best interests:

Researcher: *'Is it important for you to have Mum there [at the meeting]?'*

Service user: *'Yeah'*

Researcher: *'Why?'*

Service user: *'... err my Mum knows.'*

Researcher: *'Yeah, what sort of things does she know about?'*

Service user: *'Err, me'*

Researcher: *'You, she knows more about you?'*

Service user: *'Yeah, ... like me, yeah.'*

[Young man with learning disabilities 14]

Any dissatisfaction voiced by service users focused on the role of social workers or the level of support funded through the PB. As one service user with learning disabilities explained, if his social worker did not include him, his mother would intervene:

'See, they look at my Mum sometimes, not to me ... and my Mum says,

"You're here to talk to him."

[Man with learning disabilities 11]

Discussion and conclusions

This paper draws on interviews with 14 learning disabled and older adults with cognitive or communication impairments, and their carers. Given the small sample size and uneven representation of user groups, caution is needed in drawing conclusions, particularly about the wider transferability of the experiences reported here.

However, the sample was purposively selected; these carers were expected to be heavily involved in supporting service users in assessments and planning how PBs would be used and would therefore reveal particularly acutely the uneasy and ambiguous roles of carers in the context of personalisation. Such ambiguity is also likely to characterise a wider range of care-giving relationships, particularly those based on longevity and high levels of interdependence, such as spouse or partner care.

The paper only reports the experiences and perceptions of carers and service users and not those of the professionals involved. However, the privileging of service user and carer perspectives is entirely consistent with the ethos of personalisation; moreover, the accounts of managers and practitioners reported elsewhere (Mitchell *et al.* accepted, forthcoming; Brooks *et al.* submitted) are consistent with those reported here.

Carers in this study played important roles in supporting service users during assessments and planning support arrangements with social workers, and reported

that both service users and social workers valued these roles. Service users also valued the moral support carers provided, as they often found talking to social workers difficult. However, this dependence on carers to help articulate their needs and aspirations creates challenges in personalisation assessment and planning processes that are intended to empower service users. It may also increase the challenges for practitioners in recognising and responding to carers as co-clients, with separate support needs of their own.

Some carers detected practitioner assumptions that they would continue to provide the same level of support – in effect acting as a resource aimed at ‘care maximisation: the maintenance and perhaps marginal increase of levels of informal support...’ (Twigg 1989, p.57). Although most carers confirmed they had been asked about their willingness and ability to continue providing support in the course of the service user’s assessment, very few could remember being asked in detail about their own support needs. Moreover, some felt it was inappropriate to discuss their own needs during the service user’s assessment. Yet few carers had had separate assessments of their own. Of those who could recall having had separate assessments, opportunities to talk in private about the emotional impact of care-giving were valued. Even so, carers did not report their own assessments had covered wider aspirations relating to employment, learning and leisure, as required by the 2004 Carers (Equal Opportunities) Act.

Overall, there was little evidence that information from carers’ own assessments about their support needs contributed to estimates of service users’ PBs or to detailed plans about how these were used, as recommended by DH (2010) guidance. Rather, some

carers were able to meet at least some of their needs (particularly for breaks) through participating in service users' support planning. Here carers were assigned the role of co-worker, a model that 'encompasses the carer's interest and the carer's morale within its concerns but [is] based on what is essentially an instrumental motive.... on the way to the final outcome of increased welfare for the dependent [sic] person' (Twigg 1989, p.59). However, it does raise questions about whether carers are expected to have levels of choice and control similar to those of PB holders, if resources that are at least in part earmarked to meet their needs are included in service users' PBs. Very few carers reported receiving additional grants or PBs delivered separately to them; this falls short of the revised Carers Strategy for England (HM Government 2010), which includes a commitment that everyone using adult social care, including carers, should be able to receive PBs.

This study has revealed the complex roles that carers are assigned in service user personalisation processes and how these roles are viewed by carers themselves (and, to a lesser extent, service users). In summary, using Twigg's (1989) typology, the roles carers reported being assigned to them reflected primarily those of resource (including, in this study, being relied on for additional explanations and interpretations of the needs and aspirations of service users with cognitive or communication impairments); and of co-worker, in which any carer needs for help were identified and met primarily in order to sustain their care-giving role. Interestingly, although Twigg's typology was developed to account for how carers were treated in formal service provision and practice, it also resonated with service users' and carers' own perceptions of the latter's roles. This was apparent in service users' appreciation of the

supportive roles played by carers; in the common practice of allocating resources to sustain care-giving within service users' PBs; and by carers' widespread participation in planning service users' support in order to optimise opportunities for meeting (some of) their own needs. Carers as co-clients, with recognition of their separate and independent needs (including those relating to employment, training and leisure) appeared to be compromised by the low incidence of separate carer assessments or of PBs paid directly to carers themselves. Asking carers about their willingness and ability to continue caring during the course of service user assessments did not help carers to see themselves as co-clients.

Thus, although current English social care policies of personalisation are underpinned by aspirations of enhancing choice, control and empowerment, this study has added to previous evidence (Arksey and Glendinning 2007) that, in practice, these aspirations do not appear to extend to family carers. Routine assessment, resource allocation and support planning practices appear, from the accounts given by these carers, to focus primarily on addressing service user needs and aspirations, with carers assigned a subsidiary role. Yet, as noted above, carers have secured important recognition and rights of their own; however, these appear to sit very uneasily within discourses and practice that prioritise the empowerment of service users. The evidence from this small study strongly supports earlier recommendations (e.g. Seddon et al. 2007), for more systematic and consistent approaches among social care practitioners and their employing councils to the conduct of carers' assessments, to complement the increased profile of service user empowerment.

The tensions between Twigg's (1989) different carer ideal types are likely to increase in the future. The English Care Bill 2013 places carers' rights on the same legal footing as those of older and disabled people - in other words, it strengthens carers' claims to be co-clients with legitimate, eligible support needs of their own and rights to control the resources allocated to meeting those needs through their own PB or DP. This is only likely to occur if routine assessment and resource allocation processes are able to give more explicit recognition to carers' roles as co-clients as well as being major resources for the support of older and learning disabled service users.

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Table 1: Participant Details including length of time caring*

| Carers | | | | Service Users | | | | |
|--------------|-------------|--------|--|----------------------------|--|-------------|--------|-------------------------------------|
| Dyad ID | Age (years) | Gender | Relationship to service user and caring duration (years) | Dyad ID | Condition | Age (years) | Gender | Service user and carer co-residency |
| C1-OP | 70's | Female | Wife (2) | SU1-OP | Stroke, short-term memory | 70's | Male | Yes |
| C2-OP | 80's | Female | Wife (5+) | SU2-OPⁱⁱ | Dementia, bipolar, arthritis | 80's | Male | Yes |
| C3-OP | 70's | Female | Wife (9) | SU3-OP | Dementia, stroke | 70's | Male | Yes |
| C4-OP | 60's | Male | Husband (3+) | SU4-OP | Dementia, osteoporosis | 70's | Female | Yes |
| C5-LD | 60's | Male | Step-father(5+) | SU5-LD | Learning disabilities | 20's | Male | Yes |
| C6-LD | 50's | Female | Mother(birth+) | SU6-LD | Learning disabilities | 30's | Male | Yes |
| C7-LD | 40's | Female | Mother (birth+) | SU7-LDⁱ | Learning disabilities, epilepsy | 20's | Male | Yes |
| C8-LD | 60's | Female | Mother (childhood+) | SU8a-LD | Learning disabilities, sensory impairments | 20's | Female | Yes |
| C8-LD | 60's | Female | Mother | SU8b-LD | Down's Syndrome, visual | 20's | Female | Yes |

| | | | | | | | | |
|---------------|------|--------|-----------------|----------------|---------------------------------|------|--------|---|
| | | | (childhood+) | | impairment | | | |
| C9-LD | 40's | Female | Mother (birth+) | SU9-LD | Learning disabilities, bipolar | 20's | Female | Yes |
| C10-LD | 50's | Female | Mother (birth+) | SU10-LD | Friedreich's Ataxia | 30's | Female | No - lives independently with PA support |
| C11-LD | 60's | Female | Mother (birth+) | SU11-LD | Learning disabilities | 40's | Male | Yes |
| C12-LD | 60's | Female | Sister (15+) | SU12-LD | Learning disabilities, dementia | 60's | Male | No - lives in community home with support |
| C13-LD | 60's | Female | Mother (birth+) | SU13-LD | Down's Syndrome | 30's | Female | No - lives independently with PA support |
| C14-LD | 40's | Female | Mother (birth+) | SU14-LD | Learning disabilities, autism | 20's | Male | Yes |

*Participant details at time of interview (2012)

i: service user withdrew during interview due to difficulties responding to questions, data collected was retained in the sample

ii: service user withdrew from study partly due to ongoing ill health