

Carers and personalisation

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Carers and personalisation:

What roles do carers play in personalised adult social care?
 What roles do carers and service users want carers to play?

KEY POINTS FROM THE RESEARCH

- Staff, carers and service users all emphasised the importance of carer involvement in assessment and support planning for personal budgets (PBs). Staff reported carers were involved in all stages of the process; working particularly closely with carers of those with learning disabilities due to long-standing relationships with service users and families. Carers of people with cognitive/communication impairments wanted to be involved to facilitate service user involvement and provide information to practitioners. Service users also valued these roles.
- Local authorities have duties, as part of service user assessments, to ask carers about the support they give and their willingness and ability to continue. Managers, practitioners and carers all confirmed these questions were asked: practitioners sometimes referred to them as 'joint' or 'mini' carer assessments.
- Practitioners reported that service users' PBs were reduced to reflect help given by carers. They were therefore sometimes selective in recording carers' roles.
- Local authorities also have duties to inform carers of their right to their own assessment. Practitioners reported this was often not taken up by carers and rarely led to increased carer support. Not all carers recalled being offered an assessment and few had had one.

The Social Policy Research Unit examined how current English adult social care practice balances the interests of service users and family carers, in assessment, planning, on-going management and reviews of personal budgets, particularly when budget-holders have cognitive or communication impairments. The study examined senior local authority perspectives, everyday practice by frontline staff and experiences of service users and carers.

- It was common practice to plan how a PB would be used at the same time as the assessment. There was, therefore, no opportunity for any separate carer assessment to influence the PB or support plan. However, given their involvement in service user assessments, carers also invariably participated in service user support planning.
- Separate assessments of carers' needs were uncommon and seldom conducted before service user support was planned. Support for carers tended to be in the form of short breaks and were included in the service user's PB and support plan; few had received a separate carer grant of their own. Carers felt that practitioners assumed and expected they would continue caring.
- There was little clarity among practitioners about procedures for: ensuring carer involvement; conducting separate reviews of service users' and carers' needs; or linking separate service user and carer reviews. Carers were unclear whether some meetings constituted assessments or reviews.

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BACKGROUND

Policy and practice in English adult social care emphasises the rights of disabled and older people to have choice and control over their own personalised support arrangements, usually through the allocation of Personal Budgets (PBs). Family members providing 'regular and substantial' care also have rights to separate assessments of their needs and support to meet these needs. These policies have developed separately from each other. This is despite the interdependencies of service users and carers, particularly when service users have communication or cognitive impairments. When people eligible for adult social care are assessed, guidance from the Department of Health (DH 2010) reminds local authorities that:

- Carers should be asked about their 'willingness' and 'ability' to continue providing support. Practitioners should avoid 'inappropriate' assumptions about carers' willingness to continue caring.
- Carers have rights to a separate assessment of their needs; this should inform the level of the service user's PB and their support plan.
- Carers' needs should also be considered during service users' reviews.

FINDINGS

Local authority practice survey

A survey of councils in two typical English regions found wide-ranging practice around involving carers in PB processes. In most councils, service user assessment guidance reminded practitioners to ask about carers' 'willingness' and 'ability' to continue providing support. However, there was little guidance on carers' roles in support planning or on-going PB management. Moreover, some councils recognised their practice guidance was not always followed, because of time and budget constraints or the low priority given to carer issues. Nevertheless, many authorities considered the linkages between service user assessments and support planning and assessments of carers' needs to be adequate.

Carer involvement in service user assessment

Our study found carers were commonly involved in assessments of service users with cognitive/communication impairments; staff, carers and service users all valued this. Carers themselves wanted to be involved so they could help service users understand questions and contribute detailed information. Service users were happy about their carers' participation as they could find talking to practitioners difficult. Many did not speak to practitioners on their own.

Senior managers and practitioners reported that carers were routinely asked whether they were willing and able to continue providing support, aided by prompts on service user assessment forms. Practitioners also used these prompts to ask carers about their own support needs. Some practitioners described these as 'mini' carer assessments within service user assessments; others saw them as part of a 'joint' assessment. Most carers confirmed they had been asked about their willingness and ability to continue providing support; nevertheless some felt practitioners assumed they would continue to provide care.

However, some practitioners regarded the carer questions within service user assessments as too narrow, task-focused and overlooking the emotional impacts of caring. Most carers could not remember being asked in detail about their own needs during the service user's assessment. Service user assessment forms also had limited space to record carers' perspectives.

Carer assessments

Managers and practitioners reported that they informed carers of their rights to separate assessments; beyond this there was little consistency. Some practitioners acknowledged that separate assessments allowed carers to discuss their needs in private. Some separate carer assessments were reported, but these could be conducted some time after the service user assessment. There was also little agreement over whether the same practitioner should do both service user and carer assessments. Managers and practitioners reported that not all carers wanted a separate

assessment, particularly if they had already contributed to the service user's assessment.

Some carers did recall having a separate assessment; some could not remember being offered one; others had declined because the relevance and purpose of a separate assessment was unclear. Carers nevertheless valued opportunities to discuss the emotional aspects of caring with practitioners, although such opportunities were rare.

Carers and resource allocation

DH guidance (2010) recommends that, when calculating a service user's PB, help given by family carers is taken into account and the PB reduced accordingly, but only after a carer's assessment has been conducted. In this study, help given by carers did reduce service users' PB levels, but there was little consistency or transparency in exactly how this was done. Some practitioners reported exercising discretion in recording the amount of help given by carers because of the anticipated impact on the level of the service user's PB. Even when separate carer assessments were conducted, these were rarely linked to service user assessments to inform the PB level.

Practitioners' awareness of resources to support carers themselves was limited. Funding for short breaks was commonly included in service users' PBs. Very few carers were reported to receive PBs of their own, although occasional payments to carers (for example, for a washing machine or leisure activities) were reported by practitioners. Managers had very mixed views about developing separate resource allocation systems for carers.

Support planning and on-going management of PBs

DH guidance (2010) recommends support planning should be led by service users, with carer involvement, and conducted after calculating an indicative PB. However, practitioners reported that support planning discussions frequently took place at the same time as service user assessments. Nevertheless, practitioners reported that support planning involved carers and considered both service users' and carers' needs.

Reflecting the reported low frequency of separate carer assessments, there was no evidence of carers' having their own support plans that addressed work or leisure activities. Carers themselves had low expectations of receiving such support.

As support planning often took place during assessment visits, carers' and service users' reports of support planning were frequently confused; indeed, some carers were unsure if the service user had a written plan. Most carers reported they had participated in support planning. Service users confirmed their carers' involvement and were generally happy with this.

Despite discouragement of 'inappropriate assumptions' (DH 2010) practitioners usually asked carers to manage a PB when the service user was unable to do so. Carers in this study who managed a PB were happy to do this.

Reviews and carers

Carers' circumstances were reported by managers and practitioners to be routinely reviewed at the same time as service users. There was less consistency over whether, when and by whom any separate carer reviews were undertaken; practitioners were especially unclear how these were conducted. This was confirmed by carers; few had had separate reviews of their own needs. Moreover, it was unclear how any information from separate carer reviews were reflected in revisions to service users' PBs or support plans.

IMPLICATIONS FOR PRACTICE

Managers, practitioners, carers and service users all valued carers' involvement in assessments, support planning and reviews for PBs, but practice lacked clarity and consistency. Although managers and practitioners considered carers' needs as part of service user assessments, the adequacy of questions that focus primarily on carers' willingness and ability to continue caring is questionable and far from the intentions of the 2004 Carers (Equal Opportunities) Act. There was little evidence that separate carer assessments were routinely conducted or linked to service user assessments, PB levels and support plans. Carers were, however, routinely involved in planning how the service user's PB would be

used; carers, service users and practitioners all saw the value of this. Help from carers was taken into account in calculating service users' PB levels, but this was usually without any information from a separate carer assessment. Apart from the short breaks included in service users' PBs and support plans, there was little evidence of other carer support needs routinely being identified or met.

This suggests a need for greater clarity in:

- Identifying and responding to carers' own support needs and aspirations, including those relating to employment, learning and leisure. Questions about carers' ability and willingness to continue caring asked in the course of service user assessments fall short of this requirement. Carers may need more information on the potential benefits of separate carer assessments to encourage take-up of these.
- Creating closer links between carer assessments and reviews and those of service users. Information from carer assessments and reviews needs to be clearly reflected in service users' PBs and support plans.
- Conducting regular, separate reviews of carers' own support needs, as these may change independently of service users' needs.
- Considering how any support specifically for carers should best be delivered – as part of the service user's PB or as a separate carer PB? Support for carers (for example, short breaks) included within the service user's PB may not, on the face of it, maximise carers' choice and control.

Wider debates are needed about feasible ways, within on-going resource constraints, of delivering support to service users and carers that recognise both their independent

ABOUT THE STUDY

The study was conducted between January 2011 and December 2012 and involved:

- An email survey of local authority policy/practice in two English regions (16 councils completed out of 29).
- In-depth investigation of practice in three of these councils, through interviews with senior personalisation and carer lead managers (6) and focus groups (9) with 47 frontline staff from older people and learning disability teams. Both user groups were thought likely to have high levels of carer involvement, but with practitioner teams demonstrating contrasting practice.
- Separate interviews with carers and older and disabled people with cognitive/communication impairments (14 separate sets of carers and service users). People with cognitive/communication impairments were expected to rely particularly heavily on carers when communicating with practitioners.

Ethical approval was granted by the Social Care Research Ethics Committee.

The study was conducted by Dr Wendy Mitchell, Dr Jenni Brooks and Professor Caroline Glendinning at the Social Policy Research Unit at the University of York.

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aspirations for choice and control and their interdependent relationships. These debates should inform further development of the 2013 Care Bill and subsequent practice guidance.

REFERENCES

Department of Health (2012) *Draft Care and Support Bill*, Cm8386, HMSO, London.

Department of Health (2010) *Carers and Personalisation: Improving Outcomes*, Department of Health, London.