

This is a repository copy of *Carers and Personalisation*.

White Rose Research Online URL for this paper:

<https://eprints.whiterose.ac.uk/76736/>

Version: Published Version

Monograph:

Glendinning, Caroline, Mitchell, Wendy Ann orcid.org/0000-0002-1608-2368 and Brooks, Jenni orcid.org/0000-0001-7735-3718 (2013) *Carers and Personalisation*. Report. Social Policy Research Unit, University of York

Reuse

Items deposited in White Rose Research Online are protected by copyright, with all rights reserved unless indicated otherwise. They may be downloaded and/or printed for private study, or other acts as permitted by national copyright laws. The publisher or other rights holders may allow further reproduction and re-use of the full text version. This is indicated by the licence information on the White Rose Research Online record for the item.

Takedown

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.

THE UNIVERSITY *of York*



 spru | Social Policy
Research Unit

Carers and Personalisation

Discussion Paper for the Department of Health

Caroline Glendinning, Wendy Mitchell, Jenni Brooks

May 2013

Working Paper No.

DH 2576

Policy background

Personalised support arrangements are central to English adult social care policy and practice. The underpinning aim of enhancing choice and control over individual support arrangements can be traced back several decades, through campaigns by working age disabled people to receive cash direct payments rather than services; *In Control's* promotion of self-directed support for learning disabled adults; the piloting of individual budgets; and the mainstreaming of personal budgets across adult social care. A major emphasis of current social care practice is on optimising the choice and control that disabled and older people can exercise over their support.

Over a similar period carers have also acquired increasingly clear rights to assessments of their needs, independent of the situation or wishes of the person they support. The most recent (2004) legislation requires councils to include in these assessments carers' aspirations for employment, learning and leisure. Since 2000 carers have also been able to receive cash direct payments in their own right. The revised Carers Strategy included a commitment that everyone using adult social care, including carers, should be able to receive a personal budget (HM Government, 2008).

However, these policies have largely developed independently of each other (Clements, 2011), as has resulting social care practice. Carer lead officers in the individual budget (IB) pilot sites reported having little involvement in the planning and implementation of IBs; IB lead officers agreed that the implementation of IBs offered little time to consider carers' issues (Glendinning et al., 2009). The relative disconnection between personalisation and carers' policies was recognised by the Law Commission, which proposed that the legal framework for the provision of services to carers and its relationship to that for service users should be reviewed (Law Commission, 2008: 4.107). The outcome of this review is reflected in the 2012 Draft Care and Support Bill, which gives carers rights to public support on the same footing as the rights of the person(s) they support, although this support may be delivered through help provided to the person they are caring for (Secretary of State for Health, 2012: 19). Pre-legislative scrutiny of the Draft Bill welcomed the proposed new requirement on local authorities to assess carers' needs for support and the possibility of combining service user and carer assessments. It also recommended that the principle of promoting well-being underpinning the draft Bill should explicitly be extended to carers (Joint Committee 2013).

Research background

There is relatively little research evidence on the impact of personalised social care arrangements on carers. A limited review conducted in 2008 (Glendinning et al., 2009) found most research on the impact of direct payments involved very small studies, often of carers of disabled (child or adult) sons or daughters. The first large scale comparative study

focused on carers of adults and older people offered IBs and showed a strong probability that IBs for service users could have positive outcomes for carers (Glendinning et al., 2009; Moran et al., 2011; Jones et al., 2012). Compared with carers of people using standard services, carers of IB holders had significantly higher quality of life and were more likely to report being engaged in activities of their choice. Qualitative data from the study suggested these positive outcomes were because IBs allowed carers to pay other people to do some tasks they had previously done themselves; and because IBs improved service users' quality of life, thus hinting at the interdependence between outcomes for service users and outcomes for carers. However, the IB carers study drew attention to the 'complexities and contradictions' that could arise from the intersection of a user-focused personalisation agenda and the formal recognition of carers' independent rights and support needs (Moran et al., 2011: 15).

A more recent survey of local authorities by Carers Trust (2012) found varying practices in assessing carers and a lack of clarity on how levels of support for carers are determined. However, the survey did not examine the relationships between assessments, resource allocation and support planning processes for carers and those for service users receiving personal budgets.

Current guidance

DH (2010) practice guidance on carers and personalisation recommends, *inter alia*, that:

- No assumptions are made - carers are routinely asked what level of support they are willing and able to provide to the person they care for.
- Carers are reminded of the opportunity to have an assessment in their own right.
- Assessment of carers' needs should take place concurrently with that of the person they support and information from the two assessments should be brought together to inform support planning. Support planning should take into account the needs of both the person requiring support and the carer so there is an integrated approach; services and support to sustain the caring role should be included in the personal budget of the person requiring support.
- Adjustments to personal budget levels that take into account the availability of carer support should not be made until after a carer's assessment has been conducted.
- There is a transparent and equitable system for allocating resources for support to carers in their own right.
- Carers have maximum choice and control in the use of the resources allocated for their support - these should be allocated as personal budgets wherever possible.

SPRU research on personalisation and carers

During 2011-12 SPRU conducted a study of local authority practice relating to carers' involvement in service users' assessment, resource allocation, support planning and management of personal budgets. The study paid particular attention to the intersections with local authority duties to inform and conduct separate carer assessments where requested and to provide support for carers. The study involved:

- A survey of councils in two English regions.
- Interviews with senior personalisation and carer lead officers in 3 councils and focus groups with front-line practitioners.
- Interviews with 'dyads' of service users and their carers.

The study focused particularly on learning disability and older people's teams, as the IB carers study (Glendinning et al., 2009) had suggested that practice could differ between these teams; and on service users with communication and/or cognitive impairments, as their carers were particularly likely to be heavily involved in their assessments and support planning.

The study was commissioned by the NIHR School for Social Care Research; main findings are due to be published during summer 2013.

Practice issues arising from the SPRU study

Assessments

In response to prompts on service user assessment forms, managers, practitioners and carers all confirmed that carers were routinely asked during service user assessments about their ability and willingness to continue caring, and about any support they might need to do so. However, some practitioners considered these questions were too narrow, task-focused and ignored the emotional impacts of care-giving. Other practitioners reported that the design of assessment forms – particularly when tick box-based - did not allow detailed recording of carers' support needs. Despite these limitations, practitioners commonly regarded these questions as constituting 'mini' carer assessments or as part of 'joint' assessments.

Carers mostly recalled being asked whether they were willing and able to provide care, but most did not remember being asked in detail about their own support needs during service user assessments and some could not recall being offered a separate carer assessment. Some carers felt practitioners assumed they would continue providing care.

Practitioners reported that carers often declined the offer of a separate assessment, unless the carer knew it was an essential passport to a specific service (e.g. the emergency card

scheme). Some carers also confirmed they had declined the offer of a separate assessment because they could not see the purpose after having contributed to the service user assessment. Those carers who had had a separate assessment valued this. Some practitioners were also aware of the benefit for carers of being able to discuss the impact of caring on their own. However other practitioners admitted they were reluctant to encourage carers to have separate assessments as they did not know what practical support or resources could be offered, or knew these to be very limited.

There were wide variations in whether the same or different practitioners conducted both a service user and carer assessment. Most importantly, there was no evidence that the two assessments were routinely linked. Where a separate carer assessment was carried out, this could be conducted by a different worker, a different team or even contracted out to a local Carers Centre; it was also usually conducted some time after the service user assessment.

Moreover, practitioners reported that support planning frequently began (and was often completed) during the service user assessment visit.

Together, therefore, routine practice generally did not:

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

Carers and resource allocation

Levels of service user personal budgets were commonly reduced to take account of help provided by carers. Practitioners were aware of this and some reported limiting the information about the help given by carers that they recorded on service user assessment forms, because of the impact this would have on the personal budget level. This is a further reason for regarding information about carers obtained in the course of service user assessments as a poor indication of the actual help they give, and its impact. Moreover, given the widespread delays in conducting any separate carer assessment, reductions to service user personal budgets were apparently normally applied before any separate carer assessment had been conducted.

As recommended in DH (2010) guidance, support for carers in the form of short breaks was included in service users' personal budgets. Any additional grants for carers (for example, for a washing machine or leisure activities) were funded and delivered separately, directly to carers themselves. This fragmentation of resources was difficult for carers to understand; did not appear to optimise carers' opportunities for choice and control; and, because all or

part of their support was technically under the control of the service user, did not appear to give carers equal rights to those they cared for.

Support planning and reviews

Senior managers and practitioners reported a lack of local authority guidance on whether and how carers should be involved in planning how a service user's personal budget should be used. Nevertheless, practitioners reported that support planning usually did involve carers and took account of both service user and carer needs. Reflecting the low frequency of separate carer assessments, there was little evidence of carers having their own support plans that addressed their aspirations for work, training or leisure activities; carers themselves had low expectations of receiving such support.

Carers' circumstances were reported by managers and practitioners to be routinely reviewed at the same time as service user reviews. Where a separate carer assessment had been conducted, there was little consistency over whether, when or by whom any review was carried out. Carers themselves confirmed that reviews of separate carer assessments were rare. Moreover, there was no evidence that information from any separate carer reviews was routinely linked to that of service users and reflected in revisions to service user budgets or support plans.

Implications and recommendations

It was not the aim of the study to investigate how far routine social care practice complied with DH guidance. What the study did reveal, however, were the constraints and pressures of routine social care practice; the apparent lower priority assigned to carer assessments and support compared with those for service users; and the continuing failure to integrate practice around carer assessments and support needs fully into new personalisation processes. Thus practitioners commonly regarded questions within service user assessments about carers' willingness and ability to continue caring, and any support they needed to continue this role, as an adequate assessment of carers' own needs. The value of separate carer assessments was not widely recognised; those that were conducted were apparently not routinely linked to service user budgets and support plans.

It is important to acknowledge the tensions involved in meeting the separate, but interdependent, support needs of service users and carers – there are no easy answers. Some service users and carers will want to maintain relative independence from each other; other relationships will be characterised by high levels of mutual care-giving and interdependence. Furthermore, positive outcomes for carers depend at least partially on good support arrangements for the person they care for. Nevertheless, carers have achieved rights to independent recognition and the forthcoming legislation will strengthen this.

The study suggests that, in implementing the forthcoming legislation, the following areas of practice may need attention:

- The value of separate carer assessments and reviews needs to be much clearer, to both practitioners and carers themselves. Potential benefits include the opportunity to talk privately about the emotional and psychological impacts of care-giving; receive information and advice about paid work, lifelong learning and leisure opportunities; and obtain access to support in the form of a grant or personal budget and support plan for the carer. These benefits are unlikely to be derived from questions about carers' willingness and ability to provide care that are asked in the course of service user assessments and recorded on forms designed primarily to identify service user support needs.
- Where carers still do not take up the offer of a separate assessment (for example, because this seems inappropriate in the context of a very close, interdependent relationship with the service user), service user assessments should provide opportunities for detailed discussion and full documentation of carers' own support needs. This information should be sufficiently focused and detailed to allow any additional funding or support to be allocated specifically and separately to carers.
- Where separate carer assessments and reviews are conducted, these need to be routinely linked to those of service users, and practitioners need to be clear about the processes that can facilitate this. This was perhaps the most significant gap identified by the SPRU study. Carer assessments and reviews need to be taken fully into account in calculating service user personal budget levels and creating or reviewing support plans.
- Local authorities should include in their guidance to practitioners reference to the importance of carer involvement in service user support planning (where both the service user and carer agree to this).
- The current practice of including resources for short breaks in service user personal budgets and the allocation of separate, additional grants or personal budgets to some carers is consistent with DH guidance that support for the caring role should be included in the personal budget and support plan of the service user. It reflects the fact that some positive outcomes for carers can be derived from services or support provided to the service user. However, the consequence is to fragment local authority support for carers. Moreover, other types of support for carers that are currently allocated separately and directly to carers through carer grants or personal budgets, also constitute support for the caring role. As councils are increasingly encouraged to develop transparent resource allocation systems for carers as well as service users, this fragmentation may become unsustainable. Even at present, allocating some resources designed to benefit carers through the personal budget of the service user appears incompatible with the principles of optimising choice and control for carers and with the rights to assessments and support that carers have secured independently of the person they are supporting.

Disclaimer

The research discussed in this paper was funded by the National Institute for Health Research School for Social Care Research. However, the views expressed in this paper are those of the authors alone.

References

- Carers Trust (2012) *Progressing Personalisation*. London: Carers Trust.
- Clements, L. (2011) *Does Your Carer Take Sugar? The parallel and parasitic struggles of disabled people and their carers for equal treatment*. Unpublished paper.
- DH (2010) *Carers and Personalisation: Improving outcomes*. London, Department of Health.
- Glendinning, C., Arksey, H., Jones, K., Moran, N., Netten, A. and Rabiee, P. (2009) *The Individual Budget Pilot Projects: Impact and outcomes for carers*. York: Social Policy Research Unit.
- HM Government (2008) *Carers at the Heart of 21st Century Families and Communities*. London: HM Government.
- Joint Committee on the Care and Support Bill – Report (2013) *Draft Care and Support Bill* downloaded from:
<http://www.publications.parliament.uk/pa/jt201213/jtselect/jtcare/143/14302.htm>.
- Jones, K., Netten, A., Rabiee, P., Glendinning, C., Arksey, H. and Moran, N. (2012) Can individual budgets have an impact on carers and the caring role? *Ageing and Society*, First view on-line 31 October 2012.
- Law Commission (2008) *Adult Social Care: A scoping report*. London: Law Commission.
- Moran, N., Arksey H., Glendinning, C., Jones, K., Netten, A. and Rabiee, P. (2011) Personalisation and carers: Whose rights? Whose benefits? *BJSW*, 42: 461-79.
- Secretary of State for Health (2012) *Draft Care and Support Bill*. Cm 8386. London: TSO.