

Are personal budgets always the best way of delivering personalised social care to older people?

KEY POINTS FROM THE RESEARCH

Senior managers...

- felt that DPs offered more choice, control and independence to older people (aged 75+) than a MPB.
- acknowledged that take-up of DPs was often limited due to lack of choice, the administrative burden (despite efforts to provide support), budgetary limitations, low expectations, lack of information, stress surrounding the setting up of over operationalising support plans and risk averse staff.
- felt that younger adults had different expectations to older people, wanted different things and were more willing to take risks.
- some felt that DPs had more to offer younger than older people.

Older budget holders and their unpaid carers...

- often did not know that they were receiving a MPB, and many who did were unaware of the budget amount.
- liked the idea of having a personal budget, but a quarter of DP users needing help with these things said they had impaired control over when they ate, went to bed or bathed/showered suggesting that DPs did not always confer control.
- DP and MPB users experienced little difference in relation to health, stress and social care related quality

DEFINITIONS

A personal budget (PB) is an amount of money given to someone eligible for adult social care. All new social care users now receive a personal budget. Personal budgets can be taken in two main ways (i) direct payment (DP) – funding is transferred to a bank account controlled by the person needing care for them to spend to meet their care needs, or (ii) managed personal budget (MPB) – the money is spent on their behalf by someone else, usually a relative or unpaid carer or by a local authority operational team.

of life (QOL) outcomes. For both groups personal care needs were mostly met but needs for control, social contact and occupation were often not.

- unpaid carers were centrally involved in helping older budget holders with their PBs.
- many unpaid carers, particularly carers of DP users, experienced high stress levels.

BACKGROUND

Advocates of PBs argue that possession of a budget – particularly a DP – confers real empowerment, better enabling the control of personalised services and support. This is claimed to lead to better targeting of services and support upon need, thereby improving outcomes. However, evidence before (Glendinning *et al.* 2008) and immediately after the announcement of the Transforming Adult Social Care Grant (Woolham and Benton 2012) suggests that older people achieve less good outcomes from budget

The study represents independent research funded by the National Institute for Health Research (NIHR) School for Social Care Research (SSCR). The views expressed are those of the authors and not necessarily those of the NIHR, SSCR, Department of Health, or NHS.


National Institute for
Health Research



ownership than younger adults. Although the Department of Health, the Social Care Institute for Excellence, Age UK and the Alzheimer's Society have all published guidance on making PBs and DPs work more effectively for older people, little research has been conducted to see if this guidance and research evidence has improved outcomes for this group.

This study set out to find out about:

- the extent to which local Adult Social Care Departments (ASCDs) recognised these issues, how they were assessing them and how they would assess their own success in achieving personalised services for older people, and;
- the experiences of older people, unpaid carers and frontline care staff of DPs and PBs, their views about the pros and cons of budget ownership and whether PBs had led to better outcomes.

KEY FINDINGS

Interviews with senior manager/personalisation 'champions'

Senior managers were aware that DPs were less popular among older adults, but felt that with appropriate support, *if* they could be made to work, they could offer older people more choice, control, enhanced dignity and independence. Obstacles cited included limited choice, administrative burdens on the budget holder, cuts to social care budgets, low expectations among older people, and a culture in ASCDs that was 'risk averse'.

To address obstacles, senior managers described different ways in which older people could take their PB, including DPs and MPBs but also commissioned care, virtual budgets etc. Many referred to work with service providers to develop markets; community and voluntary agencies to set up Personal Assistant services; and support services to help set up and manage DPs, and to work to improve information about PBs and DP. The importance of support, especially when setting up the care package, and willingness to intervene if DPs did not work out were mentioned. Management support and oversight, training and local risk enablement policies aimed to set and maintain an appropriate balance between

probity, consistency, flexibility and personalisation. Staff training was seen as important to challenge risk-averse practice.

Senior managers assessed 'success' in achieving personalised care by monitoring complaints, national and local performance indicators and local user satisfaction surveys and through local intelligence gathering. They felt these measures meant that 'success' in personalisation reflected the criteria older people themselves might use. These included greater control over the timing and flexibility of care or support, choice over the gender of care workers, and carers who understood the culture of the budget holder. 'Success' was also often described in terms of enabling older people to maintain social activities and hobbies.

Experiences of older budget users and unpaid carers

Postal surveys of older people and their unpaid carers compared the experiences of DP and MPB users and their unpaid carers.

Survey of older budget users

It was hypothesised that DP users might achieve improved control over everyday life and better outcomes.

Impact of PBs on activities of daily life was not always apparent. Although among MPB users, about 40% said that their ability to exercise control over these activities was impaired, around 25% of DP users also said control over when they ate, went to bed or bathed/showered was impaired.

Impact on outcomes was also considered. The survey found that despite the average budget amount being 10% greater for DP users, differences between DP and MPB users on three outcome measure were not statistically significant:

- *EQ5-D, a health outcome scale* Participants rated their overall health on a scale from 0 to 100 (higher scores = better health). Average scores for DP and MPB users were 43.3 and 45.6 respectively;
- *The Sheldon and Cohen Perceived Stress Scale* Scores range from 0 to 40 (higher scores = higher levels of stress). Average scores were 17.1 for DP users and 18.7 for MPB users;

- *Adult Social Care Outcomes Toolkit (ASCOT)*
The score range for this scale was 0 to 100 (higher scores = better QOL outcomes). Overall scores were 0.75 for DP users and 0.70 for MPB users.

The ASCOT scale also found little difference between DP and MPB users on the eight social care related QOL domains (see figure). Although basic needs for personal care seemed adequately met for most participants in both groups, needs for social contact, meaningful occupation and control were often not met. Many older people from both groups may often have been lonely and bored.

Survey of carers

The involvement of unpaid carers in setting up and managing PBs was crucial in supporting many older budget users, but particularly DP users. However, only a fifth of DP carers said that they had ever been offered a carers' assessment by their ASCD.

The impact of PBs on unpaid carers was considerable. Carer strain was assessed using a Care-Giver Burden Scale. Almost half of carers of DP users experienced moderate to severe or severe levels of stress compared to just over a third of carers of people with a MPB.

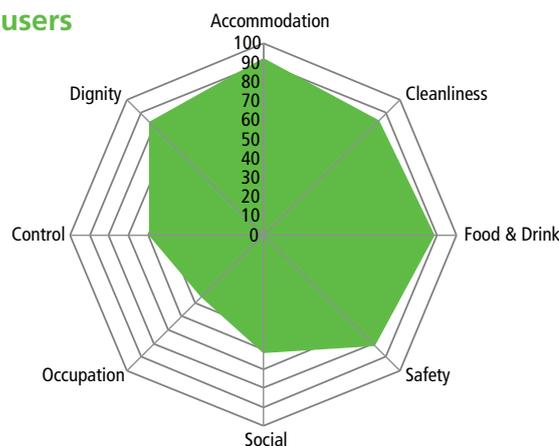
Follow-up interviews

Follow-up interviews with budget users and carers identified a number of benefits of budget ownership. These included the ability to purchase care or support that they could not otherwise afford, have their main personal care needs met and therefore to continue to live in their own home. DP users and their carers particularly felt they received care and support that offered greater continuity (same worker(s)), reliability (punctual paid staff), and respect from care workers. Being able to employ a personal assistant or a family member as a carer was particularly appreciated by some.

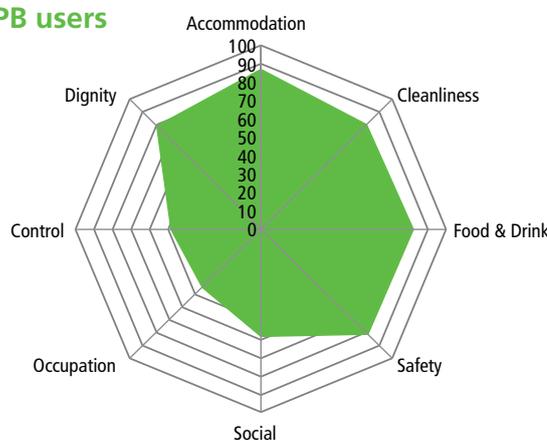
Problems were also described. Some interviewees felt that their ASCD did not provide sufficiently personalised information to enable informed choice. Others complained about a lack of service diversity, particularly in rural areas, and the inability to use the budget for anything other than personal care due to

Profile of ASCOT social care-related QOL outcomes

DP users



MPB users



the small budget size. For DP users specifically, there was anxiety about whether the DP would be sufficient if needs changed. This was linked to experiences of having to start at 'square one' with the ASCD if needs did change, as cases were not kept open. Finally, some carers felt that DPs shifted too much responsibility away from the ASCD, feeling care managers had professional skills and knowledge, and were better able to arrange care and to efficiently sort out problems with support/care providers if these occurred.

For operational staff, perceived benefits of PBs included a more holistic approach to assessment, and for people with a DP the possibility of more choice (although this was also highlighted as a concern through worries about employment of carers who had not been DBS checked). Greater flexibility in organising care, the timing of visits and the ability to save part of the budget to spend when needed were also mentioned. However, some operational staff were also critical of

what they saw as a more complicated way of providing care that did not offer greater benefits for many older people due to lack of diversity of service provision, and expressed frustration at their inability to give more detailed advice or tell budget holders which services would be best for them as this could be seen as privileging one provider over another, and held back in disseminating their knowledge. Some staff felt that the lack of diversity and choices available, and the considerable administrative work involved when employing carers directly, meant that managed budgets might be the better option for many older people.

CONCLUSIONS

Despite a good awareness among staff about issues relating to the use of PBs and DPs with older people, and attempts to tackle these, outcomes for older DP users were little different to those of MPB users. Rather than 'transformative' outcomes to empower them to participate in wider society, older people were more interested in using their budget to 'maintain' a level of independence simply to enable them to remain living in their own home. Choice seemed less important per se than the ability to organise support and care that offered continuity and reliability. Older budget users placed a high value on being able to develop a relationship with care personnel based on trust, mutual understanding and even friendship. Trust and reliability were also very important to unpaid carers. This was not always possible to achieve, even with a DP.

IMPLICATIONS FOR PRACTICE

The findings for this study have implications for policy as well as practice, as they add to a body of research evidence that suggests that DPs do not achieve better outcomes for older people and that the current policy requiring ASCDs to offer PBs, preferably as DPs, to all with eligible social care needs is based largely on a response to the demands of younger disabled adults – not older people.

The study findings suggest:

- restoration of lost abilities to enable full community participation may not always be realistic;

ABOUT THE STUDY

The fieldwork for this study was conducted between July 2012 and September 2013. In stage 1, telephone interviews were completed with 52 local authority senior managers responsible for implementing personalisation and PBs. In stage 2, postal surveys of older DP and MPB users, and unpaid carers of older budget users were carried out in three ASCDs in England. 339 older people and 292 unpaid carers replied. Follow up interviews were completed with 14 older budget users, 31 unpaid carers, and 25 operational staff in these three sites. A favourable ethical opinion for the study was received from the Social Care Research Ethics Committee.

For further information contact Dr John Woolham at Coventry University (john.woolham@coventry.ac.uk).

- independence may not always be what older people want;
- empowerment may mean the ability to ask others to do things for or with older people rather than having to do it themselves;
- control may be more effectively exercised through opportunities to develop a relationship of trust and ideally friendship with paid carers.

These insights suggest that ASCDs may need to think less about choice and more about good care: this will depend on the quality of the care relationship.

A number of practice-based implications also emerged for ASCDs and care provider organisations, including a need to:

- focus more on care and support pathways for MPB users so people choosing not to have a DP have equivalent opportunities to exercise choice and control;
- address the social and recreational needs of people receiving social care;
- provide more useful information: e.g. which service provider might best meet the needs of the budget holder;
- assess the needs of unpaid carers – particularly DP users – and to alleviate carer stress;
- find ways of ensuring that if budget holders or unpaid carers need to contact their ASCD they have a named contact who knows them so they are not 'back at square one'.