



Progressing Personalisation

A review of personal budgets and direct payments for carers

About Carers Trust

Carers Trust is the UK's largest charity for carers. With local Network Partners we work to improve support, services and recognition for carers in communities across the UK. We offer practical help, both in and outside the home, desperately needed breaks, information and advice. Together with Network Partners we work as *one* organisation united by a shared vision for carers.

Our vision is of a world where the role and contribution of unpaid carers is recognised and they have access to the quality support and services they need to live their own lives.

Carers Trust is a new charity formed by the merger of The Princess Royal Trust for Carers and Crossroads Care.

Overview

This review explores implementation of personalisation for carers, focusing specifically on personal budgets and direct payments in relation to support provided to carers.¹ It reviews evidence on current implementation and identifies areas for further policy and practice development in view of proposed changes to the law in the draft Care and Support Bill. It examines:

- What personalisation should mean for carers
- Assessment and eligibility
- Resource allocation
- Support planning and how personal budgets are spent

This paper reviews the current policy framework and includes the results of a short survey of Carers Trust professionals' network who were invited to complete an online survey in the first quarter of 2012.

Background

The Government's Vision for Adult Social Care states that councils should provide personal budgets to everyone who is eligible for social care including carers by April 2013 although it has recently been reported that this has been revised to 70%.² The Government's preferred type of personal budget is a direct payment.

The refreshed Carers' Strategy³ emphasised that carers should become recipients of personal budgets in their own right and the NHS Operating Framework 2012-13 suggested that primary care trusts (PCTs) should pool budgets with local authorities to provide breaks for carers using personal budgets.⁴

Research shows that where personalisation is being implemented individuals and carers can experience a range of positive outcomes, including support for them to continue caring; improved quality of life; improvements to physical and mental health and wellbeing.⁵ However, there is wide variation in implementation and outcomes across different areas.⁶

Local carers' organisations and Carers Trust Network Partners have identified particular issues in relation to personal budgets and direct payments for carers:

- Carers are not always informed about their eligibility for personal budgets or direct payments
- Carers do not always know how to access personal budgets

¹ Particular issues for carers in relation to involvement in and managing personalised support for the cared for person are not explored in this paper.

² Guardian Online 26 October 2012 [Council no longer required to give all social services users a personal budget.](#)

³ HM Government (2010), *Recognised, valued and supported: next steps for the Carers' Strategy*. London: Centre for Information.

⁴ Department of Health (2011), *The Operating Framework for the NHS in England 2012-13*. London: Centre of Information.

⁵ Hatton, C and Waters, J (June 2011), *The National Personal Budgets Survey (POET)*. London: Think Local Act Personal, In Control, Lancaster University.

⁶ Hatton, C and Waters, J (June 2011), *The National Personal Budgets Survey (POET)* and Department of Health, and Local Authority Adult Social Services, (2011), *Oversight of user choice and provider competition in care markets*. London: The National Audit Office.

- Confusion amongst carers and local authorities about what can be purchased with a carer's personal budget and direct payments

The draft Care and Support Bill: a new legal framework for personal budgets

Despite the clear policy directive to implement personalisation, personal budgets are not currently defined in law. Care and support plans and personal budgets are only set out in good practice guidelines (which does not have the same legal status as Policy or Practice Guidance).

The draft Care and Support Bill proposes that all carers eligible for publicly funded care and support will be entitled to a personal budget and will have the right to request a direct payment. The proposals in the draft Bill are unlikely to apply in law before 2015.

The draft Care and Support Bill defines a personal budget as: "the amount which the local authority assesses as the cost of meeting needs; the amount which the adult must pay towards their care and support; and the amount which the local authority must pay towards that cost (based on a financial assessment)".⁷

⁷ Draft Care and Support Bill 2012. HM Government: The Stationary Office.

A review of practice and next steps for implementation

1. How are carers receiving personal budgets?

Nationally, 51,191 carers received a personal budget in 2011-12 - an overall increase of 15% from 44,514.⁸ The majority of the 93 local authorities who responded to Carers Trust's survey reported that they are already providing personal budget to carers (63%) and a further 13% are planning to in 2012-13.

However 20% of respondents were not providing personal budgets for carers and 3% said they didn't know whether they were or not. One area advised that personal budgets are no longer available after finding that demand was significantly greater than the total amount the local authority had budgeted for.⁹ Three respondents advised they did not provide personal budgets for carers but did provide direct payments indicating that there is some confusion about how personal budgets and direct payments are related.

72% (39 of 54) of local authorities surveyed were choosing to give carers a one-off annual payment. This finding reflects the national picture; just under half of the total number of personal budgets provided to carers were one-off direct payments and carers accounted for 85% of all one-off payments in 2011-12.¹⁰

However, five areas advised that there was complete flexibility with regards to the frequency of payments and it was up to the carer. Authorities are offering a range of options, including: quarterly payments (10 authorities, equating to 19%), monthly payments (13 authorities – 24%), fortnightly payments (6 authorities – 11%) and weekly payments (2 areas). Whilst one authority indicated that one-off payments were most common, larger amounts could be paid in instalments. In addition, only 16 authorities advised that they offer carers the option of building up a contingency fund; 24 said that contingency funds are not an option of or carers and a further 14 didn't know or were undecided.

In relation to provision of support to carers, research shows that carers are less positive about the process, including on accessing information and advice on personal budgets; what it can be spent on and how to plan and manage personal support.¹¹ The biggest survey of personal budget users found that less than half felt that the council had made it easy for people to change to personalised support and to choose from a range of services and a number of aspects of the process were "very difficult".¹² However, there are clear differences across councils and some are progressing on providing carers with greater choice and control and on improving those outcomes.¹³

⁸ Association of Directors of Adult Social Services (ADASS) (2012), Personal Budgets Survey March 2012.

⁹ These figures do not add up to 100% due to rounding.

¹⁰ ADASS, Personal Budgets Survey, March 2012.

¹¹ Routledge, M and Lewis, J (2011), Personal Budgets: Taking Stock, Moving Forward. London: Think Local Act Personal.

¹² Hatton, C and Waters, J (June 2011), The National Personal Budgets Survey (POET). London: Think Local Act Personal, In Control, Lancaster University.

¹³ Ibid., The National Personal Budgets Survey (June 2011).

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These findings indicate that local authorities should consider how to:

- Improve quality of access and information and advice about personal budgets for carers
 - Ensure carers are informed and supported throughout self-directed support processes
 - Ensure take up of both direct payments and managed options for carers and that carers are offered a range of flexible options to support agreed outcomes
 - Examine whether one off payments are appropriate and flexible enough for meeting all carers' needs, particularly for those carers who have regular and substantial caring roles over longer periods of time
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2. How are carers being assessed for personalised support?

We found varying practice in assessing carer's needs for personalised support. Some councils are allocating personal budgets for lower level needs without undertaking a carer's assessment. 30 out of 54 of the local authorities surveyed by Carers Trust said that carers qualify for personal budgets through a carer's assessment and 28 out of 54 through a carer's assessment and meeting Fair Access to Care services (FACS) criteria. Of those authorities who reported on eligibility levels 16 out of 54 said that eligibility was being assessed as substantial or critical and two advised it was set at moderate or above.

It is a concern that two respondents indicated that carers' eligibility for their own personal budget is based on the eligibility of the person with care needs against FACS criteria rather than the level of need carers are assessed as having.

We also found that local authorities distribute personal budgets (80% - 43 local authorities) rather than local carers' charities (7% - 4 carers' charities); 5 areas reported both the local authority and local charity distribute personal budgets and only 2 areas said it was the Primary Care Trust.

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- Personalisation processes need to involve carers setting outcomes that they want to achieve in relation to themselves and their families
- Eligibility for a personal budget should be based on the assessed needs of the carer and not on the eligibility of the person they care for
- Provision of personal budgets for carers' support needs to be coherent with the assessed needs and care package of the person they are looking after, e.g. If

needs change over time and a carer needs to take a break, personalisation should enable individual carers and the person they are looking after to change the way they are supported

- Clarification is needed on whether there are any circumstances in which it may be appropriate for personal budgets to be made available for lower level needs without undertaking a carers' assessment

3. How are resources allocated for self-directed support?

There is very little available evidence about how councils are calculating personal budgets specifically for carers and it has been noted that there is a lack of guidance on resource allocation systems (RASs) and detailed criteria in relation to carers.¹⁴ Analysis of relevant case law suggests that some local authority systems are problematic and that there is a “post code lottery in relation to personalised approaches”.¹⁵

Practical and legal problems identified include:

- Fixed upper limits which do not meet assessed needs
- Failure to subject systems to disability impact assessments and carers impact assessments
- Lack of flexibility to meet both the needs of the person with care and support needs and carers support needs, e.g. ‘allocations’ for breaks and support for employment, education and leisure
- Failure to take into account carers willingness and ability to care and whether children and young people are undertaking inappropriate caring roles
- Development of Carers’ RAS but not ensuring that the carer’s assessment informs the RAS for the disabled person
- Development of Carers’ RAS with unreasonably low maximum values

Our survey revealed that only 17 out of 52 local authorities reported using a RAS and 18 out of 52 use a tiered system with set amounts which correspond to levels of need (e.g. £125 Moderate, £200 Substantial, £275 Critical). Two respondents who use a RAS advised that there were tiers within it and one respondent advised that they are currently using a system of tiered amounts but are developing a RAS. A further 12 authorities commented that they do not have a “system” as such but calculate the amount partly based on need and partly on what the carer wants.

On the issue of charging carers for support, our survey showed that the majority of areas 44 out of 54 (81%) are not including charges. However, given increasing financial pressure on local authorities we believe this is changing. Three areas (6%) reported that they are charging and three areas said that they are planning to charge when calculating a personal budget. Another authority noted that that charging is under consideration. One area advised that the carers’ personal budget is not chargeable unless spent on alternative care and it becomes chargeable.

¹⁴ Clements, L, Bangs, J and Holzhausen, E (2009), Individual Budgets and Carers. London: Carers UK.

¹⁵ Clements et al, (2009), Individual Budgets and Carers.

On the amounts carers receive, the survey showed wide variation from a maximum amount of £150 to more than £1501. Five areas reported maximum amounts of £1000, £1500, £1560, £2100 and £4680 per annum and 19 out of 30 authorities reported a maximum of between £250 and £500. 20% of respondents (11 authorities) did not have a maximum amount.

It was clear that authorities operate different policies in relation to the amount allocated to carers; five respondents advised that there was a maximum but did not say how much it was; two reported that the maximum amount was dependent on circumstances, whilst one area implements a flat budget of £300 per carer.

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- Systems for calculating personal budgets for carers need to be made transparent so that carers understand how much money they have available and how it is linked to the level of support they need
- Consideration needs to be given to whether tiered systems are appropriate for meeting the assessed needs of carers, and whether they are lawful
- Further research is needed into how tiered systems (set amounts against levels of need) compare with RASs and how such approaches risk restricting councils from meeting assessed needs
- Consideration needs to be given to how far carers' needs are being met by different approaches, including where councils are applying a flat rate payment or budget; whether flat rate payments could contravene carers rights to support and particularly in light of new duties to support carers under the draft Care and Support Bill

Development of carers' resource allocation systems should:

- Support different levels of support and higher levels of needs which may be more expensive to meet
 - Support short and long-term needs
 - Provide short and longer breaks and a full range of carers' services
 - Support carers' rights to employment, education and training and leisure
 - Be developed with carers and local carers' organisations
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4. How should support planning be implemented?

When the value of a carers' personal budget has been identified, carers should be helped to develop a care and support plan which meets their needs. Councils should help individuals to benefit from self-directed support and effective support planning is

central to how individuals choose to organise their support and spend their personal budget.¹⁶

Local authorities should ensure people who use services and their carers understand the options available for using personal budgets, either as a direct payment or as a notional budget to be held on their behalf by the council or a third party.¹⁷ Different options are also available to people depending on how they take their personal budget, i.e. there are different ways people can be helped to manage a direct payment and Individual Service Funds held by providers on behalf of their users.

Support plans need to meet the eligible needs of the carer and be in line with agreed outcomes that they want to achieve. Wherever possible, support plans should be coordinated with the person with care needs and with the needs of the whole family. Arrangements and plans should ensure needs are met in a holistic way. Guidance underlines the importance of:

- An integrated approach
- Inclusion of services and support to sustain the caring role as part of the personal budget of the person requiring support (where appropriate)
- Inclusion of problem solving, information and advice for carers (regardless of eligible needs)
- Provision of information and advice on a range of support available to carers and choice for carers on the level of responsibility they want to exercise
- Avoiding assumptions about the willingness to care and take on responsibilities, e.g. managing money, employing staff, procuring services etc.

5. How can carers use personal budgets?

There is no specific guidance on personal budgets for carers but there is guidance on direct payments. It specifies that after a carer's assessment, carers should be able to purchase services that they have been assessed as needing as carers to support them in their caring role and to maintain their own health and wellbeing.¹⁸

The 2000 Act does not define what a carer's service is other than to stipulate that a carer's service can be anything that could 'help the carer care for the person cared for'. In general a service to a carer under the 2000 Act cannot involve any intimate care of the person for whom they care (some exceptions apply, see below).¹⁹ A service is deemed to be of an 'intimate' nature if it involves physical contact such as lifting, washing, grooming, feeding, dressing, bathing or toileting the person with care needs.²⁰

¹⁶ Department of Health (2010), *Prioritising need in the context of Putting People First: A whole system approach to eligibility for social care*. London: Department of Health.

¹⁷ *Ibid.*,

¹⁸ Department of Health (2009), *Guidance on Direct Payments Guidance on Direct Payments: For community care, services for carers and children's services*. London: Department of Health.

¹⁹ Department of Health (2005), *Carers and Disabled Children Act 2000 (Equal Opportunities) Act 2004 Combined Policy Guidance*. London: Department of Health.

²⁰ Regulation 2(1) of the Carers (Services) and Direct Payments (Amendment) (England) Regulations 2001SI No. 441 and in Wales The Carers (Services) and Direct Payments (Amendment) (Wales) Regulations 2001 SI No. 2186 (W. 150)

Guidance emphasises that carers services should be focused on outcomes the carer and user want to ensure best value solutions.²¹ Therefore, if a carer is assessed as needing a service such as music lessons or relaxation therapy and the local authority decides that it will provide this support, then it can be provided as direct payment. The carer then has flexibility to choose and purchase the service that will work well for them to meet their needs.²²

Services that can be purchased with a personal budget

A wide range of services capable can be provided under section 2 of the Carers and Disabled Children Act 2000, given that anything that promotes a carer's sense of personal well-being is likely to help them 'care for the person cared for' .

In particular, the importance of breaks for carers to continue their caring role has been repeatedly highlighted and the Government recommends that one of the most effective ways of supporting carers is through providing them with breaks.²³ The guidance on direct payments specifies that direct payments should deliver outcomes carers want and carers can purchase flexible respite care as long as it is allowing carers to take a break in a way that best suits them. Examples using direct payments for flexible respite include:

- the disabled person or their carer arranging a break for themselves or they might be provided with a joint holiday (under s2 of the 1970 Act)
- To pay for a personal assistant to accompany the carer and her husband on holiday so that she can have a break but they can still enjoy the holiday together²⁴

However, the 2000 Act guidance makes it clear that:

- Carers are not currently entitled to a direct payment to purchase services to meet the **assessed needs** of the person they care for (paragraph 65).
- Carers cannot be charged for community care services provided to the people they care for (including the community care services provided to enable carers to take a break from caring) **unless those services are provided as the result of a carer's assessment under the 2000 Act.**²⁵

It is possible for carers to purchase respite care if a cared for person has refused services; the service is **not** of an "intimate nature" and they have both agreed to the service being provided. In some circumstances services of an "intimate nature" can be provided:

- When the person cared for agrees to the intimate care; or

²¹ Department of Health (2005), Carers and Disabled Children Act 2000 (Equal Opportunities) Act 2004 Combined Policy Guidance. London: Department of Health.

²² Clements, L (2011), Carers and their Rights: The Law Relating to Carers, Fourth Edition, Carers UK.

²³ HM Government (2010), Recognised, valued and supported: next steps for the Carers' Strategy. London: Centre for Information.

²⁴ Department of Health (2009), Guidance on Direct Payments: For community care, services for carers and children's services. London: Department of Health.

²⁵ Department of Health (2005), Carers and Disabled Children Act 2000 (Equal Opportunities) Act 2004 Combined Policy Guidance. Paragraph 62.

- It is an emergency and either the cared for person is unable to consent; or she/he does not consent but the intimate care is necessary to alleviate the imminent risk of serious personal harm.

Research shows that many adults with care and support needs and carers report undue restrictions on how they can use their personal budget. There is a tension between the release of resources and specifications on what personal budgets can be used for and the promise to individuals that they should be able to tailor their own support in a flexible and creative way.²⁶

Carers Trust's survey found varied practice in relation to what councils allow carers to spend their personal budgets on. Nearly half (25) of 52 local authorities told Carers Trust that carers cannot purchase alternative care ("respite" or "replacement" care) using their personal budget. Three areas advised that the carer's personal budget cannot be used to purchase anything "deemed to be for the cared-for or a community care service" and another area indicated that carers frequently request whether they can use their personal budget to purchase community care services but that this is not allowed by the authority. A further 20 authorities said that there were "other" items that carers cannot purchase but these included alcohol, tobacco, gambling, rent/mortgage and debts; utility bills or other household expenses such as food.

This evidence indicates that councils are potentially interpreting the law in varying ways and carers are being allowed to use personal budgets differently in different areas. Since respite care services are technically community care services rather than services provided under the Carers Acts, it follows that the disabled person will be liable to pay the local authority's charges for the service.

However, the guidance is clear that providing the carer has had a carers assessment, direct payments can be used for "flexible respite care" as a service under the Carers and Disabled Children Act 2000 (as long as it does not involve any intimate care unless in prescribed circumstances).

There are clearly potential issues for carers if they are restricted from spending their personal budget on a break and from tailoring their own support in a way that suits them. Carers Trust is particularly concerned about circumstances where:

- the person with care needs is not eligible to have their needs met through a community care package and the carer cannot take advantage of any personal budget provided for them to take a break
- There is no scope for the community care package to include replacement care at the times when the carer requires a break
- A carer's needs have not been assessed appropriately or inappropriate assumptions have been made about how much support they are willing or able to provide

Think Local, Act Personal (TLAP) have looked at how personal budgets are being used and suggest that the essential component is agreeing outcomes that the

²⁶ Routledge, M and Lewis, J (2011) Personal Budgets: Taking Stock, Moving Forward. London: Think Local Act Personal.

personal budget is supposed to address.²⁷ TLAP recommends that to allow flexibility and choice, outcomes need to be expressed in the broadest terms; outcomes should be directly linked to assessed eligible need and the allocated amount in the personal budget is reasonable to meet these needs.²⁸

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Local authorities should ensure that carers can use their personal budgets flexibly and that there are no undue restrictions on what carers can use their budgets for, including for “flexible respite” (in accordance with the current legal framework and in relation to the proposed new duties under the draft Care and Support Bill). This should involve:

- Consideration of a wide range of services and types of support (under the 2000 Act) linked to outcomes and preferences identified as part of a carer’s assessment
 - Ensure that if respite care is required so that a carer can take a break and this service needs to be purchased by the person cared for, then this need should be identified as part of assessment of need, and the service planned and budgeted for
 - Clarification is needed in new guidance on personal budgets for carers under the proposed draft Care and Support Bill on what personal budgets for carers can be used for in relation to managed options and direct payments
 - Further work is needed on whether local authorities are restricting carers from using personal budgets to take a break from caring and on ensuring that personalised approaches are enabling carers to tailor support
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²⁷ Stockton, S and Sanderson, H (2011), Re-thinking support planning: Ideas for an alternative approach. London: Think Local, Act Personal.

²⁸ Ibid.,

Conclusion and Next Steps

This paper has reviewed implementation of personalisation for carers focusing on support provided to carers in their own right. It has identified the following key issues:

- Confusion amongst carers about their eligibility for personal budgets and direct payments and what they can be spent on
- Inconsistency in approach to personalisation across different areas
- Variation in how personal budgets are calculated and allocated to carers and a need to improve systems and transparency for allocation of resources
- Differences amongst local authorities on what carers can use personal budgets for and specifications which may prevent carers from experiencing flexibility and choice through personalised support

This paper has suggested key points for progressing personalisation for carers. It recommends:

1. Carers need to be informed of their rights and entitlements to personal budgets and supported to understand how to access personalised support.
2. Assessment for personal budgets and support planning needs to improve taking into account the needs of the whole family and consider the carers' needs for support alongside the cared for person.
3. Personalisation needs to offer genuine choice through ensuring carers' preferences and outcomes are the basis for provision of resources and support; this needs to include consideration of whether personal budgets are an appropriate option and what support may be required (e.g. brokerage) so that personal budgets maximise choice and control.
4. Systems for calculating resources need to be developed for carers and in tandem with systems for the person with care needs; there needs to be greater transparency and accountability so that carers are informed about how much they receive and why in relation to agreed outcomes.
5. There needs to be greater clarity around how carers' personal budgets can be used flexibly and undue restrictions removed so that carers are empowered and not constrained to tailor support to suit them and the person they are caring for.
6. There needs to be clear guidance on personal budgets for carers in relation to new rights and entitlements for carers under the draft Care and Support Bill.



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