

Carers' attitudes towards direct payments

by **Daniel Lombard**

Direct payments are becoming an increasingly prevalent form of personalised support in social services. Spending on direct payments for adults in England has more than doubled **from £450 million in 2007-08 to £1.2 billion in 2012-13**.

Direct payments have been **available to carers in the UK since 2000**. These initiatives have been designed "to promote choice, control and personalised support for older and disabled people and enable them to **develop their own support arrangements**".

The policy of giving people choice and control over the way their care budget is spent, based on the principles of personalisation, has been heavily promoted by the Department of Health. **The Care Act** explicitly states that all carers should receive a personal budget and adds that "[c]arers have a right to request that the local authority meets some or all of such needs by giving them a direct payment, which will give them control over how their support is provided". The state also provides financial support via the carer's allowance, currently £61.35 a week (for people who provide care for at least 35 hours per week and look after a person on a qualifying benefit). This differs from direct payments in that it is a **state benefit designed to acknowledge the impact of the caring role** on people's incomes and contribute to their financial support. Across Britain, there were **665,000 recipients of carer's allowance** in February 2014.

Currently, there is low take-up of direct payments by carers despite efforts by policy-makers to promote their use. In England, there were **5.41 million carers in 2011**, with only **51,000 carers in England receiving direct payments in 2011/12**, less than 1% of the total.

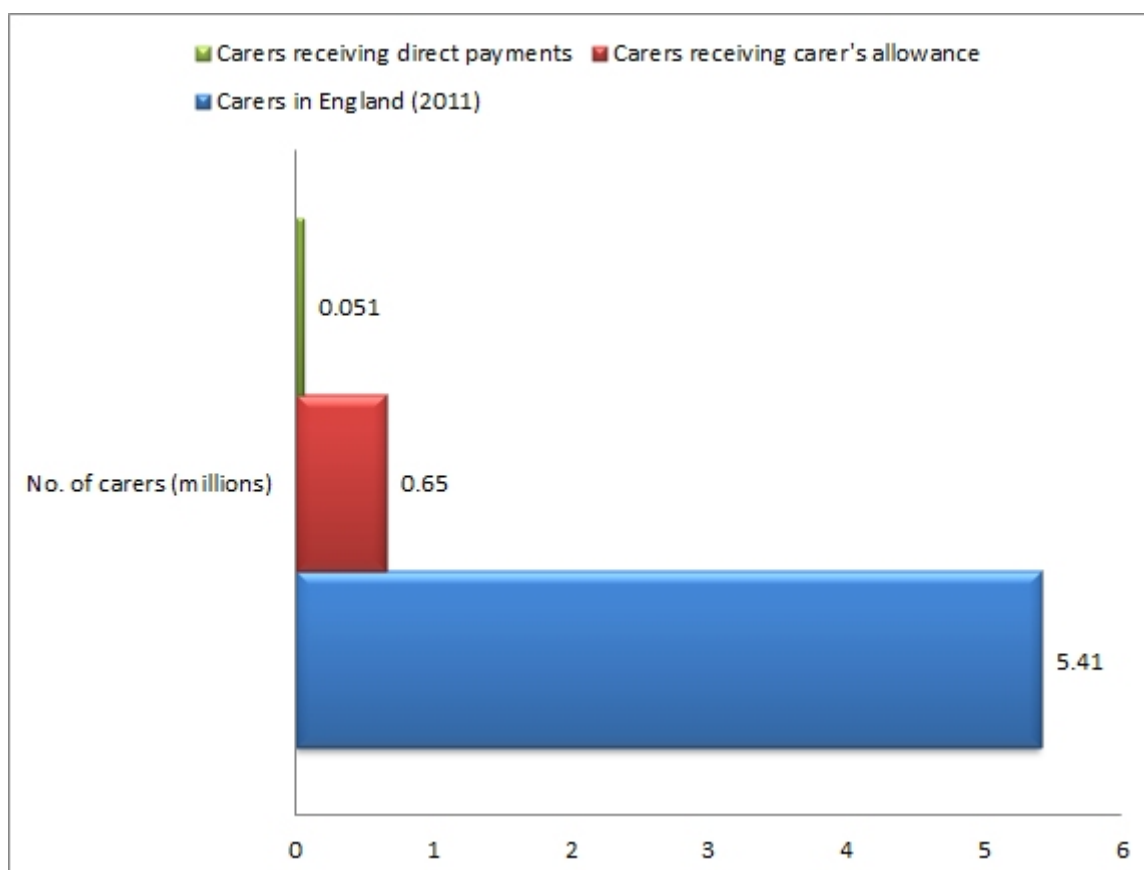


Figure 1: Carers receiving direct payments and carer's allowance

Carers' rights

But it's clear that carers' rights are moving higher up the policy agenda. How do carers feel about the prospect of being offered direct payments? What does personalisation mean to them, as distinct from the person they are looking after?

Commentators have argued that person-centred support has been developed independently of programmes designed to **increase independence for carers** and point to the lack of research on carers' experiences of, and views towards, direct payments. Debates largely focus on the perspective of the service user (for example, an older or disabled person) with the voice of the carer absent.

Qualitative study

A small-scale qualitative study of a cohort of carers, conducted for my MSc dissertation in Social Research Methods, provided insights into the attitudes of the very people who are being targeted by this policy.

Nine participants were recruited from carers' support groups in London with ages ranging from 21 to 67. Of the care recipients (i.e. the person being looked after), all of whom were relatives of the carers, three had physical disabilities, two had mental health problems, two were elderly, one had substance misuse problems and one had a severe learning disability. Two of them had experience of the personal budgets system personally, but this was not a requirement for participation. They were interviewed about their views on the policy of direct payments and how receiving such a payment might affect their quality of life, including the relationships they had with the care recipients.

Categories of relationships

Thematic analysis was used as the primary analytical method. Drawing on concepts from the literature (such as **Horton and Arber's 2004 study** of older people and family carers), analysis of the data showed there were three distinct categories of caring relationships:

- Peer-like
- Dysfunctional/disempowering (lower levels of autonomy among the recipients)
- Protective.

Attitudes towards direct payments

The typology was characterised by varying levels of burden, reward and conflict. When considering the respondents' attitudes towards direct payments in the context of their individual care-giving relationship, the findings suggested that the dynamics of the domestic environment, and relationship between the care-giver, care recipient and other family members could have an important bearing on their views towards the policy. The need for validation among care-givers was found to be higher among individuals lacking the emotional rewards of a fulfilling relationship with the care recipient. On one hand, people who saw their role as an extension of a deep and fulfilling family relationship (in the 'peer-like' group) did not show signs of requiring recognition. On the other hand, people in the dysfunctional group, who were more likely to see their role as a job, expressed the need for recognition more clearly. However, care-givers with negative experiences of interactions with health and social care services were more likely to be sceptical about the scheme.

Carers discussed the rewards they received from the role which helped compensate for the demands of caring and the lack of independence and autonomy. They ranged from mutual empathy, such as a deep understanding on the part of the recipient on the sacrifices made on their behalf, to intimacy and being able to spend lots of time with the recipient, to the showing of

initiative on the part of the recipient, particularly in relationships where the recipient has mental health problems.

For example, Bryony described an incident involving her daughter with mental illness (the care recipient), who had rarely shown initiative or the capacity for independence for a number of years, according to the interviewee. She said:

“The biggest reward, recently, after she was treated by the home treatment team, um, she went in the fridge, and she said ‘mum, these carrots have gone soft and curling up at the end, shall I throw them?’

“And that’s the first time in seven years, that she would any – show any initiative in the house. And that was incredibly – that made me cry. Because, you know, it’s really significant that, and I was crying, because to anyone else that would be so...that would be nothing.”

Ultimately, the volatility of certain care-giving relationships might make direct payments unsuitable for some carers, especially where emotional labour outweighs emotional reward. This is particularly the case if the recipient sees the carer’s engagement with social care services as **a personal moral failure**, which by extension would undermine the recipient’s sense of autonomy and independence – a clear contradiction of the aims of personalisation.

The need for further evidence

Given the small sample size a more extensive study is necessary to fully test these theories. For example, a larger-scale study, focusing on carers who are receiving direct payments, might yield further insights and could include a longitudinal element to explore how the dynamics of the care-giving experience progress or develop when carers receive direct payments.

About the author

Daniel Lombard is Research Officer within the Personal Social Services Research Unit at LSE. He is currently working on a study funded by the ESRC and NIHR on modelling the outcome and cost impacts of interventions for dementia. He is also working on an evaluation of direct payments in residential care.

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