

# Direct payments easier to spend on behalf of people with learning disabilities than for those with dementia

**Our research suggests that spending opportunities on behalf of a young, energetic person with learning disabilities may be more varied than for an 85 year old person with advanced dementia.**

It is one thing getting to grips with spending your own personal care budget, when you are older or feeling quite ill. But what happens if your mental capacity is limited? You may simply be unable to make those decisions. Nevertheless, you know what you like and don't like. So you might benefit from someone close to you spending the money for you.

Less than three years ago, the Government opened the way for an expansion in direct payments for personal social care. Direct payments can now be made to suitable people to spend on care for someone who lacks mental capacity to consent to receiving those payments.

Research on how this system works in practice has been funded by the SSCR. It is being conducted by the Mental Health Foundation in partnership with the Norah Fry Research Centre at the University of Bristol. Our work is important, particularly in understanding people who struggle to have their wishes taken into account. We want to find out how the changes affect direct payments staff working in local authorities, carers responsible for spending the money and, crucially, those who are meant to benefit from the new apparent flexibility.

The research is ongoing, and so we only have emerging thoughts about the data we are collecting.

For example, we recently visited a social enterprise café, partly funded by pooled direct payments from carers and family members of people with learning disabilities, who work at the café. 'Do you like coming to work here?' was one question we asked, recording thumbs up or thumbs down responses.

## **Capacity of carer important**

Then, there was a retired lady in her early 60s, who has taken up a direct payment for her mother, who has dementia. She spends it on personal care in her home. Sometimes, when she needs a weekend away in London to see her family, she pays someone else to stay with her mother. The direct payment provides greater freedom to find care that is better for her mother – and for her – than she could negotiate in the past. That said, some people find local authorities are risk averse and there is too much paperwork, giving them less flexibility than they would like with direct payments.

We are half way through our study and most of the work so far has focused on how different local authorities are



*'Having that payment has saved her life, and given her quality of life. Absolutely no question. She now has total control – through me, admittedly. We very much do it as a joint thing.'*

Carer

implementing this kind of system. But from our analysis suggests that this initiative works differently depending on the needs of the individual. For example, the spending opportunities for a young, energetic person with learning difficulties may be much more varied than for an 85 year old person with advanced dementia.

Success also depends on the capacity of the carer. The person doing the spending may be a middle-aged parent, used to making more decisions for their son/daughter and keen to have more control. In contrast, the carer of someone with dementia may be older themselves and new to the experience of caring for an adult. They may find direct payments

stressful and prefer the traditional system. Not surprisingly, people caring for those in later life are not taking up direct payments as much as those supporting people with learning difficulties.

Becoming a 'suitable person' is a job in itself. Some taking on the role have run their own business or been administrators. Even so, they often need a lot of back-up.

When we have finished our study, we will publish a guide for practitioners on how to make the new system work for people who lack capacity. We are also gathering frequently asked questions so we can publish leaflets for carers and service users.

**Project:** How effectively does the direct payments system work for people who lack the mental capacity to consent?

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