

# Direct payments and mental capacity

Outline of a research project  
funded by the NIHR School  
for Social Care Research

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

Since November 2009, a new group of social care service users has been entitled to use direct payments: people who may lack the mental capacity to consent. This includes people with learning disabilities and people with dementia. Under the new regulations, third parties chosen as 'suitable persons' (often family carers) may now receive direct payments on their behalf. This raises the question of what processes have been put in place to implement this legislation and how effectively it is working in practice.


Many individuals are involved in decisions about direct payments, including care managers, social workers, care coordinators advocates, brokers and finance managers. But little is known about how direct payments are currently issued for people without capacity, or of what constitutes good practice in this area. Given that take-up for direct payments remains low, the views of practitioners, carers and service users about how the direct payments system is working for people without capacity may throw light on ways to make the process more appropriate for a greater proportion of service users.

### This project

- will explore how direct payments are being administered in practice for people who lack the mental capacity to consent.

### It aims to

- investigate the views of a range of stakeholders including staff who influence decisions about direct payments
- explore the role played by 'suitable persons' who manage the direct payment of a person without capacity
- gain insight into the experiences with direct payments of service users who lack capacity (especially people with learning disabilities or dementia)
- produce a guide for practitioners and an information leaflet for 'suitable persons' and service users to inform and explain the regulations for direct payments relating to people who lack capacity.



Improving the evidence base for  
adult social care practice

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### WHAT IS THE CONTEXT?

Personalisation is a key element of social care reform in the UK, and direct payments are an important method of planning and delivering personalised care. Until 2009, people who lacked the mental capacity to say whether they wanted a direct payment were not eligible to take this option. The law then changed to allow a third party 'suitable person' to administer a direct payment on behalf of a service user who lacked capacity. This 'suitable person' is usually a family member or carer, and must act in the best interests of the recipient.

Direct payments for people without capacity are likely to be issued and administered in a variety of ways, and this may vary across different areas or different disciplines (for example, learning disability teams, older adults' mental health teams). There is therefore a need for better understanding about the processes of delivering direct payments in practice, as experienced by the various different participants:

- those paid to make or support decisions about direct payments (for example, care managers, brokers, advocates, finance managers)
- people who may be 'suitable persons' to hold direct payments for people who lack capacity
- people requiring support whose capacity to make relevant decisions is in question.

Overall, the take-up of direct payments remains low, in part because many people who need support (and their family carers) are still wary of what can seem a complex process and additional responsibility. This is likely to be especially the case for people whose mental capacity to make relevant decisions is in question.

Nearly 18 months since the law changed, it is now appropriate to look at how the new regulations are working in practice. This project will explore the process by which practitioners offer and administer direct payments for people without capacity, and highlight some

#### Direct payments

- A direct payment is a cash sum that enables a service user to choose and arrange their own care and support, either by employing individuals themselves or by purchasing support through an agency.
- Overall take-up of direct payments is low; community care statistics show that only 86,000 out of 1.54 million recipients of community based services in 2008/09 were in receipt of direct payments.

examples of good practice. The research will draw on the expertise that the Mental Health Foundation has developed through its ongoing Dementia Choices project, which explores, supports and promotes different forms of self-directed support in social care, including direct payments, individual budgets and personal budgets, for people living with dementia and their carers.

### HOW WILL THE PROJECT WORK?

The study will primarily use qualitative methods, supplemented by quantitative approaches, to investigate different practice models across various local authorities, and to highlight examples of good practice. Data will be collected from health and social care practitioners, service users and 'suitable persons' such as family carers.

#### STAGE 1: Literature review

A review of the literature will focus on how personalisation is implemented in practice for people who lack capacity to make decisions. The literature review will build upon previous work by the Mental Health Foundation and its partners, for example Dementia Choices, Best Interests Decision Study, and the National Survivor User Network personalisation project.

The review will include a large amount of grey literature coming directly from practice,

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including reports by local authorities and third sector organisations that provide advice or advocacy for people who may receive direct payments. Due to the nature of the subject area it is unlikely that there will be any trials to review, but there may be a large number of qualitative studies or case study examples.

#### STAGE 2: Expert input

The project will consult with a small number of practice experts already known to the research team.

Discussions will focus on the regulations for issuing direct payments for people who lack capacity. Participating local authorities will be asked for copies of any documented protocols on issuing direct payments for people who lack capacity. The purpose of Stage 2 will be to generate questions for Stage 3 about how direct payments work in practice.

#### STAGE 3: Service users' and carers' views

Working with at least six local authorities, this phase will identify how well the direct payment regulations are currently being implemented for people who lack capacity.

Sixty interviews will be conducted with practitioners including frontline staff (social workers, care coordinators, advocates, finance managers and brokers). These will use case vignettes to outline hypothetical scenarios for direct payments for someone without capacity, and will be designed to promote discussion about the direct payment regulations. Among the topics to be discussed will be:

- how to ascertain mental capacity
- how to collect information about Lasting Power of Attorney and court appointed deputies
- how to determine whether someone is suitable for a direct payment
- the definition of 'suitable person'
- problems and challenges experienced in issuing direct payments.

Thirty interviews will be held with 'suitable persons' who are each managing an individual's direct payment. This may include carers, or spokespeople for independent living trusts. Issues to be covered include:

- the value of the direct payment
- how it was planned to spend the money
- whether anything was refused by the local authority
- any disagreements with the service user about spending the money
- the experience of managing a budget
- the adequacy of business processes (for support planning, brokerage, monitoring).

Up to 20 interviews will be held with service users who lack capacity (10 with learning disabilities and 10 with dementia). A wide range of communication methods will be used to meet the needs of these participants. Questions will focus on the level of satisfaction with the care received and feelings of control.

#### STAGE 4: Service users' and carers' views

Analysis will provide information about the different models of issuing direct payments that are in current use for service users who lack capacity, and any issues that have arisen. These findings will result in 'a guide to current practice' which will be designed to be used as a planning tool by practitioners.

#### Project publications

In addition to the guide to current practice aimed at practitioners, the project will publish a 'FAQ' information leaflet for 'suitable persons' and service users who are taking up (or thinking of taking up) direct payments. Publications will also include a short administrative report; one or more peer-reviewed journal papers; a short note reflecting on the methods used and any issues/lessons that arise; and a brief, accessible 'Findings' document with key messages from the project. All reports and products will be freely available online, and produced in an easy read format where necessary.

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#### HOW DOES THE PROJECT FIT THE AIMS OF THE SCHOOL FOR SOCIAL CARE RESEARCH?

The research project is aimed at practitioners issuing direct payments, policy-makers, service planners, commissioners and providers in social care (both in the statutory and non-statutory sectors), brokerage and advocacy organisations. The findings of this project will enable them to better understand the process of issuing direct payments to people who may lack capacity. The project will provide information about the different models of issuing direct payments that are currently used in practice, thereby illustrating examples of good practice.

The recommendations/guide for practitioners will be of direct practical relevance, and will help equip practitioners to implement more effectively the direct payments policy as it applies to services users who lack the capacity for informed consent. This will mean that a higher proportion of disabled people, especially those with learning disabilities or dementia, receive the right support to use direct payments. It will provide accessible information on the direct payment regulations to carers and service users.

#### The NIHR School for Social Care Research

The School for Social Care Research was set up by the National Institute for Health Research to develop and improve the evidence base for adult social care practice in England. It officially launched on 1 May 2009 with funding of £15 million over five years.

The School conducts and commissions high-quality research across five overlapping programme areas:

**Prevention and reduction** – How can we best prevent or reduce the development or exacerbation of the circumstances that lead to the need for social care?

**Empowerment and safeguarding** – How can we best empower and safeguard people who use social care services?

**Care and work** – How can we best equip and support people – practitioners, volunteers, informal carers – to provide optimum social care? How can we ensure that people who use social care and their carers are enabled and supported in paid work and other types of meaningful activity?

**Service interventions, commissioning and change** – What interventions, commissioning and delivery arrangements best achieve social care outcomes?

**Resources and interfaces** – How can social care and other public resources best be deployed and combined to achieve social care outcomes?

Further information about the NIHR School for Social Care Research is available at [www.sscr.nihr.ac.uk](http://www.sscr.nihr.ac.uk)

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Mental capacity and direct payments

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Budget:  
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