

DIRECT PAYMENTS: WORKING OR NOT WORKING?





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Are direct payments working the way they should be? Informed by the experiences of people with direct payments during the Covid-19 pandemic, this report looks at how they could work better, what the issues are and how direct payments should support a good life.

The advent of the coronavirus pandemic afforded an opportunity for people involved with direct payments to reevaluate how they should work. Although direct payments are explicitly encouraged in the Care Act (2014) for people accessing care and support, experience has shown that they don't always meet people's aspirations for a more independent life.

This document re-articulates what's needed to enable people to arrange the care and support which best meets their needs and aspirations in line with the original intentions of the policy, and ultimately to contribute to a wider reform of social care.

1

INTRODUCTION

Direct payments are underscored in policy and enshrined in law. People's experience doesn't always live up to the ideal.

This resource is based on conversations during the first phase of the coronavirus pandemic. The conversations included colleagues in the Department of Health and Social Care, people who receive direct payments, those who support them and organisations that work in and around direct payment support locally, regionally and nationally. Discussions were designed to make sure guidance for direct payment recipients and those they employ was co-produced, clear and relevant. This document summarises the thinking that emerged as a result of those conversations, by what became known as the 'direct payment reference group'.

Facilitated by Think Local Act Personal (TLAP) and working co-productively, the group was able to make sure government heard about issues first hand. Whilst the group did not pretend to be fully representative of everyone with a direct payment, all those taking part talked from their own rich experiences and also drew on the insights and experience of their own extensive networks. A list of people who took part is on page 12.

At the heart of the conversations were consistent messages that people need their direct payment to work in the way originally conceived, not in the way they currently experience them. It became apparent that there is a gap between how direct payments are intended to support 'a good life' and the reality of a system that may have become unduly caught up in process.

WHO THIS DOCUMENT IS FOR

Direct payment recipients and those who support them will recognise some of these issues from their own experience. It will enable them individually and collectively to articulate the way direct payments work best to deliver better outcomes. It will help them explain to commissioners, social work practitioners, operational managers and those responsible for change and transformation what needs to be in place about rights and responsibilities.

Social work practitioners will find this a helpful reminder of the requirements of the Care Act 2014 and how it supports people to secure their wellbeing. They may find some of the tools and graphics helpful in their reflexive practice.

Commissioners can use it to evaluate the current arrangements that enable direct payments. They may identify how far they deliver the intentions of the Care Act and help people meet their desired outcomes by taking and managing a direct payment.

Staff responsible for designing and managing direct payments procedures will find it helpful to reflect on the practices they have evolved locally. They will be able to compare this to widely shared views about what good looks like and check this against views of local people.

2

LEARNING FROM COVID-19

The Covid-19 pandemic has shone a light on social care. That light has exposed things that have been working, and perhaps more the case, those that are not.

At the start of the pandemic, many people in receipt of a direct payment felt they had been forgotten. They had no effective way of ensuring government heard about their specific needs in the crisis, unlike people supported by more established parts of the sector, such as care homes and home care providers. Despite this, it seems to be the case that people with direct payment have been safer and more resilient than those supported in familiar services such as care homes.

As the sector adapts to the pandemic and hopes for a radically reformed way of organising social care, there is learning here. These lessons are rooted in policy and now established in law through the Care Act, as a result of successful campaigning by disabled people over many decades, where direct payments are seen as a key vehicle to an equal right to independent living. People's experience suggests that the law has not been implemented as originally envisaged, and the full benefits of direct payments have not been realised.

Making it Real, TLAP's framework which sets out what good care and support should look like from the perspectives of those who access services and those who work in them, was developed as an attempt to close this gap. (see Appendix)

FOUR QUESTIONS ABOUT SELF-DIRECTED SUPPORT

An action learning group looking at self-directed support, part of the **Social Care Innovation Network**, posed four questions that bring these issues to life. Our aim was to find answers to help people with direct payments realise their full potential as active citizens.

1. Whose money is it? (money for care and support taken as a direct payment)
2. Who is accountable? (for how the money is spent)
3. Can we make processes more straightforward? (getting and maintaining a direct payment and if employing a Personal Assistant, doing so well)
4. Is there a culture in the local authority of promoting self-directed support? (do they believe people can make good and safe choices and arrange good care and support themselves).

Contributing to the guidance highlighted to government policy makers how wide the gap is between the intentions of the Care Act and people's lived experience. So, when the reference group was asked to think about how direct payments should be developed in the future, it was not surprising the conversation focused on the need to get back to the roots of direct payments (and self-directed support more generally). Back to an understanding that the fundamental purpose is to enable people to arrange the care and support which best meets their needs and aspirations.

3 CORE CONCEPTS OF SELF-DIRECTED SUPPORT

When direct payment recipients were asked what needed to be in the guidance during the coronavirus outbreak, the recurring themes were:

- the need to support flexible use of the direct payment
- trusting that recipients would know best how to use their direct payment differently to stay safe and deliver the outcomes they sought
- a proportional approach to record keeping, for this to be checked in time in a proportionate way, given the context of staying safe during the pandemic
- the need to minimise process, due to staffing and workload pressures within councils at the time.

As these are all things already supported by the Care Act the group did not think new legislation was needed.

Because of this there was some reluctance to describe the specifics of what needed fixing once again. As one group member put it, 'I'm tired of going to workshops about this and saying the same things over and over and nothing different ever happening, it's like we're on a hamster wheel and can't get off'.

Without wishing to return to the wheel, the group felt some core concepts need restating as the unanimous feeling was that they have been forgotten:

- independent living and supporting its achievement to enable an equal opportunity to have a good life
- the self-directed support process developed by In Control to articulate the innovation of direct payments (see graphic on page 4)
- personal budgets which built on the In Control self-directed process and made this principle available for all eligible for adult social care
- a shift in thinking about how the health and care system works - from one where people are passive recipients gifted care and support by the state, to one of active citizenship where the state supports people to take control when they need additional support to 'maintain their wellbeing'.

These concepts are explained in the following graphics. They could be used to think about the progress that has been made in local systems and whether or not these core concepts and ambitions have been embedded and achieved. We recommend our audiences reflect on them and assess how well they have been able to realise the approach in a local offer to citizens through full and honest conversations with them.

THE 7 STEPS TO BEING IN CONTROL OF MY SUPPORT

1 My money - finding out how much



So it looks like I can get £15,000

2 Making my plan



Who else can we get to help us do this plan?

3 Getting my plan agreed



Yes - it looks like its a good plan

4 Organising my money



I'm opening a bank account for my support money

5 Organising my support



I can choose how I get my support

6 Living life



My life's changed - I'm in control

7 Seeing how it worked



It's gone well. Let's talk about what's next

1 My money - finding out how much -

Can I get money for support? How much?

2 Making my plan - I do my own plan. I

can get help to do it - as much as I need

3 Getting my plan agreed - A care

manager has to say my plan is OK

4 Organising my money - the money is

for my support - I can get it paid to me, or to someone who can look after it for me (a person, a Trust, an organisation or the care manager)

5 Organising my support - I can get help

to find and organise my support

6 Living life - I can use services but I can

spend my money on support from people in the community too

7 Seeing how it worked - I have to show

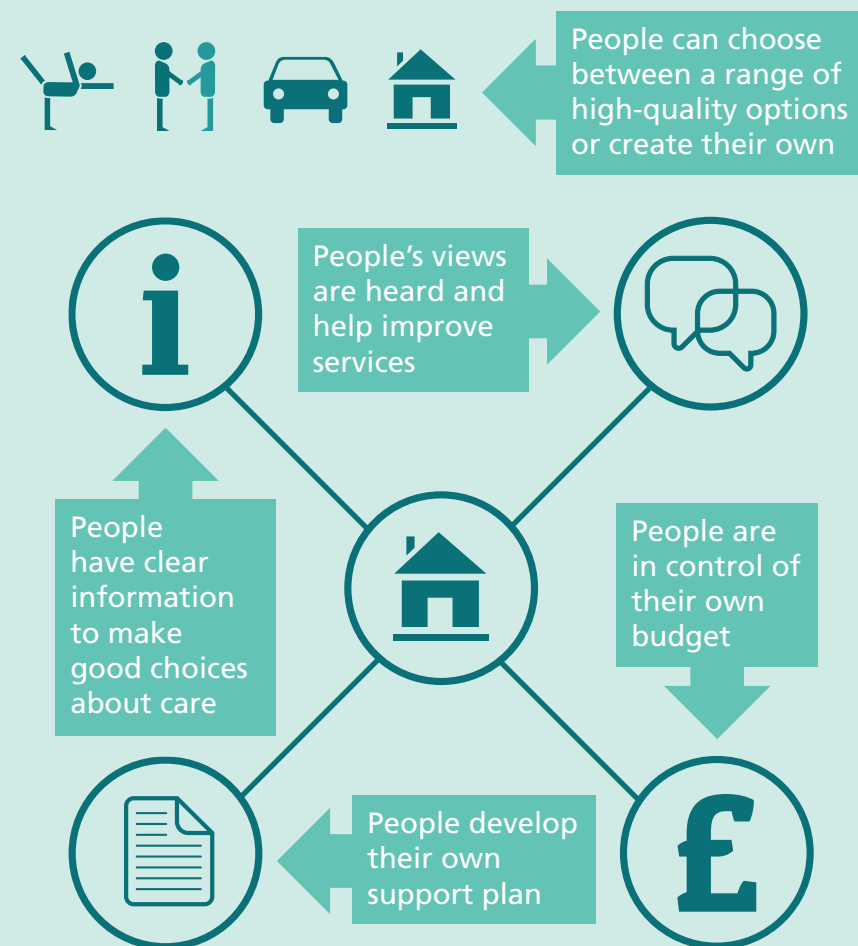
that I use the money properly.

FROM A CITIZEN PERSPECTIVE – HOW THE SYSTEM SHOULD WORK

In the current system...



In the new, person-centred system...



Source: Caring for our future: reforming care and support HM Government 2012

4

THE DEAL BETWEEN CITIZEN AND STATE

WITH A FOCUS ON DIRECT PAYMENTS

This diagram describes rights, responsibilities and undertakings between citizen and state. Some of these concepts seem to have been lost as practice has developed over time. It is consistent with In Control's self-directed support process (above). There are some fundamentals of this 'deal' that need to be clearly restated.

CITIZEN

RIGHTS

- To have as full and good a life as other citizens
- To have eligible needs met so I have the opportunity to have this full life
- To know the cost of meeting these needs
- To know all my options, their benefits and drawbacks before I choose the right option for me
- To have the help I need to choose the best option for me and get it and keep it working
- To take and manage the money if I want to in the way that works best for me
- To use the money in the way that best suits me to meet my needs
- Not to be unduly scrutinised about how I have spent the money I am entitled to
- To have things reviewed from time to time to see if everything is going well.

RESPONSIBILITIES

- To make sure all my eligible needs are met
- To look after the money for meeting these needs carefully, ensuring I can show how it's used when asked
- To be a good employer if I decide to employ my own staff, or to work well with the provider I choose if the Council arranges things.

UNDERTAKINGS

- To keep good financial records of what I've spent the money on
- To have a plan for how I will spend the money. This plan might change as life events come along. If it does, I'll let the Council/CCG know
- Not to spend the money on illegal things
- If I employ my own staff, to make sure all my responsibilities as an employer are seen to
- To let the Council or CCG have back any money I don't need, once I've decided I definitely don't need it for any future events I can't foresee now.



STATE

RIGHTS

- To decide what needs, if any, are eligible for support
- To decide a reasonable cost for meeting any eligible needs
- To decide whether making a direct payment is an appropriate way for the needs to be met, if people choose this option
- To see records of how the money has been spent and be able to understand how spend on these things has met or is meeting identified eligible needs
- To decide to stop making a direct payment
- To decide when it is best to review how things are going.

RESPONSIBILITIES

- To be transparent about decisions made
- To provide all the information and advice needed for people to make their own decisions about the best way to meet their needs
- To create a care and support plan

which details the eligible needs to be met, the cost of meeting them and the way the person has chosen to meet them. If this is a direct payment, to detail the amount and frequency of the payments

- To provide the support people need in order to manage their money and make sure if people are being employed that all associated responsibilities are being met.

UNDERTAKINGS

- To complete an assessment and care and support plan in a reasonable time
- To provide a copy of the assessment of needs made, and of the care and support plan created
- To make the payments as agreed if a direct payment is taken
- To review how things are going at reasonable intervals or when things change
- To take a balanced approach to checking that the money has been used to meet the eligible needs identified.

5 WORKING/NOT WORKING - GETTING OFF THE HAMSTER WHEEL

Working/not working is a person-centred thinking tool, promoted by many proponents of self-directed support. The group used this to think through what changes were needed to sustain the improved experience that many direct payment recipients reported during the pandemic, supported by the guidance produced by government.

The following descriptions might help different audiences think about their local arrangements and any changes they might make to enable people to realise the maximum benefit from their direct payment.

In this table the 'working' column are practices in the spirit of the Care Act, the 'not working' are practices that get in the way of direct payments working as they should. It describes alternative approaches to creating and maintaining a local system that enables direct payments. It could also be used to think about the local system for self-directed support, regardless of how people take their personal budget.

	WORKING	NOT WORKING
First contact	Helps people quickly identify whether statutory services can help them in a way that doesn't frame their view of what this help would look like.	Responds by describing the types of care and support that could be on offer, dominated by more traditional forms of support.
Assessment	Outcomes focused. A conversation helps people to identify what a good life would look like and determine which aspects require additional support and associated entitlements.	Needs focused, identifying the areas people could be entitled to support in a mechanistic fashion, framed by the Care Act wellbeing domains.
Allocation	Identifies the cost of meeting assessed needs that people are entitled to, using the cost of care and support the council would provide to meet those needs to calculate this. People are told this upfront by the person undertaking the assessment, who is empowered to decide on the amount offered (and see brokerage below also).	Identifies the cost of meeting assessed needs people are entitled to, using different rates for different ways of meeting those needs (i.e. 'a direct payment rate which is a lower rate than for paying for home care'). Decision making frequently involves reference to 'panels'.

	WORKING	NOT WORKING
Care and support planning (statutory)	Outcomes agreed in the assessment are carried forward, as is the allocation and the person's choice about taking a direct payment in lieu of services. The frequency of the payment is also detailed. Information, advice and signposting are provided to help people meet needs identified that are not eligible for statutory support.	The plan is a detailed schedule of costed services that will be put in place to meet the needs identified.
Brokerage (putting support in place)	<p>People are offered help to think through how they are going to use their direct payment to achieve their outcomes. This often comes from people like them (peer support).</p> <p>As decisions are firmed up, the true cost of care and support is determined. This is an evolving and iterative process. This might mean negotiating some fine tweaks to the initial indicative budget detailed in the care and support plan.</p>	<p>In-house brokerage services allocate work to commissioned service providers based on time and task.</p> <p>People are sometimes offered a choice of provider of services like home care. For those who want choice, a direct payment is offered to purchase these services, but often a differential rate emerges as a result (direct payment rate, home care rate).</p>
Becoming an individual employer	<p>People are offered support where they have chosen to employ their own staff to provide care and support. This is provided by people who have done this themselves (peer support) or those who have developed specialist skills in this area and whose values are rooted in promoting and delivering person-centred approaches.</p> <p>People are helped to think through recruitment focusing on values.</p> <p>They are supported to be good employers ensuring they do all the things they need to around PAYE and National Insurance and Employer Liability insurance as well as developing good employer practice such as offering training and ensuring regular supervision to review performance and development needs.</p>	<p>Information and advice about becoming an employer is provided by councils or organisations commissioned to do this on their behalf, with a focus on keeping control and managing perceived risks.</p> <p>Statutory organisations develop lists of personal assistants by using traditional recruitment approaches focusing primarily on a narrow view of relevant skills and experience rather than personal qualities and values.</p>

	WORKING	NOT WORKING
Managing money	People are offered a range of ways of managing their direct payment and helped to choose the right option for them including doing this themselves through a separate bank account; use of a payment card the statutory organisation may have pre-negotiated on their behalf; using a money management service of their choice to pay bills and process payroll paperwork.	People are offered limited options for managing their direct payment - often a payment card pre-negotiated on their behalf by the statutory organisation; or limiting the things that can be purchased by restricting the items that can be purchased on a payment card or only offering choices from an online marketplace developed by the statutory organisation.
Reviewing progress	The statutory organisation reviews their decision to make a direct payment by having a conversation with the person about the outcomes that were agreed in the assessment and how spending the direct payment has helped the person make progress with achieving the outcomes.	The statutory organisation undertakes a 'review' which often becomes a reassessment, scrutinising each item of spend to see if it considers it still eligible for statutory support, and if not, removing it from the allocation. Reviews are used as opportunities to move people onto the statutory organisation's preferred money management option, often a payment card.
Auditing spend	A proportionate approach is taken where, for most people, an audit will consist of sampling spend and checking reviews to understand how this spend has helped the person make progress with achieving their outcomes. People who need additional support to understand how to spend, in order to pursue agreed outcomes, get this support and guidance from their social worker/social care worker.	Audits involve a high degree of scrutiny where any mismatch between spend and specified ways of meeting need in prescriptive detailed care plans is considered 'in breach' and funds are 'reclaimed'.



6

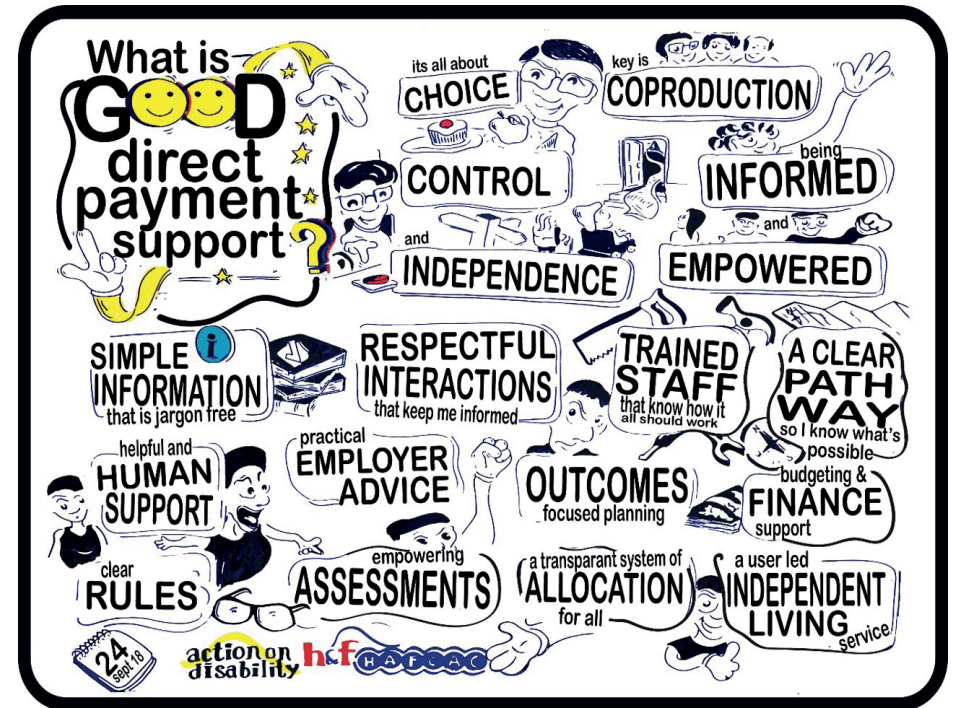
WHERE DO WE GO FROM HERE?

The experience of the direct payment reference group, originally established to support the production of guidance around Covid-19, has yielded rich thinking about how to support better direct payments. The answers are already enshrined in policy and legislation – but there is a need for further debate on how to make them a reality.

We have heard many positive stories about places in England where the pandemic guidance has been used to introduce a proportionate approach to monitoring direct payments and increased flexibilities around expenditure, in line with the intentions of the Care Act. We would like to see these improvements sustained.

We want to challenge leaders nationally, regionally and locally to use this document to help them reflect on their own local offer of direct payments, to listen to direct payment recipients they work with and support, assess and review what improvements could be achieved through their leadership.

We want to see a positive, healthy and helpful debate about the questions outlined here. Getting to these answers will contribute to a wider reform of social care, called for in all parts of the system. More importantly, it will help us all move towards the full realisation of the rights many disabled people fought hard to secure.



This is what people in Hammersmith and Fulham said good support to direct payment recipients looks like.

APPENDIX - FURTHER READING & ACKNOWLEDGEMENTS

Making It Real (2018):

Making it Real was developed co-productively by the Think Local Act Personal partnership. It describes what good, personalised care and support looks like and consists of I statements that describe an individual's perspective and We statements that express what an organisation should be doing to live up to those expectations. These examples are pertinent to the ambition for self-directed support.

- I can live the life I want and do the things that are important to me as independently as possible.
- We provide information and advice about health, social care and housing which is tailored to a person's situation without limiting their options and choices.
- I am in control of planning my care and support. If I need help with this, people who know and care about me are involved.
- I know how much money is available to meet my care and support needs. I can decide how it's used – whether it's my own money, a health or social care personal budget, or a budget managed on my behalf.
- I have considerate support delivered by competent people.

Reach Standards (2019):

The Reach standards were developed by Paradigm UK. They are a set of voluntary standards recommended by the Care Quality Commission that introduce the fundamental principles of support for living. There are strong similarities with Making It Real:

- I choose who supports me and how I am supported.
- I get help to make changes in my life.

- I choose how to be healthy and safe.
- I have the same rights and responsibilities as other citizens.

POET reports (2011, 2013, 2014, 2017):

The Personal Budgets Outcomes Evaluation Tool was developed by In Control in partnership with Lancaster University to understand the effectiveness and impact of personal budgets. TLAP has supported it by publishing their findings. Successive reports have established the things that have most positive impact on outcomes for people:

- Being fully involved in assessing needs, planning support and setting the budget.
- Having someone to support the person and carer through the planning process.
- The local authority making all aspects of the personal budget process (assessment, planning, budget setting, monitoring and review) easier and less onerous.
- Using the personal budget on community and leisure activities and being supported by personal assistants, rather than care and support services.

The evolution of government policy:

Different governments have been saying the same things incrementally over many years and have been consistent in setting a direction for the way people should be cared for and supported. This direction of travel culminated in the Care Act 2014.

continued ►

- **Valuing People (2001)** Four key principles of rights, independence, choice, inclusion lie at the heart of the Government’s proposals.
- **Our Health Our Care Our Say (2006)** We will give people more choice and a louder voice. In social care, we will increase the take-up of direct payments. We will develop a risk management framework to enable people using services to take greater control over decisions about the way they want to live their lives.
- **Putting People First (2007)** Over time, people who use social care services and their families will increasingly shape and commission their own services. Personal budgets will ensure people receiving public funding use available resources to choose their own support services – a right previously available only to self-funders. The state and statutory agencies will have a different not lesser role – more active and enabling, less controlling.
- **Valuing People Now (2010)** For people with learning disabilities and their families, transformation should mean using person-centred approaches (such as person-centred planning and support planning) and improved outcomes in terms of social inclusion, empowerment and equality.

Social Care Innovation Network: how innovations in social care can be supported by genuine self-directed support

The Social Care Innovation Network (SCIN), facilitated by Think Local Act Personal, the Social Care Institute of Excellence and Shared Lives Plus, focused its phase 2 work around action learning groups. One group centred around participating local authorities’ approach to self-directed support, in particular how direct payments were working. The outcomes were summarised in a report.

- **Taking self-directed support back to its roots (2020)**

ACKNOWLEDGEMENTS

Think Local Act Personal would like to thank the ‘reimagining self-directed support starting with direct payments’ reference group, whose discussions and thinking throughout 2020 have been summarised here.

Members of the National Co-production Advisory Group

The London Self-Directed Support Forum and some of its members

Disability Rights UK and some of its members

In Control and some of its national self-directed support network members

Learning Disability England

NHS England Personalised Care Group

Skills for Care

Chief Social Workers Office, Department of Health and Social Care

Think Local Act Personal is an alliance of over 50 national social care, health and housing partners committed to improving the delivery of personalised, community-based care and support. It brings together people who use services and family carers, central and local government, provider bodies and other key groups to work together to ensure people live better lives.

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