

# **Guidance on direct payments**

For community care, services for carers and children's services

England 2009



# DH INFORMATION READER BOX

Policy HR/Workforce Management Planning Clinical	Estates Commissioning IM & T Finance <b>Social Care/Partnership Working</b>
Document purpose	Best Practice Guidance
Gateway reference	12447
Title	Guidance on direct payments – For community care, services for carers and children's services: England 2009
Author	Department of Health
Publication date	03 Sep 2009
Target audience	Care Trust CEs, Local Authority CEs, Directors of Adult SSs, Directors of Children's SSs, Communications Leads
Circulation list	
Description	The aim of this guidance is to assist councils with social services responsibilities in making direct payments. It applies to both children's and adult services. It replaces the 2003 guidance, and has been written to reflect legislative changes that extend direct payments to previously excluded groups.
Cross-reference	N/A
Superseded documents	Community Care, Services for Carers and Children's Services (Direct Payments) Guidance England 2003
Action required	N/A
Timing	N/A
Contact	Policy Management Unit 4 Room 402, Wellington House 133–155 Waterloo Road London SE1 8UG 020 7210 4850 SCPI-Enquiries@dh.gsi.gov.uk
For recipient's use	

© Crown copyright 2009

First published September 2009

Produced by COI for the Department of Health

The text of this document may be reproduced without formal permission or charge for personal or in-house use.

www.dh.gov.uk/publications

# **Guidance on direct payments**

For community care, services for carers and children's services

England 2009

# Contents

Foreword		1
Exe	Executive summary	
Int	roduction	6
>	Aim of this guidance	6
>	Context	10
>	Scope of direct payments legislation	11
Developing direct payment services locally		13
>	Consultation	13
>	Commissioning	13
>	Support services	15
>	Advocacy	18
	<ul> <li>Support for young disabled people</li> </ul>	18
>	Complaints procedure	20
Со	nsent, capacity and ability to manage	21
>	Consent	21
>	Capacity to consent	22
	<ul> <li>Fluctuating capacity</li> </ul>	24
>	Ability to manage	26
	<ul> <li>Long-term considerations</li> </ul>	28
	<ul> <li>Enduring and lasting powers of attorney</li> </ul>	29
Using direct payments		31
>	Support for people with communication difficulties	31
>	Setting up direct payments	32
>	Assessment and care plans	34
>	Short-term needs	38
	- Short-term care in a care home	38
	– People in residential care	39
>	Equipment	40
>	Calculating the amount of a direct payment	41
>	Financial contributions	42
>	Making payments	43
>	Transfer to direct payments from direct provision	45

# Contents

Specific delivery issues			
>	Choice and risk	47	
>	Health and safety	49	
>	Close relatives	50	
>	Direct payment recipients as employers	50	
	– Employing someone suitable: children and young people	52	
	- Employing someone suitable: adults lacking mental capacity	54	
W	Where additional support is required		
>	Parents and children	57	
>	Direct payments to disabled parents with parental responsibility for a child	57	
>	Direct payments to a person with parental responsibility for a disabled child	59	
	- Intimate care for a disabled child using direct payments	60	
	- Childcare and childminding	61	
	– Education	61	
>	Transition from children's to adult services	61	
>	Direct payments for adults lacking mental capacity to consent	65	
	– Appointing a suitable person	65	
	<ul> <li>Conditions to be met by the suitable person</li> </ul>	67	
	– Where disputes arise	70	
	– Advocacy	71	
	– Approaches to risk	71	
	– Safeguarding	72	
>	Direct payments to people subject to mental health legislation	73	
>	Direct payments for carers	75	
	- Young carers	76	
Мо	onitoring and review	79	
>	Reviews for adults who lack capacity	81	
>	Financial monitoring	82	
>	Monitoring local implementation	83	

Troubleshooting		85
>	When difficulties arise	85
>	Questions to ask	87
>	When to seek repayment	89
>	Discontinuing direct payments	90
	<ul> <li>Reasons for discontinuing direct payments</li> </ul>	90
	<ul> <li>Discontinuing direct payments in the case of persons with capacity to consent</li> </ul>	91
	<ul> <li>Discontinuing direct payments in the case of persons lacking capacity to consent</li> </ul>	92
	- How to discontinue direct payments	92
Annexes		95
Annex A: Care plan for direct payments – an example		95
Annex B: Power to make direct payments		96
Annex C: Exclusions to direct payments		97
Annex D: Further information		98
Annex E: Contacts		101
Annex F: Glossary		104

# Amendment to paragraph 119 of the Guidance on Direct Payments 2009 (subject to Parliamentary approval)

The Community Care, Services for Carers and Children's Services (Direct Payments) (England) (Amendment) Regulations 2010 were laid before Parliament on 14 September 2010. The instrument amends regulations 9 and 10 of the Community Care, Services for Carers and Children's Services (Direct Payments) (England) Regulations 2009 to lift the requirement on local authorities to carry out a financial assessment when determining what amount is reasonably practicable for the direct payment recipient to pay towards securing the provision of residential accommodation. This brings the position in line with that of temporary residential accommodation directly provided by the local authority. Paragraph 119 of the Fairer Contributions Guidance is amended accordingly. The amendment reads:

119A. In considering whether to ask recipients of direct payments to make a financial contribution to the cost of their care package, the Regulations provide that the council shall determine what amount or amounts (if any) it is reasonably practicable for the payee or beneficiary to pay towards their social care support.

119B. Where a direct payment is made for an adult to enter temporary residential care, the council can determine this payment irrespective of the payee or beneficiary's means so an assessment of ability to pay a charge is not required. In such cases, where councils nonetheless decide to undertake a financial assessment, it should be in accordance with the National Assistance (Assessment of Resources) Regulations 1992 which is supported by guidance (CRAG). Where no financial assessment is undertaken, the charge made is the amount it appears reasonably practicable to the council for the resident to pay.

In all other cases (i.e. direct payments for non-residential services) the regulations provide that the council must have regard to the payee or beneficiary's means in determining the amount they should pay. The relevant guidance is Fairer Charging Policies for Home Care and other non-residential Social Services.

Fairer Contributions guidance issued in 2009 supplements the Fairer Charging guidance and provides councils with a method to help them decide how much (if anything) a person should contribute to their personal budget.

# Foreword

Direct payments are fundamental to achieving the Government's aim of increasing people's independence, choice and control by providing personalised alternatives to the social care services offered by a council with social services responsibilities.

The transformation of adult social care services initiated by *Putting People First* builds on and reinforces these principles of choice and control. Central to the transformation programme is the concept of personal budgets, giving individuals a clear understanding of how much is to be allocated for their social care support and allowing them to make their own decisions about how to spend this amount in order to meet their assessed needs. It is the Government's aim that all adults eligible for social care services will be able to have a personal budget, through which they can exercise choice and control over how their care and support are delivered.

Direct payments and personal budgets should not be seen as separate mechanisms for delivering social care services, but rather as a related set of tools enabling service users to direct how they want their care and support to be designed and delivered. The move towards personal budgets as a central component of the reform of adult social care therefore upholds direct payments as a key vehicle for managing care and support arrangements, and it is anticipated that the number of people using direct payments will increase substantially as a result.

Aiming high for disabled children: better support for families outlined the Government's aim to improve service provision across the board for disabled children and their families. It included a commitment to give families with disabled children real choice and control to design flexible service packages that respond to their needs. Direct payments are one way of enabling families and disabled young people to achieve this ambition.

Paid as cash in lieu of directly provided services, a direct payment gives the service user flexibility to look beyond 'off-the-peg' service solutions at options that may include employment, education and leisure activities as well as personal assistance to meet their assessed needs. Many people using direct payments have experienced the benefits of increased opportunities for independence, social inclusion and enhanced self-esteem.

The Health and Social Care Act 2008 amended the Health and Social Care Act 2001 to extend the scope of direct payments to include adults lacking capacity to consent to their receipt. A number of exclusions previously placed upon individuals subject to mental health legislation and to provisions of criminal justice legislation relating to mental disorder have also been lifted. As part of the wider shift towards more personalised social care services, the Government is committed to increasing the uptake of direct payments and to enabling previously excluded groups to benefit from the scheme.

th

Phil Hope MP Minister of State for Care Services

Diana Johnson MP Parliamentary Under Secretary of State for Schools

# What some recipients of direct payments say:

"The quality of my life has improved and I have regained much of my confidence. I can get out and do various activities, go to my whist club, the garden centre, the library and I am getting to grips with the internet! The support that direct payments gives me allows me to enjoy life like everyone else does. I have always played a useful part in society. I am now able to talk to other people my age (or older) about the benefits of receiving direct payments, which is good for my self-esteem. I have the freedom to make future plans, which I never thought possible."

"My husband is my husband again, now that I have a personal assistant he is not my carer all the time."

"My personal budget has paid for training courses that have given me new work skills. In turn these skills have enabled me to be self-employed, which has been crucial to me given the long periods of unemployment in my life. I have also set aside a contingency fund from my budget to use for respite breaks, which has been so important to my ongoing mental well-being. My direct payments are the safety net behind me."

"No longer do I look outside from behind the curtains of my bungalow – I am now part of the outside world."

# **Executive summary**

The aim of this guidance is to assist councils with social services responsibilities in making direct payments. It applies both to children's and to adult services. It replaces *Community Care, Services for Carers and Children's Services (Direct Payments) Guidance*, which was issued in 2003.

Direct payments are monetary payments made by councils directly to individuals who have been assessed as having needs that are eligible for certain services (including to people who care for others). Direct payments promote independence, choice and inclusion, by enabling people to purchase the assistance or services that the council would otherwise provide.

This guidance has been written to reflect the changes introduced by the Mental Capacity Act 2005, the Health and Social Care Act 2008, and the Community Care, Services for Carers and Children's Services (Direct Payments) (England) Regulations 2009. From 9 November 2009, the broad effect of these changes is to extend the system of direct payments to include people who lack the capacity to consent to the making of direct payments and to remove the exclusions that currently apply to people who are subject to various provisions of mental health legislation.

In addition, this guidance aims to reflect the Government's commitment to support independence, choice and control, as set out in *Putting People First:* A shared vision and commitment to the transformation of Adult Social Care<sup>1</sup> and Aiming high for disabled children.<sup>2</sup>

This guidance describes the legislative and policy context of direct payments. It explains how direct payments services should be developed locally, how issues of consent, capacity and ability to manage should be approached, and how direct payments should be used. It sets out specific delivery issues, explains where additional support is required and available, and describes the monitoring and review process. It also includes a section on troubleshooting. Further information and contacts are included in the annexes.

This guidance has been written primarily for use by local authorities, but the NHS and other organisations may also find it useful. Individual direct payment users may often find it more convenient to consult user guides published by the Department of Health (DH) and the Department for Children, Schools and Families (DCSF) (see Annex D).

<sup>&</sup>lt;sup>1</sup> HM Government, Putting People First: A shared vision and commitment to the transformation of Adult Social Care

<sup>(2007)</sup> www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\_081118 <sup>2</sup> HM Treasury; Department for Education and Skills, *Aiming high for disabled children: better support for families* (2007) www.hm-treasury.gov.uk/d/cyp\_disabledchildren180507.pdf

# Introduction

## Aim of this guidance

- 1. The aim of this guidance is to assist councils with social services responsibilities ('councils') in making direct payments. It applies both to children's and to adult services. Together with the annexes, it also provides guidance on how councils might manage and administer direct payments. This guidance is issued under section 7 of the Local Authority Social Services Act 1970. It replaces *Community Care, Services for Carers and Children's Services (Direct Payments) Guidance*, which was issued in 2003.
- 2. Direct payments are monetary payments made by councils directly to individuals who have been assessed as having eligible needs for certain services ('eligible needs'), including those that care for others. Direct payments are one way in which people can direct their own support. As such they promote independence, choice and inclusion by enabling people to purchase the assistance or services that the council would otherwise provide in order to live in their own homes, to be fully involved as active citizens in family and community life, and to engage in work, education and leisure.
- 3. Building on the success of direct payments, the Government is committed to personal budgets being made available to every adult eligible for social care services. Direct payments are one way in which personal budgets can be delivered by councils to meet their social services responsibilities. In this respect, generic policy and practice guidance on those social services that are the subject of personal budgets and direct payments also applies.
- 4. Direct payments were introduced in relation to social care services for adults through the Community Care (Direct Payments) Act 1996. This Act was repealed (in relation to England) by the Health and Social Care Act 2001 ('the 2001 Act') and direct payments are now governed by the 2001 Act and the Children Act 1989 ('the 1989 Act'). From April 2003 councils were required to offer direct payments to certain persons in order to enable them to obtain for themselves the services that they were assessed as needing.
- 5. The power to make direct payments to people with parental responsibility for disabled children and to disabled 16 and 17-year-olds was created by the Carers and Disabled Children Act 2000 ('the 2000 Act'). Section 17A of the 1989 Act, inserted by the 2001 Act, gave councils a duty to offer direct payments for children's services. In making direct payments under section 17A of the 1989 Act, councils are subject to the general duty provided

by Part 3 of that Act to safeguard and promote the welfare of children in need, and to promote their upbringing by their families when making these payments, in exactly the same way as when providing direct services. Before making any decision about providing direct payments, the council must ascertain and give due consideration to the child's wishes and feelings (section 17(4A) of the 1989 Act).

- 6. This guidance has been written to reflect the changes introduced mainly by amendments made to section 57 of the 2001 Act by section 146 of the Health and Social Care Act 2008, and also changes introduced by the Mental Capacity Act 2005 ('the 2005 Act') and by the Community Care, Services for Carers and Children's Services (Direct Payments) (England) Regulations 2009 ('the Regulations'). From 9 November 2009 the broad effect of the 2001 Act and the Regulations ('the direct payments legislation') is to extend the current system of direct payments to include people who lack the capacity within the meaning of the Mental Capacity Act 2005 ('capacity') to consent to the making of direct payments and to remove the exclusions which currently apply to people who are subject to various provisions of mental health legislation, particularly the Mental Health Act 1983 ('the 1983 Act'), and to provisions of criminal justice legislation relating to mental disorder.
- 7. In addition, this guidance aims to reflect the current direction of travel for adult social care as set out in the cross-sector agreement *Putting People First: A shared vision and commitment to the transformation of Adult Social Care.*<sup>3</sup> This sets out a shared ambition for radical transformation of services, promoting personalised support characterised by the ability to exercise choice and control within the context of strong and supportive local communities.
- 8. In this context, person-centred planning and self-directed support should become mainstream mechanisms for delivery of social care support. Building on the success of direct payments, every person eligible for statutory services should be able to access a personal budget a clear and upfront allocation of resources allowing them to decide how best to meet their needs. There is often a degree of confusion over the use of terms associated with these new developments. Put simply, it is helpful to think of 'self-directed support' as an overarching term describing a variety of tools to give older and disabled people greater levels of control over how their support needs are met. A personal budget is the amount of money that a council decides is necessary to spend in order to meet an individual's needs and direct payments are one way in which the person can choose to use that money in order to meet those needs. As well as being made as a direct

<sup>&</sup>lt;sup>3</sup> HM Government, Putting People First: A shared vision and commitment to the transformation of Adult Social Care (2007) www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\_081118

cash payment to the service user, a personal budget may also be held in trust by a council or third party, who will arrange services as directed by the person requiring support (an arrangement often described as a 'notional budget').

- 9. Aiming high for disabled children (AHDC)<sup>4</sup> sets out the Government's commitment to improve services and outcomes for, and to give greater choice and control to, disabled children and their families. Building on the principles underpinning direct payments, individual budgets bring together a number of funding streams and areas of expenditure to provide a more holistic and joined-up package of support for the child. Individual budgets can be held and managed by a broker, which has the advantages of: supporting parents to manage the budget better; reducing the parents' personal responsibility for arranging care; facilitating the development of tailored support designed around the particular needs of the child and family; encouraging co-ordinated provision of services; and reducing duplication in provision. Direct payments and individual budgets have key roles to play in enabling disabled children and their families to purchase the services that they need.
- 10. Not all areas of social care provision are included in the direct payments legislation, although a great many for which councils are responsible are included. The Regulations provide that the duty (or in some circumstances, a power) to offer direct payments applies to:
  - a community care service within the meaning of section 46 of the National Health Service and Community Care Act 1990;
  - a service under section 2 of the 2000 Act; or
  - a service which councils may provide under section 17 of the 1989 Act (provision of services for children in need, their families and others).

Wherever a person is assessed as needing social care services, a council should check whether there is a duty or a power to make direct payments in respect of those services.

11. This guidance has been written primarily for use by local authorities, but the NHS and other organisations that want information on the operation of direct payment schemes may also find it useful to refer to it. Individual direct payment users will often find it more convenient to consult user guides for information, which they need in order to manage their own care and support. The Department of Health (DH) and the Department for Children, Schools and Families (DCSF) publish user guides. Information about these guides can be found on the DH and DCSF websites. The guides and other helpful documents are also referenced in Annex D.

<sup>&</sup>lt;sup>4</sup> HM Treasury; Department for Education and Skills, Aiming High for Disabled Children: better support for families (2007) www.hm-treasury.gov.uk/d/cyp\_disabledchildren180507.pdf

- 12. Direct payments provide people with the freedom to design services around their specific circumstances and needs, and will remain a core component in delivering the personalisation agenda and supporting individual independence, choice and control.
- 13. Day-to-day control of the money and support package passes to the person who has the strongest incentive to ensure that it is properly spent on the care and support required, and who is best placed to judge how to use available resources to achieve the desired outcomes identified in the care plan. Depending on the circumstances, this person may be the direct beneficiary, or someone else nominated to receive the direct payments on their behalf.
- 14. Direct payments do not have to be used in the same way as if support was being provided directly by the council. Indeed, they are intended to give the individual the maximum degree of choice and control over how their eligible needs are met.
- 15. A person does not have to accept direct payments; if they wish, they can choose instead to receive services that are provided or arranged by the council. In this respect, the individual is still exercising choice over how their support is delivered. Individuals eligible for care and support should not be unfairly influenced in their choices one way or the other. However, the Government is committed to increasing the uptake of direct payments within the wider objective of making personal budgets available to all those in receipt of care and support. This includes ensuring that people from all client groups have access to the choice that direct payments bring whether the person with eligible needs is an older person, a disabled adult of working age, a carer, or a disabled child or young person, and whether or not the person has the capacity to consent to receiving direct payments. In respect of the services to which direct payments apply, direct payments should always be considered when deciding how best to meet a person's care and support needs. If the conditions are met, in most cases a council will have a duty to offer direct payments.
- 16. People assessed as having eligible needs should not be put off accepting direct payments by a lack of adequate information about how their needs can be met. Putting practical arrangements in place for self-directed support may take longer in some cases, but whether someone opts for direct payments or council-provided services, there should be no significant difference in the ease of the process.
- 17. Councils are encouraged to be proactive in making arrangements to ensure that their direct payment scheme is fully inclusive, regardless of people's age, gender, ethnic group, religion, particular impairment, personal relationships, living and caring arrangements or whether they live in an

urban or rural area. When considering whether a person's needs can be met by direct payments, councils should consider the provision of direct payments for both intensive and lower-level packages, as well as long- and short-term provision.

- 18. Councils are also encouraged to think about how direct payments can be assimilated into preventive and rehabilitative strategies. *Putting People First* emphasises the benefits of creating a strategic shift in resources and culture away from intervention at the point of crisis and instead towards prevention and early intervention, which is focused on promoting independence and improved well-being and on avoiding escalation of need at a later stage.
- 19. As part of the move towards more personalised services, the Government wants to see more extensive use of direct payments, in particular by those groups that have not made wide use of them up to now, including older people and people with mental health problems. For that reason, councils have not just a power, but a duty, to offer direct payments in most circumstances. This has important implications both for the way in which councils undertake assessment and support planning in partnership with individuals, and for councils' own commissioning procedures and planning.
- 20. Direct payments can be made to parents with parental responsibility for a disabled child, or to disabled parents with parental responsibility for a child (either to meet their own assessed needs or those of their child). In addition, if the person with assessed needs is an adult who lacks the capacity to consent to the receipt of direct payments, then subject to certain conditions, direct payments may now be made to another person on behalf of the person needing support.
- 21. In all other circumstances, including where direct payments are paid to someone nominated by the service user, the service user should remain in control, and is accountable for the way in which the direct payments are used. In the case of children who benefit from direct payments, this control will be shared with their parents, depending on the child's age and understanding. People may ask carers or other people to help them manage direct payments, for example by helping them to secure the services to which the payments relate, or by actually receiving and handling the money. However, if the service recipient is able to consent to the making of the direct payments, then they should retain overall control and responsibility for the direct payments.

### Context

22. The Government's aim, in promoting direct payments, is to increase individuals' independence and choice by giving them control over the

way that their care and support is designed and delivered. Therefore the council makes the payment or payments **instead** of providing or arranging for the provision of the services. The person then uses the payment to secure for themselves the support required to meet their needs and in so doing achieve their identified outcomes. In the case of disabled children, or children with disabled parents, a person with parental responsibility for the child, usually the parent, buys support to meet the needs of their child or the child's family. In the case of a person who lacks capacity to consent, a 'suitable person', such as a family member or friend, is appointed to use the direct payments to arrange care and support to meet the person's needs.

23. As a first principle, councils should aim to leave choice in the hands of the individual, allowing people to address their own needs as they consider best, while satisfying themselves that the agreed outcomes are being achieved. Where a child is assessed as needing services under section 17 of the 1989 Act, the council also has to be satisfied that the direct payments will 'safeguard and promote' the welfare of the child for whom the service is needed.

## Scope of direct payments legislation

- 24. Where a council makes direct payments, it retains its functions in regards to overall provision of the service under the applicable social services legislation. However, so long as the council is satisfied that the person's needs will be met through the arrangements made using direct payments, the council is not obliged to provide or arrange those services for that person.
- 25. In a few cases (see paragraph 26 below), councils have a power rather than a duty to make direct payments. Otherwise, direct payments **must** be made to all other individuals who are eligible to receive them and who want them. This might include those people in the groups listed below who have been assessed as needing relevant services:

### • Older people and disabled people aged 16 and over

This includes in particular older people who, despite being the largest single group of people using community care services, have been the least likely to access direct payments. This may also include disabled adults and disabled young people aged 16 or 17.

#### • A person with parental responsibility for a child

This may include a parent or others, such as a grandparent, with parental responsibility for a disabled child. Not all parents have parental responsibility for their children. Conversely, a carer may acquire parental responsibility

for a child, usually as a result of a court order, even if they are not one of the child's parents. This definition may also include a disabled person with parental responsibility for a child.

#### • Carers aged 16 and over

A council may decide that a person requires services because they provide, or intend to provide, a substantial amount of care on a regular basis for someone aged 18 or over. Carers (but not employees, persons working under contract or volunteers for a voluntary organisation) may obtain direct payments in respect of their own needs for services as carers.

#### • An appointed 'suitable person'

This means a person appointed to receive and manage direct payments on behalf of someone who lacks capacity to consent to the making of the direct payments. The suitable person will often, but not always, have been given a lasting power of attorney or have been appointed by the Court of Protection as a deputy under the Mental Capacity Act 2005. Usually the suitable person will be a family member or friend who may previously have been involved in the care of the person eligible for services.

- 26. In the vast majority of cases therefore, it is expected that councils will have a duty to make direct payments to people with eligible needs. However, there are some exceptions in respect of certain people subject to mental health legislation or aspects of criminal justice legislation relating to mental disorder, where councils may have a power rather than a duty to make direct payments. More detail about these exceptions can be found in the section on direct payments to people subject to mental health legislation, page 73.
- 27. People who have been placed under certain conditions or requirements by the courts in relation to drug and/or alcohol dependencies are excluded from receiving direct payments. The relevant criminal justice provisions are listed in Annex C. In such cases, the council still has a duty to provide services to meet the eligible needs of the service user, although direct payments cannot be made in respect of such needs.
- 28. Each eligible individual should be offered the choice of having their needs for a relevant service met through direct payments rather than through services provided or arranged by their local council as part of the support planning process. If individuals wish, councils can arrange mixed packages with some directly provided services and direct payments for other needs. This can, for example, give somebody the opportunity to familiarise themselves with managing direct payments before taking on responsibility for arranging support to meet all their needs.

# Developing direct payment services locally

# Consultation

*Putting People First* and *Aiming high for disabled children* describe the need to involve and engage people and organisations representing them in the design, commissioning and evaluation of services. If councils are to enhance local involvement in community care services, then they must consider ways of making direct payment services more responsive to the needs and wishes of their local community. The best direct payment schemes have been developed by councils and people needing support working together to draw up a scheme that meets local needs. Councils should avoid focusing on one group of potential recipients to the exclusion of other groups. They should not make the assumption that organised groups necessarily represent all individuals and their carers in the locality who might benefit from the flexibility offered by direct payments.

29. Care should be taken to include people with different kinds of impairment, people from different ethnic backgrounds and people of different ages in consultation. In particular, councils should consider how best to consult older people and people with mental health problems who have previously found it difficult to access direct payments, as well as people with learning disabilities and sensory impairments.

#### **Example 1: Promoting direct payments**

Council A has produced a promotional video for use with prospective direct payment recipients. Produced by the Direct Payments Advice and Information Service, this 15-minute video features a range of people talking about their experiences of obtaining and managing direct payments, and the effect they have had on their lives. Also available in a subtitled version, the video can be used by individuals who want to find out more about direct payments or who need some reassurance about the responsibilities involved. It can also be used in staff training sessions.

# Commissioning

30. Establishing systems based on choice, control and self-directed support will require councils to develop robust commissioning strategies to ensure the supply of high-quality, personalised services that people need and want to buy. This may require significant change to existing commissioning

arrangements to meet changing patterns of demand as the uptake of personal budgets and direct payments increases.<sup>5</sup>

31. Commissioners will need to focus on their use of resources, for example the local balance of investment in preventive services, community-based services and other services, so that funds can be used more flexibly. Informed by the Joint Strategic Needs Assessment, they will also need to shape local markets so that new services develop and existing services adapt to meet individual needs in more person-centred ways. Both will rely on commissioners and providers working together in partnership, with citizens at the centre of the process.

#### Example 2: Developing a flexible commissioning strategy

Council B decided it was time to revise its commissioning strategy for older people. Over a long period, the council had built up a pattern of commissioning typified by block contracts. The Joint Strategic Needs Assessment and a local consultation on personalisation raised a number of significant issues, including:

- low numbers of older people using personal budgets and direct payments;
- a lack of support planning and brokerage services available for older people;
- an increase in the uptake of residential care placements despite older people saying that living in the community was their top priority;
- poor usage of leisure facilities by older people;
- a steep decrease in the numbers of older people using day centre facilities; and
- an under-representation of older people from black and minority ethnic groups in all services.

In response, the council developed a strategy to:

- commission local user-led organisations (ULOs) to provide information, advice and support planning and brokerage services for older people using personal budgets and direct payments;
- replace block contracts for domiciliary care and other services with outcomesfocused framework contracts, underpinned by individual service funds;
- systematically disinvest in residential care (while ensuring that there is sufficient residential accommodation in the council's area), reinvesting in expanded re-ablement, assistive technologies, low-level preventive services and supported living arrangements;
- review leisure facilities to ensure that they are accessible to and catering for older people; and
- explore ways of matching people with similar interests so they can pool budgets and do more of the things they want to do during the day.

<sup>&</sup>lt;sup>5</sup> Department of Health, Commissioning for Personalisation: A Framework for Local Authority Commissioners (2008) www.dhcarenetworks.org.uk/Personalisation/PersonalisationToolkit/Blueprint/Commissioning/?parent=3110&child=3241

## Support services

- 32. Effective provision of high-quality, personalised services relies on good information and support services to enable people to know how and where to access services and to share with other service users their experiences of what works and what does not. Experience has shown that developing support services is a key determinant of successful implementation of self-directed support. Insufficient investment in support services makes it much more difficult for councils to promote personalisation of services and achieve greater uptake of direct payments.
- 33. When discussing direct payments with people, councils should consider, wherever possible, putting them in touch with a support group or ULO such as a local centre for independent living, or a peer support group of people who already receive direct payments. In addition, people who are funding their own care and support are also likely to benefit from support services offering information and advice.
- 34. Councils are encouraged to consider ways in which they can offer support in connection with personal budgets and direct payments more widely. Councils might decide that they can provide a support service directly, in partnership with a local voluntary organisation, or by some other means. Support provided through voluntary organisations and ULOs has been shown to be particularly effective and valued by recipients. The Government is committed to promoting the development of ULOs, with the aim that, by 2010, each locality should have its own ULO to support and facilitate independent living.<sup>6</sup>
- 35. The experience of existing recipients of direct payments is that they find it easier to seek advice from someone who is independent of their local council. People with personal experience of receiving direct payments, either to arrange their own support or on behalf of another person, can often be very effective advocates or mentors for people opting to receive direct payments for the first time. They can offer a valuable source of emotional support, understanding and advice, and act as positive role models to others. Parents of disabled children often have informal networks with other parents of disabled children. Strengthening such local schemes and networks and using the Core Offer could be an effective way of providing information, advice and support to parents and could help aid the rapid expansion of the direct payment scheme.<sup>7</sup>
- 36. A support service helps to produce better outcomes for both individuals and councils. When establishing and reviewing support services, councils should

<sup>&</sup>lt;sup>6</sup>www.dh.gov.uk/en/SocialCare/Socialcarereform/Userledorganisations/index.htm

<sup>&</sup>lt;sup>7</sup> The Core Offer is a statement of the standards that families with disabled children can expect across the country from local services. More information on the Core Offer can be found at www.everychildmatters.gov.uk/socialcare/ahdc/coreoffer/

seek to ensure that the range of support provided reflects the needs of local people receiving social care support and their carers. A good support service can make direct payments an accessible and attractive option for a wide range of people. Having offered direct payments where appropriate, councils should seek to ensure that people who express an interest do not have to wait unduly for further advice.

# Example 3: Providing support in connection with direct payments and personal budgets

A ULO set up and run by disabled people for disabled people won contracts to provide a range of support services across three council areas to people who have – or are interested in having – direct payments or a personal budget.

Through its independent living advisers, the ULO provides telephone support and home visits to deliver advice and information to service users on what direct payments are, how they can use them and what their responsibilities are. This means that service users are fully informed when they make a choice about receiving direct payments or personal budgets direct, and about how to manage them.

When people decide they want to receive direct payments, the ULO provides a comprehensive payroll and accounts service, supporting recipients to manage their direct payments and therefore reducing the burden of having to calculate and administer payments for their personal assistants. The ULO also helps direct payment recipients to recruit personal assistants by administering a register that users can access at any time, either if they are looking for a personal assistant or if they need emergency cover. The ULO provides training for direct payment users and their personal assistants on a wide range of topics to enable them to be confident in the day-to-day management of their care and support.

These support services help promote and encourage the uptake of personal budgets and direct payments. In 2008, the ULO supported nearly 2,500 clients through the process of accessing direct payments.

- 37. Support services might include training and practical assistance in addition to providing information, advice and peer support. Examples of the range of areas in which support might be welcomed include:
  - a list of local provider agencies or available personal assistants;
  - support and advice in setting up and maintaining a direct payment scheme, including financial management;
  - help for people to draft advertisements, job descriptions and contracts;
  - help in explaining the safeguards needed in the employment of people to work with children or adults;

- rooms for interviews and assistance with interviewing;
- an address for responses to advertisements;
- support and advice about the legal responsibilities of being an employer;
- support and advice about being a good manager of staff;
- support and advice about issues of religion and ethnicity;
- information about income tax and National Insurance;
- a payroll service;
- advice on health and safety issues, including moving and handling;
- regular training, for example on assertiveness or budgeting skills;
- some emergency cover support;
- signposting to other services such as welfare benefits and advocacy; and
- advice about user-controlled trusts.
- 38. People who receive direct payments may need particular support when they first take on responsibility for managing their own or someone else's care or become employers for the first time.
- 39. Councils will wish to ensure that local support services are sufficiently accessible to everyone eligible to receive direct payments. Skills and knowledge are required to work with people with particular support needs, especially where there are issues of consent and the ability to manage. This might include people with learning disabilities, communication difficulties or mental health problems or older people with dementia.
- 40. It is often important for a person with parental responsibility for a disabled 16 or 17-year-old to have access to support services. This may be particularly important if the 16 or 17-year-old is receiving help from their parent to manage the direct payments or if they are receiving a package of care where some elements are managed by the parent and some managed by the young person. People with parental responsibility for a disabled 16 or 17-year-old may also find it useful to meet disabled adults who receive direct payments, in order to aid preparation for the transition to adult services once the young person reaches 18. The community and voluntary sectors are often able to promote links between families with disabled children, both for parents and for children and young people.
- 41. Support services may need to contract people with specialist skills as appropriate. As the number and variety of personal budget recipients expand, councils should review the support services they provide, or arrange

to ensure that people from different backgrounds have sufficient access to peer support and other services that match their particular needs, and that the aims of the services continue to be met.

- 42. The Government has produced a national guide for people who receive direct payments<sup>8</sup> and a parents' guide for parents with disabled children.<sup>9</sup> Councils may find it helpful to supplement this with local information. Councils should also allow for differing communication requirements, for example for non-English speakers, British sign language, for deafblind people, large print, audio and Braille.
- 43. People in receipt of Independent Living Fund (ILF) awards often require similar advice to people using direct payments. Councils are encouraged to consider the needs of ILF recipients when setting up and reviewing local support services. In addition, other people such as carers of people who are receiving direct payments may also need advice about how direct payments work. This is particularly important if they are assisting their friend or relative with managing the payments. People who are considering becoming direct payment recipients on behalf of someone lacking mental capacity, for example, may be more confident about taking on the role if they know they have access to information and support.

## Advocacy

44. Many people who receive direct payments also find it helpful to have access to advocacy support. This will include some older people, people with learning disabilities and people with mental health problems, for example. Advocacy may also be useful in providing support for people who lack mental capacity to consent to the making of direct payments. A support service may also be well placed to act as an advocate for local recipients as a group when their council is considering changes to the scheme. However, it may well be preferable to separate any support role from an advocacy role on behalf of individuals to avoid any conflict of interest. Extra time may be needed to set up the direct payments to ensure that the advocate fully understands the individual's wishes.

#### Support for young disabled people

45. Young people who receive direct payments may also find it helpful to have access to advocacy support. This should be separate from any support or advocacy provided to their parents.

<sup>&</sup>lt;sup>8</sup> Department of Health, *A guide to receiving direct payments from your local council: A route to independent living* (updated 2009) www.dh.gov.uk/en/SocialCare/Socialcarereform/Personalisation/Directpayments/DH\_076522

<sup>&</sup>lt;sup>9</sup> Department for Education and Skills/Council for Disabled Children, *A parent's guide to direct payments* (2006) http:// publications.everychildmatters.gov.uk/default.aspx?PageFunction=productdetails&PageMode=publications&ProductId=D FES-0202-2006&

#### Example 4: Providing support and advocacy

Martin, who has profound and complex disabilities with high-level support needs, began to use direct payments when he became 17 years old. Although at first some professionals involved expressed their concern, Martin and his family persevered, with the help of his circle of support.

There have been plenty of ups and downs with recruiting and retaining personal assistants, but receiving direct payments has made a big difference to Martin's daily life. He is no longer totally dependent on his parents to organise interesting things for him to do each day, or to support him to do them. He has help to do ordinary everyday activities such as shopping, visits to interactive museums, swimming, eating out and going out with his friends. Most exciting for Martin, he has support during his family holiday, giving him the freedom to choose when to go out, instead of having to rely on the rest of the family. For the first time ever, Martin now spends weekends in his own home without his parents, supported by two friends who act as personal assistants, giving him all the support and attention he needs.

46. Where there is a difference of views between parents and disabled young people aged 16 or 17, the council should make their own assessment of whether the young person has the ability to manage the direct payments themselves. If, in the council's opinion, the young person is able to manage the direct payments, with appropriate support, and direct payments would be consistent with the council's duty to safeguard and promote the welfare of the young person, then it has a duty to make the payments.

#### Example 5: Differences of opinion

Jennifer is a 17-year-old with a physical disability who wishes to move away from home to go to college. To help her do this she wants to engage her own personal assistant to help her get ready for college in the mornings, rather than rely on the council domiciliary service. Her parents were unhappy at the decision as they felt that she would be unable to manage her needs independently. In addition, they were reluctant to let her leave home. The council has worked closely with the local support and advocacy services. Jennifer's parents have accessed separate advice and information and now fully support her decision. 47. In some cases, a disabled young person aged 16 or 17 may express a wish to manage direct payments but the council, after assessment (which will include seeking the parents' views), may conclude that they are not yet capable of managing direct payments by themselves, even with appropriate support. When the young person does not agree with the council's assessment, they should be advised of their right to make formal representations under section 26 of the Children Act 1989 and to have assistance to do so, including access to advocacy services.<sup>10</sup>

## **Complaints procedure**

- 48. Councils are required to operate a procedure for handling and considering any complaints that are made to them in respect of the discharge of their social services functions or about any failure to discharge those functions. The making of direct payments is a social services function within the meaning of section 1A of the Local Authority Social Services Act 1970. People who receive, or consider that they should receive, direct payments are entitled to have access to this procedure in the same way as someone whose services are provided directly or arranged by the council.
- 49. There is a similar duty under section 26 of the Children Act 1989, which can be used to complain about direct payments made under section 17A of that Act. *Getting the Best from Complaints* provides guidance for councils on implementing the Children Act 1989 complaints procedures for children and young people, with an emphasis on resolving problems quickly and effectively and learning from them.<sup>11</sup>

<sup>&</sup>lt;sup>10</sup> Department for Education and Skills, Get it Sorted: Providing Effective Advocacy Services for Children and Young People Making a Complaint under the Children Act 1989 (2004) www.dcsf.gov.uk/consultations/index.cfm?action=con Results&consultationId=1235&external=no&menu=3

<sup>&</sup>lt;sup>11</sup> Department for Education and Skills, *Getting the Best from Complaints: Social Care Complaints and Representations for Children, Young People and Others* (2006) www.everychildmatters.gov.uk/resources-and-practice/IG00152/

# Consent, capacity and ability to manage

## Consent

50. Councils may make direct payments in the following circumstances:

- i. Where a person has been assessed as having eligible needs, including disabled children aged 16 or 17, provided that the person is able to consent to the making of the payments either to themselves or to their nominee.
- ii. Where the person with eligible needs does not have the capacity to consent to the making of direct payments, the payments can be made to an appointed suitable person who will manage the payments on their behalf.
- iii. For disabled children aged under 16 or for children under 16 for whom a disabled person has parental responsibility, direct payments can be made to (and with the consent of) a person with parental responsibility, usually a parent.
- iv. Direct payments can also be made to carers to allow them to purchase the services they are assessed as needing **as carers** to support them in their caring role and to maintain their own health and well-being.
- 51. As well as giving users greater control and independence, direct payments carry with them responsibilities. The individual receiving the direct payments (directly or through a nominated person) to meet their own assessed needs and any individual receiving the payments on behalf of someone else who does not have capacity to consent is accountable to their local council for the way in which the money is spent. Users also take on responsibility for obtaining support through their own arrangements, which may involve legal responsibilities.
- 52. Councils should be satisfied that there is an understanding of what is involved in managing direct payments. This is an area where people may particularly welcome support. Obtaining consent might be a process involving continuous discussion, rather than a single event. When someone has the mental capacity to consent but needs additional support, direct payments can be made to a nominee who can help the person to manage the direct payments.
- 53. The council should also make clear that a person does not have to accept direct payments and that, alternatively, it can provide or arrange direct services if someone decides not to accept direct payments. It should also

discuss with people who are to receive direct payments what they should do if they no longer wish to receive direct payments.

54. Situations may arise where people refuse to accept direct payments because they object to a specific aspect of the terms on which the payments are offered, for example the amount or the conditions attached. In such cases, the individual should have access to the usual complaints procedures, like those who have been refused direct payments.

## **Capacity to consent**

- 55. Someone who has eligible needs but who lacks the requisite capacity to consent to direct payments can still receive them to meet their assessed needs. However, councils must still establish whether or not a person has capacity to consent before making direct payments. Councils have a duty and/or a power to offer direct payments to a person with the capacity to consent, as long as they appear to the council to be able to manage them, alone or with support. On the other hand, while councils still have a duty and/or a power to make direct payments in respect of someone who lacks the capacity to consent, it is only possible for such a person to receive direct payments if there is an appropriate and willing 'suitable person' to receive the direct payments on their behalf.
- 56. Broadly, 'mental capacity' means the ability to make a decision. Under the 2005 Act, a person lacks capacity in relation to a matter if, at the material time, they are unable to make a decision in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain.<sup>12</sup>
- 57. It is vital that each person's capacity is assessed on an individual basis, in relation to the specific decision to be made. Assumptions should never be made that someone will lack mental capacity simply because of the existence of a particular condition. Therefore, examples of an impairment or disturbance in the functioning of the mind or brain may include, **but are not limited to**:
  - conditions associated with some forms of mental illness;
  - dementia;
  - significant learning disabilities;
  - the long-term effects of brain damage;
  - physical or medical conditions that cause confusion, drowsiness or loss of consciousness;
  - delirium;

<sup>&</sup>lt;sup>12</sup> See section 2 of the Mental Capacity Act. The Code of Practice for the Mental Capacity Act provides guidance and information for anyone who works with or cares for people who lack capacity, including family, friends and unpaid carers – see www.publicguardian.gov.uk/mca/code-of-practice.htm

- concussion following a head injury; and
- the symptoms of alcohol or drug use.
- 58. Under the 2005 Act, the starting assumption must be that a person aged 16 or over has capacity to make a decision, unless it can be established that they lack such capacity. Under the 2005 Act, a person should not be treated as unable to make a decision unless all practicable steps to help them to do so have been taken without success. Therefore, before concluding that someone lacks capacity to decide whether to consent to the making of direct payments, councils should satisfy themselves that they have taken all practical steps to try to help the person to reach a decision for themselves.

#### Assessing capacity to make a decision

Councils should consider the following questions when assessing capacity to make a decision:

- Does the person have a general understanding of what decision they need to make and why they need to make it?
- Does the person have a general understanding of the likely consequences of making, or not making this decision?
- Is the person able to understand, retain, use and weigh up the information relevant to this decision?
- Can the person communicate their decision (by talking, sign language or any other means)? Would the services of a professional (such as a speech and language therapist) be helpful? Can anyone else help the person to make choices or express a view (for example, a family member, carer or advocate)?
- Is there a need for a more thorough assessment (perhaps by involving a doctor or other professional expert)?
- 59. An assessment of a person's capacity must be based on their ability to make a specific decision at the time it needs to be made, and not their ability to make decisions in general. Neither can a person's capacity be judged simply on the basis of their age, appearance or condition, or an aspect of their behaviour. Rather, anyone assessing someone's capacity to make a decision for themselves should use the two-stage test of capacity:
  - Does the person have an impairment of the mind or brain, or is there some sort of disturbance in the functioning of their mind or brain? (It does not matter whether the impairment or disturbance is temporary or permanent.)

- If so, does that impairment or disturbance mean that the person is unable to make the decision in question at the time it needs to be made?
- 60. Anybody who claims that an individual lacks capacity to consent to the making of direct payments should be able to show that they reasonably believe that the individual lacks capacity to make such a decision at the time it needs to be made. If there is any uncertainty concerning a person's capacity to consent to the making of direct payments, a council should therefore ensure that a record is kept of the steps taken to establish a lack of capacity.
- 61. Professional involvement might be needed if:
  - an assessor concludes that a person lacks capacity, and the person challenges the finding;
  - family members, carers and/or professionals disagree about a person's capacity; and/or
  - the person being assessed is expressing different views to different people they may be trying to please everyone or telling people what they think they want to hear.

#### **Fluctuating capacity**

62. Councils should give consideration to the fact that capacity is not always constant. Some people will have fluctuating capacity. They may have a problem or condition that gets worse occasionally and affects their ability to make decisions, but at other times they may be perfectly capable of making such decisions. Councils should therefore review, at appropriate intervals, the making of direct payments to someone lacking capacity to consent, to ensure that individuals with care and support needs always have as much control as possible over decisions that affect them and that any risk to their health and well-being is identified and addressed.

#### Factors indicating that someone may regain or develop capacity in the future

- The cause of the lack of capacity can be treated, either by medication or some other form of treatment or therapy.
- The lack of capacity is likely to decrease in time (for example, where it is caused by the effects of medication).
- A person with learning disabilities may learn new skills or be subject to new experiences which increase their understanding and ability to make certain decisions.
- The person may have a condition that causes capacity to come and go at various times (such as the early stages of dementia, manic depression or some forms of psychotic illness), so it may be possible to arrange for the decision to be made during a time when they do have capacity.
- 63. If a council is satisfied that a person who previously lacked capacity has regained it on a long-term or permanent basis, then it has a duty to discontinue the direct payments to the suitable person and instead to make payment to the person requiring care and support. However, before it does so, the council must consult with the person about whether they wish to receive direct payments. Most importantly, councils should not terminate direct payments to the suitable person before beginning to make direct payments to the service recipient themselves (except where councils have decided to refuse direct payments) or arrange services for them, according to their wishes and subject to their entitlement. This will ensure that there is no period when they are not receiving care and support and therefore that there is no gap in the provision of their care.
- 64. If the council is satisfied that the regaining of capacity is only temporary (i.e. that capacity will fluctuate), then it can continue to make direct payments to the suitable person. However, in this situation, the suitable person must allow the beneficiary to manage their own direct payments during any time when they have gained or regained the capacity to consent and are able to manage payments themselves. In this way, arrangements for the making of someone's direct payments do not have to be continually revisited as they lose or regain capacity. This makes things easier in practical terms for the suitable person and the council, and provides continuity of arrangements for the person requiring care and support.
- 65. Councils may wish to raise with direct payment recipients the option of giving a family member or friend a lasting power of attorney to manage their affairs relating to personal welfare should they lose the capacity to consent to direct payments at a later date (see the section on enduring and lasting powers of attorney, page 29).

## Ability to manage

- 66. Councils should not confuse whether somebody has the capability to manage direct payments, with whether they have mental capacity (within the meaning of the 2005 Act) to consent to such payments. It does not necessarily follow that because a person has capacity to consent they are also capable of managing direct payments.
- 67. If the person consents to the making of direct payments, the council has a duty, or in some cases a power, to make those direct payments. This is provided the council is not prevented from doing so for other reasons specified in the Regulations, for example if the council is not satisfied that the person's needs can be met using direct payments. In particular, the council must be satisfied that the person is capable of managing the direct payments (either alone or with available help).
- 68. If a person lacks capacity to consent and a suitable person is willing to receive direct payments on behalf of the person lacking capacity, it is the suitable person who must be capable of managing direct payments (either on their own or with available help). Provided that the suitable person meets all conditions specified in the Regulations and appears to the council to be able to manage direct payments, the council has a duty or a power, as appropriate, to make direct payments to that suitable person.
- 69. Councils should not make blanket assumptions that whole groups of people will or will not be capable of managing direct payments. A council cannot make direct payments if it cannot be satisfied that the potential beneficiary is capable of managing the payments, by themselves or with available assistance. However, very many people will be able to do so, particularly if they have access to help and support.
- 70. Where a council makes a judgement that someone is unable to manage direct payments, this should be made on an individual basis, taking into account the views of the individual and the help that may be available to them. If the council concludes that someone is not, even with assistance, able to manage direct payments, it is important to discuss with them, and in appropriate circumstances, with any family or friends the reasons for coming to such a conclusion. Where an individual does not agree with the council's judgement, they should have access to advocacy and, if available, arbitration, to ensure that their arguments are properly considered and/or they have access to complaints procedures.
- 71. Councils should give the person support and information about what receiving direct payments will involve as early in the process as possible. In order to make an informed decision, people need to understand what is involved in managing direct payments. Managing direct payments is not

simply about handling money. Direct payments also involve people making their own arrangements, with assistance if necessary, to obtain care and support which the council would otherwise have arranged or provided.

#### Advice on making decisions about the ability to manage

If a council is concerned that a person who wishes to receive direct payments may not be able to manage the payments, the council should ensure that it takes into account and subsequently records all relevant factors before making a decision not to make direct payments. These decisions may need to involve professional staff who are trained to assess capability and help people make decisions, and who should consider:

- the person's understanding of direct payments, including the actions required on their part;
- whether the person understands the implications of taking or not taking on direct payments;
- what help is available to the person;
- what kind of support the person might need to achieve their identified outcomes; and
- what arrangements the person would make to obtain this support.
- 72. If the person who is deciding whether to accept direct payments does not already have care arrangements in place, for example if they have been newly assessed, the council may need to provide services in the interim. Where the individual is expressing doubt about their ability to manage, this might mean that they are experiencing some difficulties, but this does not necessarily mean that they are incapable of managing the payments altogether. It may be appropriate to offer a mixed package of direct payments and council-arranged services to give the person experience of operating direct payments. This may be particularly useful for those people, such as older people, who are used to receiving direct services and who may need to increase their confidence.
- 73. Some people may have capacity to consent but may need help with managing the money or may simply want someone else to receive direct payments on their behalf. In such cases, the payments may be made to a third party (nominee) for the recipient and day-to-day management of finances may be delegated in this way. The nominee could, for example, also hold a lasting or enduring power of attorney for the beneficiary. However, the beneficiary must have control over how support is delivered.
- 74. Where someone needs assistance in managing direct payments, the council might wish to explore ways of delivering this so that adequate help is
available over a sustained period, not just for the set-up period. Recipients may choose to ask family or friends, advocacy or support groups to help them in this way. They might also choose to buy in assistance, for example with keeping records, management of day-to-day relationships with staff or using a payroll service.

75. In certain circumstances, a trust may take on the employment of staff and the financial management of the payments. In such cases, councils should seek to establish that there is an understanding by those appointed to manage the administration of the payments of what is involved, before making direct payments. Where the beneficiary of the direct payments has the capacity to consent, they must retain overall control over decisions and be accountable for the way in which the direct payments are used.

#### Long-term considerations

- 76. Many people with an episodic condition can manage direct payments very adequately. Nevertheless, some people may be better able to cope with direct payments if a friend, relative or some other third party is willing to provide greater assistance when their condition worsens. Statements of wishes and preferences should be used as part of the process of managing a fluctuating condition.
- 77. Provided it appears to the council that a person is currently capable of managing direct payments, or managing the payments with help, there may still be a duty or power to make direct payments, even if it is known that the person is likely to lose the ability to manage in the future. The council should make suitable arrangements to ensure that direct payments do not continue if appropriate support cannot be arranged to enable such people to continue to manage or if their condition deteriorates so they become incapable of managing payments, even with help. People whose condition is likely to fluctuate or deteriorate permanently should be given an opportunity to explore any worries they may have about their ongoing ability to manage direct payments.
- 78. Where individuals are worried about dementia or other cognitive impairment, councils may wish to direct them to an appropriate voluntary sector organisation (see Annex E). It is important that the needs of people with dementia and their carers are properly considered.<sup>13</sup> Direct payments should not be discontinued if the person requiring support is able to manage with appropriate assistance. If the service recipient loses capacity to consent, but there is someone appropriate, able and willing to act as a suitable person to receive direct payments on that person's behalf, then the

<sup>&</sup>lt;sup>13</sup> The Government published the first National Dementia Strategy in 2009, setting out initiatives designed to make the lives of people with dementia, their carers and families better and more fulfilled. (See www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Olderpeople/NationalDementiaStrategy/DH\_083362)

council should consider making direct payments under section 57(1A) of the 2001 Act to that suitable person.

## Example 6: Using direct payments to manage longer-term conditions

Mrs J is 75 years old and has dementia. She lives with her husband of a similar age who was showing signs of considerable stress in trying to support his wife to live at home. Mrs J had attended a day centre which unfortunately only resulted in further distress since it exacerbated her disorientation and led to further difficulties for Mr J when she returned home.

Mr J was struggling to cope and admitted at one stage that he could see no way out. It was agreed that Mrs J should receive direct payments, to be managed by Mr J, who was appointed by the council as a 'suitable person'. Having agreed with the council the conditions under which the direct payments would be made, Mr J used them to employ a personal assistant, involving Mrs J in the choice of person and knowing from her behaviour and response that she was happy with this particular person. Both Mr and Mrs J really warmed to the personal assistant, who would take Mrs J out when she wanted to go out or sit in the house and help her with activities she wanted to do while Mr J went out to have a break, knowing that his wife was being cared for at home. This arrangement made a huge difference to the quality of the couple's lives and Mr J reported that the direct payments had helped him get his life back.

As Mrs J's dementia advanced, her capacity to consent diminished further. Her needs were reassessed but it was established through her behaviour that she was happy with current arrangements. Therefore, a decision was taken in her best interests that Mr J should receive increased direct payments on behalf of his wife to meet her needs.

#### Enduring and lasting powers of attorney

- 79. The 2005 Act replaced the enduring power of attorney (EPA) with the lasting power of attorney (LPA). It also introduced new types of decisions that a person ('the donor') can authorise others to make on their behalf. Whereas EPAs only covered decisions relating to property and affairs (including financial matters), LPAs can also cover personal welfare decisions for people who lack capacity to make such decisions for themselves. The donor can choose one person or several to make different kinds of decisions.
- 80. EPAs can be used while the donor still has capacity to manage their own property and affairs, as can LPAs, to manage property and affairs, so long as the donor does not say otherwise in the LPA and so long as they are registered with the Office of the Public Guardian. However, personal welfare LPAs can only be used once the donor lacks capacity to make the welfare decision in question (and once the LPA is registered).

- 81. In determining whether someone is a suitable person to receive direct payments on behalf of someone who lacks capacity to consent, it would usually be expected that, where there is a willing **representative** that is to say either a court-appointed deputy or a donee of lasting power of attorney that person would act as the suitable person. However, other persons could also act as a suitable person (see the section on appointing a suitable person, page 65).
- 82. Since the 2005 Act came into force, only LPAs can be made. However, existing EPAs made before that date will continue to be valid and can still be registered and used. A person would have made an EPA in the expectation that, if they lost capacity, the person appointed as attorney would lawfully be able to continue to deal with their property and affairs once the power was registered.
- 83. Now that direct payments can be made to persons lacking capacity to consent, an attorney under an EPA could potentially act as a suitable person for the donor of the attorney, should that person lose capacity to consent to the making of the direct payments. Like any suitable person within the meaning of section 57 of the 2001 Act, the attorney under EPA would have to consent to receiving the direct payments on behalf of the person lacking capacity.

**Example 7: Using a power of attorney to plan for future care arrangements** Sue was diagnosed with early stage dementia. While meeting with her solicitor to draw up her will, Sue mentioned that she would like to make arrangements for what she wanted to happen to her should she lose the ability to make her own decisions about her health and care. Her solicitor told her about the option of an LPA which she subsequently made and registered, allowing her son Timothy to make decisions about her personal welfare, should she lack the capacity to make such decisions herself.

When it became clear that Sue's condition had considerably advanced, Timothy approached her local council for support. He did not want his mother to go into a care home and, following assessment of Sue's needs, the option of direct payments was put forward. Following an assessment of capacity, it became apparent that Sue did not have sufficient understanding of the implications of direct payments in order to consent to their receipt or take responsibility for their management. She could not communicate her needs and wishes effectively and was not consistent in her responses, sometimes answering 'yes' and sometimes 'no' to a repeated question.

As Timothy already had a registered LPA, the council suggested that he might like to receive the direct payments on behalf of his mother as a suitable person, on the understanding that she should be consulted as far as was reasonably practicable about how it should be spent to meet her needs. Sue is therefore still able to benefit from the flexibility of direct payments which provide her and her family with choice in how her care needs are met.

# **Using direct payments**

# Support for people with communication difficulties

- 84. People with learning disabilities may have little real knowledge about how their support is currently provided, who pays for this support or who controls the spending. Information about direct payments may be meaningless if people do not understand the system they are replacing. In addition, people with learning disabilities may have little control over their current support arrangements and may not even be aware that they have choices.
- 85. Valuing People Now, which sets out the Government's strategy for people with learning disabilities over the next three years, recommends starting with the assumption that everyone can benefit from personal budgets and direct payments. Councils need to ensure that there is appropriate support and a range of opportunities available from which people with learning disabilities can commission their own support to enable them to achieve their ambitions and aspirations.<sup>14</sup>
- 86. Councils will need to think carefully about how best to present information about care and support options including direct payments to people with learning disabilities and other cognitive impairments so as to maximise the potential for people to make informed decisions. Supporting people in making choices about how they want their needs to be met should be an integral part of the assessment and review process.
- 87. If it is not initially obvious how an individual communicates choices, care should be taken to involve in the process people who know the service user well and understand how they express their preferences. This will help build up a picture of the type of support which would best meet the individual's needs, desires and aspirations. For further information on how to make direct payments work for people with learning disabilities, councils may wish to consult with Values into Action, which produces a range of guidance on this subject. Details of some of their publications can be found in Annex D.

<sup>&</sup>lt;sup>14</sup> HM Government, Valuing People Now: a new three-year strategy for people with learning disabilities (2009) www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\_093377

#### Example 8: Making direct payments work for people with learning disabilities

Miss O'Leary has been unhappy at her local day centre for some time. Support workers who help Miss O'Leary get ready in the morning for the transport to the local day centre are reporting that she is often distressed and not co-operative. At the centre Miss O'Leary has begun to refuse structured groups and activities, and family and friends are concerned that she is becoming increasingly withdrawn. Through a series of meetings with support staff, family and the local advocacy organisation, she is supported to re-plan her time and focus on the things she would like to spend time doing and the people she wants to see.

Miss O'Leary decides she would like to spend more time swimming, doing voluntary work and socialising with friends in the evenings and cut down her attendance at the centre to one day per week instead of five. The council agrees to fund direct payments of £200 per week and her social worker makes an application to the Independent Living Fund (ILF) to increase the payments to £400 per week which the ILF agrees to fund. Miss O'Leary decides that rather than appoint someone to manage the direct payments she would prefer a trust arrangement. Her brother, a social worker, an advocate and a friend agree to become trustees and an independent living trust is set up to manage the payments on her behalf. The trust employs Miss O'Leary's personal assistants and manages all the financial matters associated with the direct payments. Decisions are made inclusively and Miss O'Leary is helped to recruit people she enjoys working with and review her timetable periodically. After a short time she is clearly more expressive and extrovert and the symptoms of withdrawal subside.

# Setting up direct payments

- 88. If an individual has eligible needs, then the council should work with that individual to develop a plan for their care and support. *Putting People First* sets out a vision where all people eligible for social care services should be in control of their own lives, directing the resources available to them to meet their needs in the way that suits them best. Planning in this way should be outcome-focused and person-centred, exploring what is important to the individual concerned and how they can spend their direct payments to organise and create support in order to achieve their aims.
- 89. Some people may already have ideas about how they would use direct payments, and may have discussed these with the care manager or social worker at the assessment stage. Other people may need advice or advocacy to help them think through the implications of their choices or possible alternatives they may not have considered. A local support group can be invaluable in assisting with this. If there is a local register of approved providers of services to direct payment recipients who are willing for their

details to be passed on, the council could bring the register to the attention of the individual. Councils should not *require* the individual only to contract with providers from the register, and will also need to think carefully about setting up and maintaining a register, including the potential legal implications.

90. In discussions with individuals about how their needs might be met through direct payments, councils should be prepared to be open to new ideas and be as flexible as possible. By exploring innovative and creative options, people should be encouraged to identify how they might most effectively achieve outcomes in a way that aligns with their personal wishes and preferences.

# Example 9: Using direct payments collaboratively to achieve better outcomes for individuals

Re-energise is a user-led sports and social group for people with mental health needs. Members use their direct payments to support the running of the group which focuses on recovery, relapse prevention, social inclusion and choice. Rather than seeing themselves as passive recipients of services, members of Re-energise take an active role in the group's activities and development. The group aims to promote active participation and to put the values and needs of users first.

As well as sports and leisure activities, the group organises weekly social outings such as the cinema, theatre, meals out, horticultural and cultural visits and anything else that members would like to do. As a user-led organisation, Re-energise offers its members the opportunity to share their experiences and offer one another help and advice in a friendly, relaxed and informal atmosphere. Its members have clearly felt the benefits of this kind of support. The group has grown rapidly from meeting once or twice a week with about five members to meeting every day with about 30 members and its model is now being established elsewhere in the country.

- 91. In developing care and support plans, councils will want to be satisfied that the person's assessed needs can and will be met. In the case of services for children in need, a council is required to satisfy itself that the child's welfare will be safeguarded and promoted using direct payments. Where the user's needs fluctuate over time, it will be important to discuss in advance how direct payments will be used to secure support that varies according to need.
- 92. Councils may set reasonable conditions on the direct payments, but need to bear in mind when doing so that the aim of direct payments is to give people more choice and control over their support and how it is delivered.

For example, individual choice and control would not be delivered were a condition to be set that someone who receives direct payments might only use certain providers. Conditions should be proportionate and no more extensive, in terms or number, than is reasonably necessary. Councils should also avoid setting up disproportionately intensive monitoring procedures. Financial payments should not begin until the recipient has agreed to any conditions that the council considers are necessary in connection with the direct payments. In order to avoid delays for people requiring support, councils should take all reasonable steps to resolve issues about conditions in a timely manner.

93. Many people will prefer to use direct payments to take on their own personal assistants as employees. This option gives them the most direct control over the assistance they receive, but it also carries the most responsibility (for example to pay tax, National Insurance contributions and statutory sick and maternity pay). Others may choose to contract with independent agencies and not to employ personal assistants themselves or to contract with self-employed individuals.

#### Example 10: Getting started with direct payments

As part of a community care assessment or children in need assessment in Council C, the assessor discusses with the individual the option of using direct payments. If the person decides they are interested in direct payments, the assessor completes a referral form and sends it to the direct payments project manager, who liaises with the Direct Payments Support Scheme (DPSS) to arrange a joint visit.

The project manager produces a start-up pack for each person, explaining how much their direct payments are, what date they start from, how much their contribution is, and so on. It also contains copies of the financial monitoring form and timesheets, as well as two copies of the agreement. This is taken to the individual by the DPSS, which goes through the paperwork and monitoring requirements. People are asked to forward a copy of their direct payments bank statement, financial monitoring form, timesheets and invoices to the project manager each month.

The DPSS organises a well-attended direct payments user group every three months, and produces a newsletter containing the minutes of the meeting, as well as topical issues.

## Assessment and care plans

94. Detailed policy and practice guidance on assessment (including risk assessment) already exists, and should be followed whether or not the person being assessed is likely to choose to receive care and support directly from

the council or to obtain their own support through direct payments.<sup>15</sup> Whichever form of support an individual chooses, there should be no difference in the assessment of their needs, although under the Regulations a council must also be satisfied that the person's eligible needs can be met by means of direct payments. Councils should plan with regards to outcomes, rather than specific services.

95. If encouraged, many individuals will already have clear views about where they might need assistance to achieve identified outcomes. Support might be provided for people in their own homes, including equipment and modifications to their home, or help with personal and domestic activities. People might require support to return to work, perhaps through employing a personal assistant or undertaking an educational course to improve their skills. Some people might use their direct payments to facilitate better social inclusion, others to aid their general well-being, for example through fitness classes or arts and cultural activities. Further guidance on what direct payments (and other forms of personal budget) might reasonably be spent on is published by the Chartered Institute of Public Finance and Accounting (CIPFA).<sup>16</sup>

#### Example 11: Working together to support people to live at home

Mr Smith is a young man with HIV infection. An opportunistic infection in his central nervous system has left him with severe physical impairment. Following a joint assessment with Mr Smith and the NHS, his council arrange a direct payments package enabling Mr Smith to employ a team of personal assistants to provide the ongoing social care that he needs. The package is also funded by the ILF. The council's housing department help him to move to a wheelchair-accessible flat. As a result, Mr Smith, who feared he would be discharged from hospital to a nursing home, is able to live independently and has returned to full-time employment. Assistance with the costs associated with the support that he needs at work is provided by the Access to Work scheme, which is funded by the Department for Work and Pensions.

<sup>&</sup>lt;sup>15</sup> Guidance on assessment of adults is contained in the guidance on the *Single Assessment Process*, published in January 2002 www.dh.gov.uk/en/SocialCare/Chargingandassessment/SingleAssessmentProcess/DH\_079243 and in the *Fair Access to Care Services* guidance, published in May 2002 www.dh.gov.uk/en/Publicationsandstatistics/Publications/ PublicationsPolicyandGuidance/DH\_4009653. Guidance on assessment of children is contained in the *Framework for the Assessment of Children in Need and their Families*, and requires a holistic assessment of the needs of the disabled child as well as the parents and any siblings www.dh.gov.uk/en/Publicationsandstatistics/Publications/ PublicationsPolicyandGuidance/DH\_4003256

<sup>&</sup>lt;sup>16</sup> CIPFA, Direct Payments and Individual Budgets: Managing the Finances (2007) http://secure.cipfa.org.uk/cgi-bin/ CIPFA.storefront/EN/product/HE016

- 96. Councils should also consider how direct payments might promote preventive and rehabilitative strategies. Good assessment can result in the timely provision of direct payments which may forestall the need for more extensive support in the future. People at all levels of need may be able, with the right type of tailored intervention, to reduce or even eliminate their dependency on social care support. Care and support plans should be constructed with such outcomes in mind, focusing on what people will be able to achieve with the right help, rather than simply putting arrangements in place to stop things from getting any worse.
- 97. Support planning involves allowing people to make their own informed decisions including decisions about risk. Councils have a responsibility to ensure that, wherever possible, the choices made by the individual are respected and supported. The benefits of increased autonomy and social inclusion may have to be weighed against the risks associated with particular choices. It is very important that discussions about such choices are accurately recorded in writing, to ensure that both the council and the individual are clear about any potential consequences and how the risk can be managed.<sup>17</sup>
- 98. Councils are reminded that there should always be a care plan, a written copy of which should be given to the individual. This advice applies equally where people direct their own support or where the council directly provides or arranges services. It also applies whether or not direct payments or a personal budget are received by the person receiving support or by someone else on their behalf. Annex A contains a checklist of points, which should be resolved before direct payments start and which should be covered in the care plan. The care plan should be sufficiently clear about what will be done to enable people to meet their agreed outcomes, but should not be so detailed as to undermine the service user's exercise of choice and control over their support arrangements.

<sup>&</sup>lt;sup>17</sup> More information on support planning, personalisation and risk management can be found in Department of Health, Independence, choice and risk: a guide to best practice in supported decision making (2007) www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\_074773

## Example 12: Using direct payments to meet a range of assessed needs

The following examples demonstrate how direct payments can be used to create a variety of innovative care packages that meet individuals' assessed needs in the most appropriate way and which also represent best value for money:

- Mr A lives alone and has had some difficulties in cooking his meals. Sometimes he would forget to turn off the oven or would leave the tap running by mistake. In view of this he began to use his council's meals at home service. However, while this service was good, it only allowed Mr A to heat up ready-made meals. He actually wanted support to enable him to cook for himself and become more independent. After discussions with his care manager who suggested direct payments, Mr A now pays a care worker to support him to go shopping for himself and cook healthy meals. He can choose what meals he wants to prepare and is learning more about healthy nutrition in the process.
- A group of four men with mental health needs discovered through meeting at their day centre that they all had an interest in learning to play the guitar. As this was not something that the day centre could easily provide, and having been informed about the flexibility offered by direct payments, the four decided to pool their individual direct payments to arrange guitar lessons two mornings a week. One person manages the direct payments on behalf of the group. The group agree that learning to play the guitar enables them to acquire new skills and confidence in a fun and sociable environment. They have progressed to the extent that they are now recording their own music.
- Mrs N is a Bangladeshi woman who, in order to maintain her independence and well-being, requires assistance with personal care. She was not satisfied with the services directly arranged by the council because they could not provide a personal assistant who could speak her language or demonstrate sufficient understanding of Mrs N's religious beliefs, which are particularly important to her. After discussion of the options available to her, Mrs N decides to use direct payments to pay a personal assistant from her own community to assist her. Part of her carer's role is to help her participate in prayers, including the need for cleansing in preparation.
- Miss D is 19 and has a physical disability. Her parents are separated and her father does not live locally. She has direct payments to provide her home care but does not visit her father as often as she would like. The Direct Payments Support Scheme contacted an agency in the council where her father lives about providing care while Miss D visited, and Miss D now regularly stays with her father for the weekend, using her direct payments to pay the local agency.

# Short-term needs

99. For people whose needs are short term, direct payments can support their return to independence. In such instances it will be important to discuss at the outset how the ending of the direct payments will be managed. Consideration should also be given to looking at how people could use direct payments to regain or retain their independence, and live in their own home, for as long as possible. Councils should consider in particular how to make the administration of direct payments sufficiently fast and flexible so that they can be used for hospital discharge or intermediate care.

## Example 13: Using direct payments to meet short-term needs

Mrs Khan is waiting to be discharged from hospital following a hip replacement. She has discussed with the hospital social worker the help that she will need at home with personal care and mobility while she recovers. In the past, Mrs Khan has occasionally paid a local woman that she knows to help out with heavier work around the house. Following a discussion with her social worker, she decides to get direct payments so that she can buy extra help from her neighbour to provide the support she needs day to day.

100. Many parents with parental responsibility for a disabled child will wish to use direct payments to arrange support at home or improve access for their child to services in the community. In addition, they may want to use direct payments to arrange short-term breaks for their child. Such breaks usually serve two purposes: allowing the parents more time for other activities, for example with their non-disabled children, and affording the disabled child an opportunity to make new friends and participate in new activities. Parents may look to an established voluntary organisation to provide such breaks either in foster families or residential homes or they may wish to make their own arrangements.

## Example 14: Short breaks for disabled children using direct payments

Yvonne is 14 and has severe autism and a learning disability. Her mother has direct payments for short breaks as the parent of a disabled child. She has found appropriate breaks for her daughter at specialist providers, but also employs personal assistants to take her daughter to Centre Parcs.

## Short-term care in a care home

101. Direct payments are intended to support independent living and, as such, they cannot be used to pay for adults to live for the long term in residential care. They can be made to enable people to purchase for themselves a short stay in residential care, provided that the stay does not exceed a period of four consecutive weeks in any 12-month period. The Regulations also specify that where the interim period between two stays in residential care is less than four weeks, then the two stays should be added together to make a cumulative total, which should also not exceed four weeks if it is to be paid for with direct payments. On the other hand, if two stays in residential care are more than four weeks apart then they are not added together.

- 102. Once a direct payment recipient has had four consecutive weeks in residential care, or two or more periods separated by less than four weeks which added together total four weeks, then they cannot use their direct payments to pay for any more residential care until 12 months have passed from the start of the four-week period. On the other hand, as long as each stay is less than four weeks and there is an interim period of at least four weeks between two or more stays which added together exceed four weeks, then the service recipient may use their direct payments to pay for residential breaks throughout the year.
- 103. For example, someone might have one week of residential care every six weeks. Because each week in residential care is more than four weeks apart, they are not added together. The cumulative total is only one week and the four-week limit is never reached. Another person might have three weeks in residential care, two weeks at home and then another week in residential care. The two episodes of residential care are less than four weeks apart and so they are added together making four weeks in total. The person cannot use their direct payments to purchase any more residential care within a 12-month period.
- 104. People can receive additional weeks in a care home once they have reached the four-week maximum. They cannot purchase the stay using their direct payments, but if the council considers that a longer stay is needed, it can still arrange and fund stays for the person. There is no restriction on the length of time for which the council may arrange such accommodation for someone.
- 105. Direct payments also cannot be made in relation to the provision of residential accommodation for a disabled child or disabled young person for any single period in excess of four weeks, and for more than 120 days in any period of 12 months.<sup>18</sup> The time limit is imposed to avoid inappropriate use of residential accommodation.

#### People in residential care

106. People who are living in care homes may receive direct payments in relation to non-residential care services. For example, they may have temporary access to direct payments to try out independent living arrangements before making a commitment to moving out of their care home. Direct payments can also be used by people living in care homes to take part in day-time activities. This can be particularly empowering for young people in transition.

<sup>&</sup>lt;sup>18</sup> The Community Care, Services for Carers and Children's Services (Direct Payments) (England) Regulations 2009

# Equipment

107. Councils may make direct payments to enable people to purchase equipment or adaptations that would otherwise have been provided by the council. Whether or not an individual is eligible for social care services, councils may wish to consider the benefits of making equipment or adaptations available in order to support people to live independently in their own home and reduce or eliminate their need for further support. A one-off direct payment spent on the right piece of equipment, for example, can support independence and improved outcomes.

## Example 15: Purchasing the right equipment to support independent living

Ian is blind and struggles to cook using a hob and oven. In the past, he has been used to receiving meals on wheels, but he would like to be more independent in the kitchen. With this in mind, a direct payment was used to purchase a talking microwave, which gives him voice prompts and verbal timing options, making it much easier for him to cook simple meals without having to rely on assistance.

- 108. Direct payments cannot be used to purchase services or equipment for which the council is not responsible, for example services that the NHS is required to provide. Direct payments are not a substitute for Disabled Facilities Grants.
- 109. When making direct payments, councils will need to satisfy themselves that the person's eligible needs will be met by their own arrangements. In the case of direct payments for the purchase of items of equipment, councils will wish to ensure that the direct payment recipient is adequately supported by specialist expertise. This is particularly true in the case of major items, when advice may be needed to ensure that the equipment purchased is safe and appropriate.
- 110. Where a council makes a direct payment for equipment, it needs to clarify with the individual at the outset where ownership lies as well as who has responsibility for ongoing care and maintenance (just as it should where it arranges for the provision of equipment itself). A council will need to consider what conditions, if any, should be attached to the direct payment when it is used to purchase equipment, for example concerning what will happen to the equipment if it is no longer required by the individual. Equipment can also be purchased as part of making a package cost-effective, for example supplying pagers or mobile phones to personal assistants.

# Calculating the amount of a direct payment

- 111. It is up to the council to decide on the amount of direct payments. However, the direct payments legislation provides that it must be equivalent to the council's estimate of the reasonable cost of securing the provision of the service concerned, subject to any contribution from the recipient. This means that the direct payments should be sufficient to enable the recipient lawfully to secure a service of a standard that the council considers is reasonable to fulfil the needs for the service to which the payments relate. There is no limit on the maximum or minimum amount of direct payment either in the amount of care it is intended to purchase or on the value of the direct payment.
- 112. To support the delivery of personal budgets, many councils have begun to explore resource allocation systems as a way of determining how much money a person should get in their personal budget to meet their needs. The aim of the system should be to provide a transparent process for the allocation of resources, linking money to outcomes while taking account of the different levels of support people need to achieve their goals. It allows people to know how much money they have available to spend so that they can make choices and direct the way their support is provided.<sup>19</sup>
- 113. A resource allocation system should be applied as a means of giving an approximate indication of what it may reasonably cost to meet a person's particular needs according to their individual circumstances. It is important for councils to ensure that their resource allocation process is sufficiently flexible to allow someone's individual circumstances to be taken into account when determining the amount of resources they are allocated in a personal budget.
- 114. In estimating the reasonable cost of securing the support required, councils should include associated costs that are necessarily incurred in securing provision, without which the service could not be provided or could not lawfully be provided. The particular costs involved will vary depending on the way in which the service is secured, but such costs might include recruitment costs, National Insurance, statutory holiday pay, sick pay, maternity pay, employers' liability insurance, public liability insurance and VAT. Some councils have found it helpful to include a one-off start-up fund within the direct payments to meet these costs as well as other forms of support that might be required, such as brokerage, payroll services and Criminal Records Bureau checks on employees.

<sup>&</sup>lt;sup>19</sup> DH Care Networks have produced a Resource Allocation Guide, setting out principles and challenges as well as examples of models adopted, which is available at www.dhcarenetworks.org.uk/Personalisation/PersonalisationToolkit/Blueprint/ ResourceAllocation/

- 115. A council is not obliged to fund associated costs if, taking into account the user's assessed contribution, the total costs exceed the council's estimate of the reasonable cost of securing the service and if a service of the requisite standard could in fact be secured more cost-effectively in another way. The council is also not obliged to fund particular costs that are incurred by the individual on a discretionary basis, for example non-statutory liabilities such as an *ex gratia* bonus payment. The council might decide that they are able to increase the amount of the direct payments to enable the person to arrange support in a particular way if it is satisfied that the benefits of doing so outweigh the costs and that it still represents best value. Direct payment recipients can use their own resources to purchase additional support if they wish to do so.
- 116. There may be cases where an individual thinks that the total value of the direct payments or the personal budget should be greater than the council proposes, and/or that their contribution or the amount they are asked to pay by way of reimbursement should be less than the council proposes. Where these cases cannot be resolved through discussion, councils should advise the individual that they can pursue the matter through the council's complaints procedure.
- 117. The council should give individuals as much notice as possible of the value of direct payments or a personal budget, and the contribution or repayment they will be expected to make to the cost of their care package. This should be done before the payments begin, or their level is changed, to provide the opportunity for any dispute over the level to be resolved before the payments begin or the change takes effect. If that is not possible, while any complaint is being considered, individuals may choose either to manage on the amount of direct payments being offered or to refuse to accept the direct payments. If a person does not agree to direct payments, the council remains responsible for arranging the care and support they are assessed as needing.
- 118. A preventive strategy may necessitate a higher investment to achieve long-term benefits and savings. Provision of direct payments that allow a person to remain in their own home may represent long-term savings if that person does not then require hospital or residential care. Similarly, the provision of direct payments to a person in need of rehabilitative care may result in a more sensitive and personalised service, which in turn may ease a person's recovery.

# **Financial contributions**

119. In considering whether to ask recipients of direct payments to make a financial contribution to the cost of their care package, the Regulations

provide that the council shall determine, having regard to the beneficiary's means, what amount or amounts (if any) it is reasonably practicable for the beneficiary to contribute towards their social care support. For people assessed as needing community care services or carer services that councils provide themselves, the relevant guidance is *Fairer Charging Policies for Home Care and other non-residential Social Services*. The Government has recently consulted on new guidance to accompany the existing Fairer Charging guidance, which provides councils with a model to help them decide how much (if anything) a person should contribute to their personal budget.<sup>20</sup>

- 120. There are two ways in which an individual may make a financial contribution to the cost of their care. The council may make direct payments that are equivalent to its estimate of the reasonable cost of the service and subsequently seek reimbursement (gross payment). Alternatively, the council may deduct from its estimate the assessed contribution before the payments are made and make direct payments net of the amount that the individual is expected to make (net payment). Councils should take into account the views of users when producing their policy on charging, allowing sufficient flexibility to respond to individual circumstances.
- 121. Councils are reminded that the Regulations do not give them the power to seek contributions for services provided under section 117 of the Mental Health Act 1983 (after-care). Accordingly, where councils make direct payments instead of providing services under section 117 of the Act, they may not seek payment, whether by way of reimbursement or a contribution. Where the need for services arises under section 17 of the 1989 Act and payments are made to a person with parental responsibility for a child aged 16 or 17, or to a person in receipt of certain benefits, the same restrictions on charging apply.

# **Making payments**

122. It is up to councils to decide how frequently payments should be made. In considering what procedures to put in place, councils should bear in mind the possible effect of different options on the circumstances of people who are likely to receive direct payments. People need to be in a position to pay for services when payment is due. The arrangements for making direct payments should be reliable, as late or incorrect payments may put at risk people's ability to buy the support they need. The council may also need to set up procedures for making additional payments in emergencies, for

<sup>&</sup>lt;sup>20</sup> Department of Health, Fairer Charging Policies for Home Care and other non-residential Social Services (2003) www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\_4117930; Department of Health, Fairer Contributions Guidance: A consultation on the extension and revision of the statutory guidance for charging for non-residential social services in relation to personal budgets (2009) www.dh.gov.uk/en/Consultations/Liveconsultations/DH\_093730

example if needs change or regular payments go astray. Councils should tell recipients, before direct payments begin, how and when the payments will be made, and the procedures for receiving additional payments in an emergency.

## Example 16: Using direct payment money flexibly

Mr Williams is an older man living alone, who has become blind, lost confidence and has few social contacts. He is not gregarious and does not want to go to a day centre. He feels stressed and anxious trying to cope with everyday tasks. At his assessment it is agreed that his needs are to reduce his anxiety, prepare food safely, shop, regain social activity, manage his finances, build 'mental maps' of his outdoor environment and have emotional support to help regain his independence. A direct payment package is made available to enable him to employ a personal assistant to achieve these outcomes.

As Mr Williams' confidence returns, he becomes more ambitious in his activities. He is able to 'bank' some of his direct payment in order to travel with his personal assistant to visit his granddaughter in London, a trip he has not made before. The direct payment pays for the assistant's travel while Mr Williams pays his own train fare.

Mr Williams' direct payment scheme allows him to roll forward any underspend on his package. Although this is monitored quarterly, to check that the package is working (a large unspent balance might indicate a problem in managing the payments), amounts are only adjusted annually, to give him maximum flexibility.

123. The flexibility inherent in direct payments means that individuals can adjust the amount they use from week to week and 'bank' any spare money to use as and when extra needs arise (this might be particularly helpful for people with long-term and fluctuating conditions). As long as overall the payments are being used to achieve the outcomes agreed in the care plan, the actual pattern of support does not need to be predetermined.

# Example 17: Making lump sum payments to meet occasional or fluctuating needs

Mrs Awousu is an older woman who lives with her daughter. She is very selfsufficient in many ways but she has difficulty with mobility, which puts her at risk of falls and causes anxiety for her daughter. A small home care package has been arranged to help in the mornings, but her daughter provides most of the assistance and needs a break now and again.

To allow her daughter time away, extra assistance is arranged, but it is not needed 24 hours a day. In any case, Mrs Awousu does not want someone constantly in attendance, especially as she has a personal alarm in case she should need to alert a neighbour, and she does not want to use a residential care service. In addition to the morning visit, the main periods when help is needed are at mealtimes and at night.

Social services have agreed funding to enable a suitable level of support to be purchased, to be deployed as and when Mrs Awousu wishes to use it. This has been set at a rate that allows Mrs Awousu to employ a personal assistant whom she knows and who is willing to work at the times she wants. She is there in the evenings to prepare a meal and help Mrs Awousu to bed, and she sleeps over in case any further attention is needed in the night.

Under the direct payment scheme, a lump sum is paid into the direct payment account at the beginning of the year to cover the agreed level of service. Mrs Awousu's daughter has undertaken to help her mother look after the paperwork (with initial help from the direct payment team), and sends accounts in to the finance office every three months to show how they have used the fund. At the latest review both mother and daughter report that this arrangement is working well.

# Transfer to direct payments from direct provision

124. People who are already receiving support provided or arranged by their council directly may wish to switch to direct payments. They may also wish to combine a package of direct services and direct payments. They may not raise these possibilities themselves, so the council should raise them at, or following, a person's review. This guidance applies equally to people with whom the council is undertaking an assessment for the first time and existing service users with whom the council is discussing a switch to direct payments. Where councils move to make personal budgets available to individuals eligible for social care, discussion should take place about the ways in which this budget can be deployed, including in the form of direct payments.

# Example 18: Combining direct services with direct payments to increase independence

Mr F is a young man with autism and challenging behaviour who lives with his father. Prior to receiving direct payments, he attended a day centre for five days a week and received respite care for 56 nights per year. His behaviour was challenging in both services and additional one-to-one support was required to enable him to engage in any activities.

Mr F's council has recently moved to make personal budgets its mainstream delivery mechanism for social care. It was felt that Mr F might benefit from the flexibility and choice provided by direct payments and so he reduced his day centre attendance to three days a week and employed a personal assistant to provide support on other days. With the family's general agreement, Mr F's father was appointed as a suitable person to manage the direct payments and has been able to employ a small team of care workers to support his son, limiting changes in staff contact and providing a seamless service for Mr F. Mr F is now also able to take part in activities at his mother's house, with whom he stays on a regular basis.

Mr F now has a personal budget comprising a mixed package of care that includes local authority provision, ILF-funded care and direct payments. The combination enables him to benefit from formal daycare, short breaks, social and leisure activities, domestic support and personal care. He appears to be much happier; he engages more with staff and peers and presents far less challenging behaviour.

# Specific delivery issues

# **Choice and risk**

- 125. In adult social care, the shift towards personalisation, user empowerment and self-directed support means that councils now have to work towards providing users and carers with choices, rather than just services. The issues of safeguarding and personalisation must be considered together to support the development of a joint choice, empowerment and risk policy, promoting more open and transparent practices to enable people to make informed decisions.<sup>21</sup> Safeguarding should be an integral part of mainstream activity, firmly embedded in commissioning strategies, assessments, support planning and reviews. (More information about safeguarding children is provided on page 52.)
- 126. To this end, councils will need to actively develop strategies to identify risks, assess them and manage them in partnership with direct payment recipients (as well as with all other service users). Crucially, approaches to risk should be focused on user empowerment in making choices about their care and support, individuals should also be able to make choices about the risks that they are comfortable with. Enshrined in the Mental Capacity Act is the principle that people must be assumed to have the capacity to make decisions unless it is established that they do not.
- 127. Responses to the recent consultation on the review of the *No Secrets* guidance for safeguarding adults clearly demonstrate that people want to take responsibility for the risks that they take, albeit in the context of support and partnership to facilitate such decisions.
- 128. Responses to the *No Secrets* consultation also highlighted that prevention is key to effective safeguarding. While it will never be possible to eliminate all risks, effective interventions can be made to prevent escalation and significant harm. Recipients of direct payments and other forms of personal budgets should have access to timely information, know how to get help when things go wrong and be confident that they will be listened to when they raise concerns.
- 129. Promoting the use of Criminal Records Bureau (CRB) checks is important to help ensure that appropriate staff are employed within social care. Councils should take steps to inform direct payment recipients about the option, and in some cases a duty, to make such checks on those they employ, as well

<sup>&</sup>lt;sup>21</sup> For further guidance about risk, councils should refer to the Department of Health document *Independence, choice and risk: a guide to best practice in supported decision making* (2007) www.dh.gov.uk/en/Publicationsandstatistics/ Publications/PublicationsPolicyAndGuidance/DH\_074773

as about the associated benefits and limitations of such checks. Provisions within the Safeguarding Vulnerable Groups Act 2006 also enable a new duty to be placed upon local councils to inform direct payment recipients of their right to receive information under the new Vetting and Barring Scheme when it comes into force (see the section on direct payment recipients as employers, page 50). Except where there is a duty, individuals will retain the choice about whether or not to carry out a check, but this will allow direct payment recipients the opportunity to decide how they vet the people they employ, and to ensure that they are making an informed choice.

- 130. Councils should consider the importance of regular reviews tailored to the specific needs of the individual, including consideration of the level of risk they may be exposed to. Reviews should be undertaken in partnership, allowing for the fact that people may not get everything right first time and that it is normal for people to want to change their minds and make adjustments to improve things. Where problems arise, councils should be prepared to consider the reasons for such problems. Rather than assuming that the risks to that person of receiving direct payments are too high, councils should be prepared to work with the recipient to identify changes that can enable them to manage, perhaps with a greater level of assistance in the short or longer term.
- 131. Some direct payment recipients may need only light-touch reviews, perhaps conducted over the telephone. Others, particularly those whose circle of support is limited to a very few people or those who lack capacity to consent to direct payments, may be more isolated and vulnerable and will therefore require more frequent, face-to-face reviews to prevent problems arising or early interventions to avoid escalation. (See page 79 for further information about monitoring and reviews, including arrangements for direct payment recipients lacking capacity.)

## Supporting choices about risk in adult social care

Questions to consider during support planning and at review might include the following:

- What support networks does the person have in place? Are there issues of social isolation or exclusion that might increase risk or make problems harder to identify?
- Are family members and carers in agreement with the person's choices about their care and support? If not, what can be done to resolve disputes?
- Is additional support required? Would the person benefit from further information, advice, peer support or independent advocacy?
- Does the person have particular communication requirements in order to be able to voice concerns?
- Does the person have the capacity to make their own decisions? If not, and if someone else is receiving the direct payments on the person's behalf, are there other people to provide support and make checks on the situation?
- Does the person have fluctuating or deteriorating needs that need to be monitored?
- Can the person's home environment be improved by means of specialist equipment or assistive technology?

# Health and safety

- 132. Councils will wish to consider the health and safety implications of direct payments, both for themselves and for recipients. As a general principle, councils should avoid laying down health and safety policies for individual direct payment recipients. Individuals should accept that they have a responsibility for their own health and safety, including the assessment and management of risk. They should be encouraged to develop strategies on lifting and handling and other tasks, both in the home and outside it where lifting equipment, for example, may not be available.<sup>22</sup>
- 133. As part of the process of supporting informed choice, councils will wish to take appropriate steps to satisfy themselves that recipients and potential recipients are aware of the health and safety issues that affect them as individuals, anyone they employ, and anyone else affected by the manner in which their support is delivered.

<sup>&</sup>lt;sup>22</sup> For further information, councils should refer to Health and Safety Executive (HSE) guidance on lifting and handling entitled *Handling home care* (2002). Councils should note in particular the HSE's advice that "implementation of policy and practice on lifting and handling should not place any unreasonable restrictions on the client's rights to autonomy, privacy or dignity".

134. As part of this process, councils should give the recipients and potential recipients the results of any risk assessments that were carried out as part of the initial assessment or support plan. This allows the individual to share the assessment with the care agency or the employee who provides the service. They can therefore take reasonable steps to minimise the risks to the health and safety of any staff they employ. (The recipient or potential recipient has a common law duty of care towards the person they employ.<sup>23</sup>)

# **Close relatives**

- 135. Unless a council is satisfied that it is necessary to meet a person's needs, or, in the case of a child, that it is necessary to promote the child's welfare, a council may not allow people to use direct payments to secure services from:
  - a spouse (husband or wife);
  - a civil partner;
  - the other member of the unmarried or same-sex couple of which they are a part; or
  - a close relative with whom they live, or the spouse or partner of that close relative.
- 136. This restriction is not intended to prevent people using their direct payments to employ a live-in personal assistant, provided that that person is not someone who would usually be excluded by the Regulations. The restriction applies where the relationship between the two people is primarily personal rather than contractual, for example if the people concerned would be living together in any event.

# Direct payment recipients as employers

- 137. For some people who receive direct payments, it may be their first experience of being an employer and they may welcome support during the recruitment process, whether they intend to employ a personal assistant or hire a self-employed assistant or an agency to provide services.
- 138. Individuals should be made aware of their legal responsibilities in terms of providing written details of the main terms of the employment contract within two months of commencement of the employment.<sup>24</sup> The essential terms that must be provided include, for example:
  - the date on which employment commenced;
  - hours of work;

<sup>&</sup>lt;sup>23</sup> The HSE has also published guidance on health and safety for employers and employees, entitled *Homeworking*. See www.hse.gov.uk/pubns/indg226.pdf

<sup>&</sup>lt;sup>24</sup> See section 1(3) of the Employment Rights Act 1996.

- particulars of remuneration (which must meet the national minimum wage);
- place of work;
- job title;
- whether the job is fixed-term or permanent;
- statutory entitlement to sick pay and annual leave;
- pension scheme provision (where appropriate); and
- notice requirements.

Any changes to the terms must also be notified in the same way.

- 139. If support services are provided, councils may wish to include a payroll service, which will take responsibility for administering wages, tax and National Insurance for the direct payment recipient. A written contract between the employer and the employee will help ensure that the parties have the same understanding about the terms of employment and statutory disciplinary and grievance procedures. Helpful guidance on employment law issues is also available from websites such as www.direct.gov.uk and www.businesslink.gov.uk.
- 140. Concern about becoming an employer should not be allowed to discourage people who would otherwise be willing and able to manage direct payments. The aim should be to inform the potential recipient accurately, responsibly, constructively and supportively. This should not be done in such a way as to put off the recipient, for example by overstressing the extent and complexity of these responsibilities, but neither should the council fail to make recipients aware of what is involved. Recipients should be able to make informed choices. In all cases the council remains responsible for continuing assessment and review to ensure that the person's assessed needs for services can be met by direct payments.
- 141. The only contracts that are binding on minors are contracts for 'necessaries', that is contracts for necessary goods and services. Even then, such a contract will not be enforceable against a minor if it is found to contain unreasonable and onerous terms. This will need to be taken into consideration when deciding whether to make direct payments to a disabled 16 or 17-year-old, and it is suggested that in each case legal advice be obtained.
- 142. For more detailed information regarding employment issues, individuals can refer to A guide to receiving direct payments from your local council.<sup>25</sup>

<sup>&</sup>lt;sup>25</sup> Department of Health, A guide to receiving direct payments from your local council: A route to independent living (2008) www.dh.gov.uk/en/SocialCare/Socialcarereform/Personalisation/Directpayments/DH\_076522

## Employing someone suitable: children and young people

- 143. The legal position with regards to vetting those who work with children is due to change with the introduction of the Vetting and Barring Scheme from October 2009. Therefore, consideration needs to be given both to current arrangements and to the changes that the new scheme will bring about.
- 144. At present, the Protection of Children Act 1999 enables a person who is considering employing an individual to care for their child, or a disabled 16 or 17-year-old who is considering employing a care worker themselves to ask the council to carry out checks under the Protection of Children Act 1999 via the CRB. When the person with parental responsibility or the disabled young person requests such a check the council has a duty to comply.
- 145. Councils should work in partnership with parents to help them make arrangements that are designed to safeguard and promote the welfare of the child. The majority of parents will be both willing and able to do this, but councils should only arrange direct payments for a parent of a disabled child when they are satisfied that this is the case.
- 146. If a parent still wishes to employ an individual after a CRB check has indicated the individual's unsuitability to work with children, the council would have to make it clear that it could not agree to the direct payments under these circumstances. The council's actions must be determined in the light of its duty to safeguard and promote the welfare of children in need. Councils should be aware that it is an offence under the Criminal Justice and Court Services Act 2000 if an individual knowingly offers work with children to, or procures work with children for, an individual who is disqualified from working with children, or allows such an individual to continue in such work.
- 147. When the parent or young disabled person has chosen to ask for a CRB check to be carried out, they should be advised that they may wish to continue to receive services from their council or current provider or contract with a registered agency for the services they need until the prospective candidate for employment is approved.
- 148. A council may also refer to the Secretary of State a relevant individual who it considers to be guilty of a misconduct that has harmed a child or has placed a child at risk of harm for potential inclusion on the Protection of Children Act list. Councils should make those with parental responsibilities aware that the fact that a CRB check reveals no criminal convictions does not necessarily mean that someone is a suitable person to work with children. They should still offer advice about employing someone using direct payments as outlined in the box following paragraph 156. A relevant

individual is one who is or has been employed to provide care to a child and that employment is funded by direct payments under section 17A of the Children Act 1989.

- 149. An individual wishing to work with a child will make an application for a CRB check to be carried out. The application will be countersigned by the council. A fee is required for each CRB check. The individual making the application for employment will normally be asked to pay the fee. The council may wish to consider the cost of the check in its estimate of the reasonable cost of securing the provision of the service so that the direct payment user may reimburse successful candidates.
- 150. The new Vetting and Barring Scheme will begin to be introduced in October 2009, and for those who use direct payments to work with children it will apply in two key areas. When fully operational, the Vetting and Barring Scheme will provide for people who wish to work with both vulnerable adults and children to register to undergo an advanced vetting procedure and subsequently be subject to continuously updated checks that will reveal any relevant criminal information relating to them. Once operational, parents or disabled young people employing someone in this capacity will be able to ask to check the registration details of any potential employees and to request to be kept informed of any updates to their registration status. The check will be carried out via a free online system that will not require any additional software or hardware.
- 151. Secondly, it will be an offence for any barred person to work with children in the areas covered by the scheme, or to seek or offer to do so. Anyone convicted of this offence may be liable for a prison sentence of up to five years and a fine. It will also be an offence to allow anyone known or reasonably suspected of being barred to do such work. Therefore, councils should strongly advocate that parents and disabled young people take advantage of their eligibility to check those who wish to work for them, not simply to ensure that they benefit from the additional safeguards the scheme brings, but also to ensure that unsuitable people are brought to the attention of the relevant authorities.

# Example 19: Using direct payments where there may be child protection and/or child safety concerns

Mrs Garrett cares for her son Kieran, who has Smith-Magenis Syndrome. Kieran has very limited verbal communication and needs constant supervision. Social services have organised a support package for Kieran and his family that includes attending an out-of-school club.

The staff at the out-of-school club tell Kieran's social worker about a number of bruises on his legs. In discussion with Mrs Garrett, the social worker finds that she is leaving Kieran in his bedroom so she can do housework. Kieran bruises his legs when he tries to climb over the safety gate.

The social worker arranges for a carer's assessment and occupational therapist advice on safety in the home. Mrs Garrett wants to spend more time with Kieran and her other child. Her carer's assessment includes domestic help three times a week to give her more time with the children, and she will use the direct payments to employ a local person to undertake this. Mrs Garrett wants to continue to use social services for short breaks.

Mrs Garrett is grateful for the advice about safe employment practice. The domestic worker understands the need for background checks, and Mrs Garrett asks the council to carry out these checks.

## Employing someone suitable: adults lacking mental capacity

- 152. Adults with capacity to consent to direct payments are not obliged to obtain CRB checks for someone they employ with the direct payments. Similarly, a suitable person who is a close relative (or spouse or partner of a close relative) or friend of the person lacking capacity is not required to obtain CRB checks for people they employ by means of the direct payments. However, in both cases, the council should still inform the direct payment recipient that, while a CRB check is not mandatory, they may still wish to consider obtaining one as part of their overall risk management plan. Choice should be left in the hands of the direct payment recipient, but the council should ensure that the recipient has all the information they require to make such a choice.
- 153. If, on the other hand, the suitable person managing direct payments on behalf of someone lacking capacity is not a close relative (or spouse or partner of a close relative) or friend of that person or is a corporation or an unincorporated body, then they are required by the Regulations to obtain a CRB check for anyone they engage to provide services with the direct payments.

- 154. In this case, the suitable person unknown to the person requiring care will be a regulated activity provider under section 6 of the Safeguarding Vulnerable Groups Act 2006 ('the 2006 Act'). Under the 2006 Act a person is a regulated activity provider if, among other things, they are responsible for the management or control of regulated activity and they make, or authorise the making of, arrangements for another person to engage in that activity. A regulated activity includes any form of care for or supervision of vulnerable adults and any form of care for or supervision of children (unless the care or supervision is merely incidental to care for or supervision of persons who are not children).
- 155. However, a person who is someone's surrogate is not a regulated activity provider (see section 6(8B) of the 2006 Act) when consenting to the suitable person receiving direct payments or when deciding whether someone should be a suitable person. Under the 2001 Act and the Regulations, a surrogate of a person is a donee of a lasting power of attorney created by that person or a deputy appointed by the Court of Protection who has been given powers relating to decisions about securing community care services to meet that person's needs. A suitable person who is a regulated activity provider will be required to ascertain that anyone they employ to provide services is not barred from engaging in the regulated activity concerning vulnerable adults. When the new Vetting and Barring Scheme comes fully into force, the regulated activity provider will be required to monitoring in relation to the regulated activity.
- 156. More generally, people using direct payments to employ someone (whether to provide services to themselves or to another person lacking mental capacity) will be able to check that employee's registration with the Vetting and Barring Scheme and register an interest in any updates to their status (i.e. they will be informed if a person ceases to be registered with the Vetting and Barring Scheme). The scheme works in a very similar way with regards to vulnerable adults (including direct payment recipients) as it does for children (see paragraphs 150 and 151 above).

## Advice about employing someone using direct payments

The information given to direct payment recipients should cover the following general advice:

- Be suitably cautious. If you have any doubts about the individual, do not take them on.
- Always ask for two written references and check them carefully following up with a telephone call is often advisable.

- Ask all the questions that are important to you, for example about smoking and eating habits or what their hobbies are. If you are employing someone to look after your child, you need to find out where they might be taken, and any other individuals the child might have contact with when being cared for.
- Get a friend, parent or someone you trust to spend some time with you and your new personal assistant initially.
- Make sure that the personal assistant has your support and welfare, or that of your child, as their priority.
- If you are unhappy with the person caring for you, seek advice and try to find someone else.

# In addition, when employing someone to look after a child or where the employer is a 16 or 17-year-old:

- If you choose to ask for a criminal records check, ensure that such a check has been completed within the last month.
- Take note and listen to everything that your child is communicating about the care they receive. Especially with non-verbal children, take note of unusual or regressive behaviour.
- Try to spend time ensuring that your child is able to settle with the new person.
- Do not employ someone under the age of 16 to undertake a paid caring role as people under 16 are unlikely to be sufficiently mature to take on such a responsibility.
- Information about the risk of child maltreatment should be clear and straightforward without unnecessarily raising anxieties.
- See A parent's guide to direct payments at www.everychildmatters.gov.uk

# In addition, in the case of a suitable person employing someone on behalf of an adult who lacks capacity:

- If you choose to ask for a criminal records check or if one is required, ensure that such a check has been completed within the last month.
- As far as is reasonably practicable, take note and listen to everything that the person lacking capacity is communicating about the care they receive. Consult family members, friends and carers who might have particular experience of communicating with the person.
- Anyone who thinks that someone might be abusing a vulnerable adult who lacks capacity should contact their local council or the Office of the Public Guardian or seek advice through the Community Legal Service.<sup>26</sup>

<sup>&</sup>lt;sup>26</sup> See Department for Constitutional Affairs, *Mental Capacity Act 2005: Code of Practice* (2007) www.dca.gov.uk/legal-policy/mental-capacity/mca-cp.pdf

# Where additional support is required

# Parents and children

157. Existing guidance emphasises the importance of:

- the family as the natural and most appropriate place for children;
- councils working in partnership with parents;
- recognising that children are individuals with their own wishes and feelings; and
- holistic, multi-agency and co-ordinated family assessment, taking account of the needs and views of children and parents.<sup>27</sup>
- 158. Councils are required to provide information about services available in their area.<sup>28</sup> It will be essential that families have information about the full range of services, including the option of direct payments.

# Direct payments to disabled parents with parental responsibility for a child

- 159. The former Commission for Social Care Inspection report *Supporting Disabled Parents* found that disabled parents and their families continue to face difficulties in accessing services which support family life.<sup>29</sup> Needs assessments for disabled adults should include parenting responsibilities, and councils should ensure a co-ordinated approach between adult and children's services and with other agencies. The availability of advocacy and brokerage schemes can support families to benefit from the flexibility and choice offered by personal budgets and direct payments.
- 160. Disabled people who are parents could be assessed as needing services under both community care legislation and/or the 1989 Act to assist them in their parenting role. This means that direct payments can be used to meet the social care needs of them, their children or their family that arise from their disability. It is important that the needs of the disabled person and their family are looked at holistically, bearing in mind that specific duties may arise under particular legislation. In the interest of the family and to avoid duplication, councils should ensure that the assessment process

<sup>&</sup>lt;sup>27</sup> See the Assessment Framework, paragraph 3.32 and the National Service Framework for Children, Young People and Maternity Services: disabled children and young people and those with complex health needs (Standard 8)

<sup>&</sup>lt;sup>28</sup> Children Act 1989, section 17 and Schedule 2, Part 1

<sup>&</sup>lt;sup>29</sup> Commission for Social Care Inspection, Supporting disabled parents: a family or a fragmented approach? (2009)

is streamlined and co-ordinated between adult and children's services and other relevant departments.

# Example 20: Using direct payments to support disabled parents

Ms Marks is 28 and recently became a mother for the first time. Shortly after the birth, Ms Marks had a sudden onset of multiple sclerosis, which left her with paralysis from the chest downward. She called on social services for support. In addition to her own needs as an individual, she was especially concerned about the impact on her relationship with her new baby and the potential consequences of a loss of physical contact. Without help Ms Marks would be unable to care for the baby during the week when her partner was at work, but she also wanted to make sure she had time on her own with her family. Her social worker informed her that she could get services to support her in carrying out parenting tasks and sent her a leaflet about direct payments.

Ms Marks is offered support from Monday to Friday while her partner is at work. Following the assessment framework, the social worker focused particularly on family and environmental factors affecting Ms Marks' capacity to parent and the potential of community care and children's services to meet the needs of the family in the round. Following this, the social worker set up a meeting with the direct payment support service. The direct payments adviser helped Ms Marks and her partner to write a job description, advertise and recruit someone to support her with looking after her baby.

Under Ms Marks' direction, the personal assistant is able to support the baby on her mother's knee, allowing her to cuddle and hold her. Ms Marks has the help she needs to feed the baby with a bottle, and support with other tasks such as lifting and bathing the baby. In a short time, the baby learnt how to hold on to her mother, so that she can pick the baby up without support, and the personal assistant is able to take a more appropriate supporting role rather than direct caring. With the support she receives, Ms Marks is also able to prepare an evening meal for the family, which gives her partner the freedom to spend more time with the baby, and reduces the stress on the family.

161. Where there is a disabled parent, the council may be under a duty to assist the family if they are assessed as needing help in bringing up their child.

## Example 21: Supporting parents with mental health problems

Ms Jones is a mother of two children aged 17 and 10. She has a long history of severe mental health problems, and multiple hospital admissions. After the birth of her younger child, she was in hospital for a long time and it was not expected that she would be able to care for her family. However, she went home with support provided every night, and looked after her children. The agency providing the support often sent new people, which caused her considerable anxiety. Sometimes they let her down, and the children were distressed by the intrusive nature of the arrangement.

Reviewing the situation, the social worker arranged contact with the direct payments adviser. Because Ms Jones was anxious, and finds change difficult, the process had to be very slow. She was supported at this time by her advocate and by the community mental health team. Gradually she gained confidence. She is impressed with how clear the direct payments adviser was about roles and the processes involved. She feels this is particularly important for people with mental health issues.

Ms Jones has now been on direct payments for two and half years and says she will never go back to how her support used to be provided. She has a team of two personal assistants plus two back-ups, providing cover every night. They have never let her down and are extremely committed to her. She has had no hospital admissions since she started direct payments, has gained in confidence, and now finds that even doing the direct payments administration gives her a sense of achievement. The children have particularly benefited from direct payments. They have a stable family life. They know the personal assistants well and have consistency in their lives. They have all been on holiday for the first time as a family, with a personal assistant joining them.

For social services and other professionals involved, investment in a long planning process, following a long period of dependency, has resulted in a sustainable, good-quality outcome for the whole family.

# Direct payments to a person with parental responsibility for a disabled child

- 162. In this section, the terms 'parent' and 'parents' refer to any person who has parental responsibility for a disabled child, whether or not they are also the child's parent.
- 163. Where a parent opts for direct payments, councils remain responsible under the 1989 Act for assessing and reviewing the needs of the child and their family in the normal way.

- 164. In considering direct payments, some parents will require advice about their child's need for additional support or protection. Other parents need support and sometimes permission to let their disabled child take risks in their everyday lives. This may include allowing their 16 or 17-year-old to manage their own support through direct payments.
- 165. Councils should make clear the steps that people with parental responsibility for a disabled child ought to take to satisfy themselves that the person offering help with the care of their child is an appropriate person.<sup>30</sup> It is important that people with parental responsibility for disabled children are fully alerted to any risks of abuse and provided with advice to minimise those risks. Parents should ensure that any childcare they pay for is either provided by a school or that the provider is registered with Ofsted, so that they can be sure that individuals who are caring for their child (and in the case of childminders, any other adult living in the childminder's home) have an up-to-date Criminal Records Bureau (CRB) check.
- 166. The responsibilities of people with parental responsibility for disabled children are often made more arduous by the difficulty of accessing mainstream services such as childcare, after school clubs and leisure activities. Families with disabled children may not think existing services provided or commissioned by their local council are suitable for their child and may well be able to make more appropriate arrangements for themselves. Direct payments can enable people with parental responsibility for a disabled child to make such arrangements.
- 167. Parents should be encouraged and supported to use direct payments with a view to enabling their disabled children to access the same kinds of opportunities and activities as their non-disabled peers. Direct payments to people with parental responsibility for a disabled child are provided within the framework of Part 3 of the 1989 Act, which requires councils to provide a range of services to safeguard and promote the welfare of children in need.

## Intimate care for a disabled child using direct payments

168. Parents may use direct payments to purchase services of an intimate nature to meet the assessed needs of their disabled children. However, as children mature, parents should be encouraged to give greater weight to the child's views about how their intimate care needs are to be met. Particular care should be taken to ascertain the child's wishes when they have a cognitive and/or communication impairment.

<sup>&</sup>lt;sup>30</sup> HM Government, Working Together to Safeguard Children (2006)

# Childcare and childminding

- 169. Councils should make available the list of Ofsted registered childminders and other Ofsted registered providers of childcare in their area through their Families Information Service. Parents can find their nearest Families Information Service by calling 0800 234 6346. The service can also advise, for example, on which childcare providers have facilities appropriate to the needs of a particular child.
- 170. Section 79D of the 1989 Act states that anyone caring for a child under 8 for over two hours a day and for payment in their own home has to be registered with Ofsted as a childminder. Parents of disabled children should be aware of this requirement, designed to safeguard the welfare of young children, when purchasing support via direct payments.
- 171. As well as use of direct payments, there is other financial support available to help pay for childcare – including childminders. All 3 and 4-year-olds can now benefit from a minimum of 12.5 hours a week of free early years provision. This will rise to 15 hours a week by 2010. In some local areas free provision is also available for 2-year-olds.
- 172. Parents may also be entitled to help with the costs of childcare through the childcare element of Working Tax Credit. An online calculator is available at www.taxcredits.inlandrevenue.gov.uk/Qualify/DIQHousehold.aspx
- 173. Guides to choosing childcare for children up to the age of 16 can be downloaded free from: http://publications.dcsf.gov.uk/default.aspx?
  PageFunction=productdetails&PageMode=publications&ProductId= DCSF-00126-2009&

# Education

174. Social services departments are encouraged to develop appropriate links with educational services and with the Connexions service. Connexions makes available a network of personal advisers to 13 to 19-year-olds to ensure that the needs of young people are met in an integrated and co-ordinated manner. They have specific responsibilities towards disabled young people and where necessary can continue working with disabled young people until the age of 25. They should inform disabled young people about direct payments.

# Transition from children's to adult services

175. Parents often face challenges or problems in supporting and preparing their children for an independent adult life. The transition to financial independence and independent living is not usually a single event, nor does it happen quickly.<sup>31</sup> Families with disabled children often face additional challenges that may delay or limit the children's move towards independence. For any young person (with or without a disability) the process of growing up involves the gradual taking on of more and more responsibility for themselves.

176. In some cases the young disabled person at age 16 or 17 may wish, as part of the transition to adulthood, to take control of part or all of the direct payments that have to date been managed by the person with parental responsibility. This can allow them to gain experience of managing direct payments in a gradual way prior to reaching adulthood.

#### **Example 22: Increasing independence**

Zenab left home during term time to attend a special residential boarding college. The subject of direct payments had been introduced into the curriculum as preparation for adult life. Zenab's parents were reluctant to agree to the college placement, but did so for educational reasons once they were satisfied about the degree of supervision of the students.

For the last three years Zenab has been going to a social group for disabled children during the holidays. However, Zenab is tiring of this service and wants direct payments to employ a personal assistant so that she can organise alternative means of meeting people her own age. Following discussion with the social worker, the family accepts that it could be in Zenab's best interests and agrees to a trial period of direct payments for a short vacation.

- 177. Disabled 16 and 17-year-olds are entitled to take advantage of the flexibility of direct payments where this will safeguard and promote their welfare. Direct payments enable them to make more decisions for themselves and to provide opportunities for them to have more control over their lives.
- 178. Some disabled 16 and 17-year-olds may have previous experience of direct payments because their parents are receiving them to meet the family's needs. However, many disabled 16 and 17-year-olds' parents will have been receiving services direct from their council.
- 179. A way to develop a young person's ability to manage the direct payments can be to put in place transitional arrangements, initially set up with the young person managing only a proportion of their support with direct payments. This proportion could increase as the young person matures, with the objective of full management of the support package at age 18.

<sup>&</sup>lt;sup>31</sup> For more information on developing local transition services visit www.everychildmatters.gov.uk/resources-and-practice/ IG00322

# Example 23: Enabling social inclusion for young people with high support needs

Jack is 17, lives with a foster family and goes to a residential special school. He communicates by body language and has clear ways of saying 'yes' and 'no'. During the school holidays, Jack employs a personal assistant, Mark, who is very skilled at understanding Jack's communication. Through Mark's assistance, Jack has been able to develop his interest in digital arts, attend summer schools and make new friends in his local area.

180. Young disabled people may receive assistance with managing the direct payments, just as any other direct payment recipient may do. Where that assistance takes the form of a user-controlled trust or similar arrangement, it should be set up in the knowledge of the views of those people with parental responsibility. Their ability to express their views should not be undermined by the arrangement.

# Example 24: Overcoming disabling barriers with direct payments

Adam has just reached school leaving age. His transition plan agreed at the last review of his statement of special educational needs stated that he would receive home tutoring with a new internet learning pack because he has to have a series of minor operations in the next academic year. He has previously attended residential school where there is the possibility of regular weekend respite. He needs constant attendance and therefore his return to home places high demands on his parents and siblings.

Following an assessment of the needs of Adam and his family, it is decided that Adam will receive direct payments so that he can employ a personal assistant to help him travel to the football stadium and pool hall. He will receive local council transport to go to some organised social and cultural activities at school, including a voluntary organisation-led support group for young disabled people at transition. In addition, Adam's parents will receive direct payments to employ the same personal assistant to ensure that Adam is not left alone when all the other members of his family have work and other unavoidable commitments.

181. The above case study highlights how services and direct payments can be used imaginatively by seeking to overcome disabling barriers that prevent the child from accessing social and leisure opportunities available to non-disabled peers. It also shows the importance of linking the different agencies that support disabled children.<sup>32</sup>

<sup>&</sup>lt;sup>32</sup> Department of Health, Assessing Children in Need and their Families: practice guidance (2000), paragraph 3.70 – www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\_4006576
182. It will be important for councils to recognise and respect the views of parents who have been managing the delivery of support for their child in setting in place any new arrangements once the young person reaches their majority. There may be situations where a parent has been receiving direct payments to meet the assessed needs of their child who, on reaching the age of 18, does not have the requisite mental capacity to consent to the making of those direct payments. In such cases, it will often be appropriate for the person with parental responsibility to continue to receive the direct payments for the young adult lacking capacity, in the role of a suitable person. This will ensure continuity of care for the young person, through arrangements made by the person who is likely to be best placed to understand their needs and preferences. However, direct payments to the person who had parental responsibility can only continue in this way with that person's consent. Councils should ensure that they make appropriate arrangements to prepare for transition so that, whether or not support is provided through direct payments, there is no disruption to the provision of support.

### Example 25: Planning transition for young people lacking capacity

Michael is an 18-year-old man with severe learning disabilities and challenging behaviour who lives with his parents and his older brother. Several years ago, the introduction of direct payments to enable Michael's parents to purchase support for him had a hugely positive impact on the whole family. Michael had responded well to the personal assistants employed and had become calmer and less aggressive, indicating to his family and professionals familiar with his circumstances that he was happy with the arrangements.

As Michael approached the age of 18, discussions were held between the children's services team, the senior nurse from the community team for learning disability, the direct payments support team and Michael's family about his future support arrangements. As the care package had been running so successfully for such a long time, it was decided that it would be in Michael's best interests for his mother to act as a suitable person and so continue to receive direct payments to manage his support. The decision was made by means of a multi-disciplinary meeting which emphasised that Michael's best interests were of first priority. All the parties concerned agreed that he was to be at the centre of all decision making and that every effort should be made to ascertain his views about how his care should be delivered.

183. If people with parental responsibility are going to continue in their caring role, such carers may be entitled to receive direct payments as an alternative to carers' services directly provided by the council under section 2 of the Carers and Disabled Children Act 2000. Carers' services would be provided

to support the parent carer in their caring role and to help them maintain their own health and well-being.

# Direct payments for adults lacking mental capacity to consent

- 184. The Health and Social Care Act 2008 made amendments to the Health and Social Care Act 2001 to extend the possibility of direct payments to adults who lack the capacity to consent to receive them, where it is in their best interests, enabling them to benefit from the flexibilities that direct payments offer. Direct payments can now be made to a suitable person who receives and manages the payments on behalf of the person who lacks capacity. With certain exceptions, councils now have a duty to make direct payments in respect of a person lacking capacity, provided that there is a willing suitable person who meets all the conditions set out in the Regulations.
- 185. Groups benefiting from this extension of the direct payment scheme may include some adults with head injuries and some people with dementia. In addition, severely disabled children moving into adulthood, who would previously have lost the direct payments they received as a child, can now continue to receive them on reaching the age of 18.
- 186. Before making direct payments for someone lacking capacity, the council must first obtain the consent of the suitable person who will receive direct payments on behalf of the person lacking capacity. In addition, where there is a surrogate of the person lacking capacity, the council must obtain the consent of that surrogate to make direct payments. Under the 2001 Act and the Regulations, a surrogate of a person is a donee of a lasting power of attorney created by that person or a deputy appointed by the Court of Protection who has been given powers relating to decisions about securing community care services to meet that person's needs (see paragraph 190 below).

## Appointing a suitable person

187. Someone cannot just decide to be a suitable person in order to receive direct payments on behalf of another person. In most cases, the suitable person will be a family member or a close friend already involved in the provision of care for the person concerned. However, whatever the relationship of the proposed suitable person to the person requiring care, the council must still follow the process set out in the Regulations, to ensure that the best interests of the person lacking capacity are prioritised above all other considerations.

- 188. In the first instance, councils should establish whether someone who has offered to act as a suitable person qualifies as a representative. Someone can be made a representative in one of two ways:
  - if the person has been given lasting power of attorney by the person needing services at some point before they lost mental capacity; or
  - if the person has been appointed a deputy for the person needing services by the Court of Protection under section 16 of the Mental Capacity Act 2005.
- 189. Unless the council establishes that the representative is either unwilling, incapable of managing direct payments or for some other reason inappropriate to act as a suitable person, by virtue of the powers already given to them to manage the affairs of the person lacking capacity, they would normally be the first choice of suitable person.
- 190. If the representative does not wish to act as a suitable person, the council should then look to see if there is an alternative person who would be willing to act as a suitable person. If the representative is also a surrogate, then they will need to consent to the appointment of someone else as a suitable person to manage the payments on behalf of the person who cannot consent. A surrogate is also a representative, that is to say a donee of lasting power of attorney or a court-appointed deputy. However, in order to be a surrogate rather than just a representative, the person's powers must cover decisions about securing services to meet a person's care needs. Lasting powers of attorney, for example, can cover a range of matters, including both personal welfare and property and affairs decisions, and may contain exclusions or restrictions.
- 191. Similarly, there may be specific circumstances in which a person other than the representative, in particular a close family member or a friend involved in the provision of care, is considered to be the most appropriate choice of suitable person by those consulted about making direct payments in respect of the person lacking capacity. If the council is satisfied that this arrangement would work in the best interests of the person lacking capacity, then it may, with the agreement of any existing surrogate, accept that individual as the suitable person, instead of the representative.
- 192. If there is neither a surrogate nor any other representative, then the council itself must make the decision about whether or not someone should act as a suitable person to manage the payments on behalf of the person who cannot consent.

- 193. In all cases, whether or not there is a surrogate to assist the council in its decision, and whether or not the proposed suitable person is a representative, the council should, so far as is reasonably practicable and appropriate, consult and take into account the views of the following people before making the decision to make direct payments to a suitable person:
  - Anyone who has been named by the direct payment beneficiary before they lost capacity as someone to be consulted, either on the subject of direct payments to the suitable person, or related matters such as matters regarding their personal welfare.
  - Anyone currently engaged in caring for the person lacking capacity to consent or anyone with an interest in their personal welfare.
  - As far as is practicably possible, the person who lacks capacity themselves. Councils should ensure that they have taken all reasonable steps to ascertain the wishes of the person lacking capacity regarding who should act on their behalf. This includes consideration of any written statement of wishes and preferences made by the beneficiary before they lost capacity.
  - Any representative or surrogate of the person lacking capacity. Generally speaking, an attorney or a deputy should always be consulted, even if they are not going to take on the role of suitable person. For instance, a professional person with a lasting power relating to a person's property and affairs might still have information about the person's wishes and feelings which should be taken into consideration when deciding whether someone is a suitable person to act on their behalf.
- 194. There may be occasions where it is in the best interests of the person lacking capacity to consent for their personal information to be revealed to the people consulted. Councils should ensure that social care staff who are trying to determine a person's best interests act lawfully at all times, following their own professional guidance, as well as other relevant guidance concerning confidentiality. Legal advice should be sought where necessary.

## Conditions to be met by the suitable person

- 195. As with all direct payments, the council must be satisfied that the beneficiary's needs can be met by means of the direct payments and that the recipient (in this case the suitable person) is capable of managing the direct payments.
- 196. To help ensure that the suitable person does not mismanage or misuse the direct payments, the Regulations set out a number of conditions that the council should require of the suitable person before it makes direct payments to that person on someone else's behalf.

- 197. Unless the council is satisfied that it is necessary to satisfactorily meet the person's needs, direct payments may not be used to secure services from the spouse, civil partner or partner of a person lacking capacity. Neither can they be used to secure services from a close relative, spouse or partner of a close relative of the person lacking capacity who is currently living in the same household as the person lacking capacity. There may be occasions when the council decides that it is necessary for the suitable person to use the direct payments to secure services from a member of the family of the person lacking capacity. However, such situations are likely to be exceptional and the council should be satisfied at all times that arrangements are made in the best interests of the person lacking capacity.
- 198. The suitable person manages the direct payments on behalf of the person lacking capacity, on the understanding that in doing so, they must act in the best interests of that person, within the meaning of the 2005 Act. This includes, as far as is reasonably practicable, encouraging and permitting the person lacking capacity to have the fullest input possible into decisions affecting them. The suitable person should be required to take all practical steps to ensure that decisions are taken in the best interests of the person who lacks capacity. This may involve consulting other people close to the person lacking capacity, or health and social care professionals where appropriate. To ensure that the service recipient can maintain as much control and independence as possible, the suitable person should be required to notify the council as soon as they believe the person has regained capacity.

# Principles of best interest

A person trying to act in the best interests of someone lacking capacity should:

- do whatever is possible to permit and encourage the person to participate, or to improve their ability to participate, as fully as possible, in acts and decisions;
- try to identify and take into account all the things that the person who lacks capacity would take into account if they were acting for themselves, including their past and present wishes and feelings and any beliefs and values which would be likely to influence their decisions;
- not make assumptions about what might be in the interests of the person lacking capacity simply on the basis of the person's age, appearance, condition or behaviour;
- assess the likelihood of the person regaining capacity;
- consult others when making decisions, including anyone previously named by the person as someone to be consulted, anyone engaged in caring for the person, family members, close relatives, friends or others who take an interest in the person's welfare, any attorney appointed under a lasting power of attorney made by the person and any deputy appointed by the Court of Protection to make decisions for the person; and
- for any major decisions, make sure a record is kept of the process of working out the best interests of that person.

# Example 26: Involvement in decision making through non-verbal communication

Kirsten is a young woman aged 27. She has multiple impairments – both physical and cognitive – and has complex health needs and epilepsy (which is not controlled). Kirsten does not use verbal language to communicate nor does she understand verbal language. Her cognitive ability is such that she cannot make abstract decisions about the future. She communicates through gestures, body movements, emotions and changes in her routine behaviour.

When Kirsten left school, aged 19, she started in a day service five days each week. The service worked well – Kirsten showed that she was happy and enjoyed going through smiles, eye contact with staff, laughing, blowing kisses and eating well. However, after about three years, staff in the service noticed that towards the end of the week Kirsten started to be less interested in the activities, fell asleep regularly and often did not want to eat. Kirsten's family felt that she was telling them that five days in the same environment was too much.

The local authority therefore agreed that Kirsten could have direct payments to employ a personal assistant instead of her day service on Fridays. A support group was set up to meet regularly and help manage the direct payments and ensure that they were used to meet Kirsten's needs. Kirsten's father agreed to act as a suitable person and manage the finances.

On Fridays, Kirsten can now sleep until 10.30am, which means that she is awake during her day and enjoys a range of activities in her local community – for example, shopping, train journeys to the seaside, visits to museums, parks and the ice-rink. She indicates her enjoyment through eye contact, smiles, blowing kisses, kicking her legs out and eating well.

Over the years Kirsten's family have obtained an extension of the proportion of her support package that is delivered through direct payments. Kirsten also receives Independent Living Fund funding, which enables her parents to continue to work and to arrange additional support for Kirsten to go on holiday once a year and gives them additional short respite breaks. These arrangements mean that Kirsten can continue to live at home with her family, who are all able to retain a level of independence. Kirsten now employs four personal assistants, which provides flexibility of cover when one is on leave or ill.

On one occasion when respite arrangements for Kirsten broke down at the last minute, the local authority immediately offered direct payments to pay for carers to stay with Kirsten at home – meaning that the family was still able to get away for a few days' holiday.

Kirsten's family and those who support her are familiar with her particular methods of communication and are able to take these into consideration when making decisions that affect her life. Her communication signals are written up in a communication passport so that everyone has a common understanding of what Kirsten is trying to tell them and can respond in a consistent way. Kirsten is able to try out new things because, by knowing and observing her, her supporters are able to identify what is right for her.

## Where disputes arise

- 199. The suitable person may face disagreements with others involved in or concerned for the welfare of the person lacking capacity to consent. Family members, partners and carers may disagree between themselves about how the direct payments should be spent, or they might have different memories about what views the person expressed in the past. Carers and family might disagree with a professional's view about the person's care or treatment needs.
- 200. The local council should support the suitable person to balance these concerns and decide between them. The council should include the person

who lacks capacity (as much as they are able to take part) and anyone who has been involved in earlier discussions. It may or may not be possible to reach an agreement at a meeting to air everyone's concerns, but any decision must always be in the person's best interests, following the best interests principles in the 2005 Act.

## Advocacy

- 201. An advocate may be useful in providing support for the person who lacks capacity to consent either in terms of deciding who should act as a suitable person on their behalf or, subsequent to that decision being made, how the direct payments should be used to meet their assessed needs. Advocates may be especially appropriate if:
  - the person who lacks capacity has no close family or friends to take an interest in their welfare;
  - family members disagree about the person's best interests;
  - family members and professionals disagree about the person's best interests;
  - the person who lacks capacity has already been in contact with an advocate; or
  - there is a concern about the protection of a vulnerable adult.

#### Approaches to risk

- 202. The changes to the direct payment scheme brought about by the Health and Social Care Act 2008 were designed to enable adults lacking mental capacity to consent to direct payments to benefit from the choice and flexibility that direct payments can bring. People lacking mental capacity may not be able to exercise the same level of choice and control as other direct payment recipients. However, direct payments can still provide a vital means of ensuring that choices about the person's care and support can be made by those who are best placed to understand their needs and preferences and who know how to involve them as much as possible in decisions to support their best interests.
- 203. However, councils should be very clear about the unique position of adults lacking capacity, who may not only be more vulnerable to abuse, but also less able to tell people when it is happening. Councils should therefore take steps to develop a comprehensive risk management strategy, which should inform the care plan and subsequent arrangements for monitoring and review. It is likely that reviews may need to be conducted more frequently and in person rather than on the telephone, particularly in the

early stages of the direct payments being made. Councils should consider involving other people known to the person lacking capacity, particularly those consulted when the suitable person was first appointed, as well as independent advocates where appropriate. The Mental Capacity Act Code of Practice specifies that Independent Mental Capacity Advocates (IMCAs) can be used in care reviews where the person concerned has no one else to be consulted.<sup>33</sup>

## Safeguarding

- 204. There are various legislative provisions that have been put in place to support safeguarding measures for adults lacking mental capacity. The Regulations specify that if the suitable person is not the spouse, civil partner, partner, close relative (or spouse or partner of a close relative) or friend involved in the provision of care of the person lacking capacity, then the council must obtain a CRB check for that suitable person, as a further protective measure for the person lacking capacity. For example, the suitable person may be an independent care broker or a solicitor acting as a professional deputy, who may not previously have been personally known to the service recipient.
- 205. Anyone caring for a person who lacks capacity for the purpose of the 2005 Act who wilfully neglects or ill-treats that person can be found guilty of a criminal offence under the Act punishable by up to five years in prison, or a fine, or both.<sup>34</sup> In addition, the Fraud Act 2006 created a new offence of 'fraud by abuse of position'.<sup>35</sup> This may apply to a range of people including attorneys under a lasting power of attorney (LPA) or enduring power of attorney (EPA) or deputies appointed by the Court of Protection to make financial decisions on behalf of a person who lacks capacity. Someone acting as a suitable person receiving direct payments on behalf of someone lacking capacity to consent to the making of direct payments may be guilty of fraud if they dishonestly abuse their position, intend to benefit themselves or others, and cause loss or expose that person to the risk of loss. Without discouraging people from taking up the role of suitable person, councils should also make clear to anyone considering the role the consequences of financial misconduct or other forms of neglect or ill-treatment.

<sup>&</sup>lt;sup>33</sup> The Independent Mental Capacity Advocate service was set up as a consequence of the 2005 Act to support and represent the views of particularly vulnerable people who lack the capacity to make important decisions about serious medical treatment and changes of accommodation, and who have no family or friends that it would be appropriate to consult about those decisions. For more information, see Department of Health, *Making decisions: The Independent Mental Capacity Advocate (IMCA) Service* (2007) – www.dh.gov.uk/en/Publicationsandstatistics/Publications/ PublicationsPolicyAndGuidance/DH\_073932

<sup>&</sup>lt;sup>34</sup> See section 44 of the Mental Capacity Act 2005

<sup>&</sup>lt;sup>35</sup> See section 4 of the Fraud Act 2006

206. The Regulations also provide councils with the power to impose other conditions on the suitable person if they think fit. If councils believe that it is necessary to ensure the best interests of the person requiring services to impose other conditions, then this should be done.

# Direct payments to people subject to mental health legislation

- 207. Previously, many people with mental disorders who were subject to compulsory measures under the Mental Health Act 1983 (and similar legislation) were excluded from receiving direct payments. The Regulations remove most of those exclusions, with the result that local authorities will now also be able to make direct payments to people who are subject to such mental health legislation, therefore enabling people previously excluded to benefit from greater choice and control over their support.
- 208. It is expected that, in most cases, people subject to mental health legislation will now enjoy exactly the same rights to direct payments as anyone else. However, in a few cases, councils will have a power (but not a duty) to make direct payments to such people.
- 209. Under the Regulations, councils now have a power (although not a duty) to make direct payments to people ('restricted patients') who are conditionally discharged under the 1983 Act (or the equivalent Scottish legislation). By definition, conditionally discharged restricted patients are offenders who have been detained in hospital under the 1983 Act (or the equivalent Scottish legislation) and who remain liable to recall to hospital if necessary for their own health and safety or the protection of others.
- 210. Councils also have a power, rather than a duty, to make direct payments in respect of services which the person in question is under an obligation to accept as a result of any of the provisions of the 1983 Act, the Criminal Procedure (Insanity) Act 1964, the 1991 and 2003 Criminal Justice Acts, the Powers of Criminal Courts (Sentencing) Act 2000 and similar Scottish legislation set out in Annex B.
- 211. For example, if it is a condition of a person's community treatment order under the Mental Health Act 1983 that they accept a particular type of community care service, then the council would have a power, but not a duty, to make direct payments in respect of that service (provided, of course, all the other criteria for making direct payments are met). The provision of a discretionary power is intended to give councils greater flexibility in cases where they are concerned that there may be risks in making direct payments in respect of services which the person concerned may prefer not to receive. The person concerned might not, for example,

be as committed to making a success of the service as would normally be the case where people use direct payments to arrange their own care.

- 212. Even where these provisions apply, local authorities still have a duty to make direct payments in respect of any service not covered by a specific condition, in the same way as they do for any other eligible person. Therefore the situation may arise where a council has a duty with regard to some services and a power with regard to others, when making direct payments to someone subject to legislation set out in Annex B.
- 213. Although the Regulations allow councils to exercise discretion in making direct payments to people subject to conditions relating to mental disorder, councils should be flexible in their approach and prepared to support individuals to take up direct payments wherever possible. Councils will wish to consider what support is available to the service user and where this support can be strengthened by access to support services, information and advice, brokerage and, where appropriate, independent advocacy. It is important to have in place a comprehensive risk management strategy within the support plan, agreed between the service user and the council, including what arrangements will be put in place for proportionate monitoring and review.
- 214. Where councils decide that it is not appropriate to make direct payments, they should put the reasons for the decision in writing, and make a written record available to the individual. They should also inform the individual about how to access complaints procedures if they are not satisfied with the decision of the council, as described above in paragraphs 48 and 49.
- 215. People who are subject to conditions relating to drugs and alcohol under provisions listed in Annex C remain excluded from direct payments. In such cases, the council still has a duty to provide services to meet the eligible needs of the service user, although direct payments cannot be made to meet such needs.

# Direct payments for carers

216. Direct payments allow carers to purchase the services they are assessed as needing as carers to support them in their caring role and to maintain their own health and well-being. Making direct payments in this way should not affect the carer's entitlement to Carer's Allowance and other benefits.

### Example 27: Using direct payments to deliver outcomes that carers want

Mrs Patel cares for her husband, who has had a stroke. Mrs Patel lives a long way from the shops, and using public transport makes her life very difficult. Mr Patel is happy to be on his own, but his wife is uneasy about leaving him alone for long. Mr Patel does not want anyone but his wife to care for him and he doesn't want to use day services. He used to drive until he had his stroke, and owns a car, but Mrs Patel cannot drive.

Talking with Mrs Patel about the outcomes she would want to see, the care manager realises that support to get around would be the most important help for her. Following discussion, it is clear that Mrs Patel would be willing and able to manage direct payments and it was agreed that she would spend them on taxi fares.

## **Example 28: Direct payments for flexible respite**

Council D offers a flexible form of respite to carers in the form of a one-off direct payment, with the intention of allowing them to take a break from their caring role in the way that best suits them. For example, carers have opted to spend their direct payments on:

- the registration fee for a charity trek to Everest Base Camp;
- improving the pathway from the house to the road to make it easier for someone in a wheelchair to get into a car to go out;
- 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 together;
- a washing machine so that the carer does not have to make trips to the launderette; and
- horse-riding lessons for the carer to enable her to have a break, do something she enjoys and get some exercise.

### Young carers

- 217. *Putting People First* recognises the importance of supporting family units and preventing children from having to take on inappropriate care roles. Direct payments are available to allow for flexibility in the small number of circumstances where a 16 or 17-year-old is choosing to undertake a substantial caring role for a disabled adult for a period and where the council has decided to provide the carer with a service to meet their needs as a carer. It could in some circumstances be more helpful to the young carer to receive direct payments, for example to allow them to arrange for carer services to be delivered in such a way as to minimise any disruption to their education that would result from their decision to care.
- 218. An example where it might be appropriate for a 16 or 17-year-old to provide assistance is where they are involved in looking after a terminally ill relative. In such a temporary situation, direct payments may provide flexibility, which enables them to have a break from caring.

## Example 29: Considering direct payments for 16 and 17-year-old young carers

Mrs Bridges is 45 and looks after her terminally ill husband. Up to now Mr Bridges has refused to have anyone care for him but family members, but his condition is worsening. Mrs Bridges is desperately trying to keep her job, and in the summer holidays her three children, Colette (13), Noel (15) and Ben (17) are taking on much of the caring during the working day.

Mrs Bridges is worn out, stressed and anxious. She approaches social services, even though her husband is unhappy about this, because she is so concerned about the impact on Noel, Colette and Ben of looking after their father without outside help. She has an additional concern about how they will all manage if she loses her job.

The assessor undertaking an initial assessment is confident that Mr Bridges is eligible and that his wife is a substantial and regular carer. He is also aware of the council's responsibilities under the 1989 Act, so he involves a Children and Families professional in the assessment process. The complete assessment of the situation leads to the provision of home-care and hospice-at-home services for Mr Bridges, which he reluctantly accepts because the assessment process has helped him to think more clearly about the impact his condition is having on his children.

Colette and Noel are assessed as children in need. Services are provided to make sure that they can go away for a break with their mother, meet other children in similar situations for mutual emotional support, and get back into the swing of ordinary leisure activities with their peers with whom they have lost contact.

Ben, however, expresses a very strong wish to carry on being involved in helping to look after his father until he dies, minimising the impact on his father of care provided by 'outsiders'. As Ben is 17 and the assessor believes it would be in his best interests to be allowed to continue in his caring role, Ben is assessed under the provisions of the Carers and Disabled Children Act 2000 to support him in his caring role, rather than simply to reduce it.

Ben and his father have always been close and share an enthusiasm for modern art. Ben has taken a year off to care for his father, but is hoping to go to art college in due course. In lieu of a carers' service to help him engage in leisure activities, which everyone agrees he needs, he opts for direct payments. When Mr Bridges is being cared for by home carers or nurses (community care services), Ben uses these direct payments for trips to art galleries, all of which he discusses at length with his father on his return. 219. When assessing whether the young carer is willing and able to manage the direct payments, the council should consider the impact of that additional responsibility on the young person. The council might also consider the variety of ways in which the young person could be supported to manage any direct payments. For instance, the young carer might need to be informed that they may be able to have the payroll aspects of managing direct payments dealt with by a local payroll service.

# Monitoring and review

- 220. When a person chooses to receive direct payments, they take on responsibility for securing the necessary support to meet their assessed needs and so achieve the outcomes identified in their care plan. Monitoring arrangements should be consistent both with the requirement for the council to be satisfied that the person's needs can and will be met, and with the aim of promoting and increasing choice and independence.
- 221. Councils should focus on achieving agreed outcomes, rather than on the service being delivered in a certain way. The council should discuss with individuals what steps it intends to take to fulfil its responsibilities, and may also wish to discuss how it might support them in securing quality care that meets their needs in the way best suited to them. The council should be prepared to consider variations to what it proposes.
- 222. Councils should aim to ensure that the information that the direct payment recipient is asked to provide is straightforward and the least onerous possible, consistent with monitoring requirements. Guidance from the Chartered Institute of Public Finance and Accountancy (CIPFA) provides more advice about risk management and proportionate monitoring.<sup>36</sup>

<sup>&</sup>lt;sup>36</sup> CIPFA, Direct Payments and Individual Budgets: Managing the Finances (2007)

### Example 30: Adjusting direct payments to meet changing needs

Mrs Harris lives with her daughter and son-in-law, Joan and Ted Wright, and also has a modest amount of support from a home care agency sent by social services. She is 82 and needs assistance because she is very frail and has quite severe hearing loss. Her memory has also become less reliable, and she becomes disoriented and distressed in unfamiliar surroundings. For this reason, previous arrangements for short-term breaks in a residential care home proved unsuitable. However, social services recognise the family's need for time for themselves and introduce them to the direct payment scheme. The social worker secures her manager's agreement for funding for eight weeks' intensive assistance over the year at the rate the department would have paid for an equivalent residential service.

Mrs Harris understands that receiving direct payments could enable her to have support at home as she wishes, and that her daughter could help her manage the account and make the arrangements. At first, the direct payments money is paid in a lump sum with a view to Mr and Mrs Wright arranging assistance in two-week periods to cover their holidays. However, as they become more familiar with the scheme, the family finds ways of using it more flexibly. For example, they can arrange brief periods of assistance for Mrs Harris at short notice so that they can go out for an evening or have a weekend away. They change the payment routine to the more usual fourweek cycle, which means that the cash flow suits their way of purchasing care and it is easier to keep track of the paperwork required by the council.

The money is used to pay a neighbour (who is well known to Mrs Harris) for the shorter periods. Mrs Harris's granddaughter, who is self-employed and an experienced personal assistant, covers the longer episodes, and the council agrees that this arrangement is the most appropriate way of delivering the required service. A review confirms that the system works smoothly, and Mrs Wright has occasional contact with the direct payment team when she needs advice about such things as budgeting.

- 223. Each council will need to establish how it will know if someone is experiencing difficulty with managing their direct payments. It may be appropriate to rely on someone who has been managing their own care for some time asking for extra help if they need it. It is important, however, that councils should not assume that this is an adequate safeguard, particularly when someone has a fluctuating or deteriorating condition such as HIV/AIDS or Alzheimer's, or when the person begins to receive direct payments for the first time.
- 224. Where a council wishes to ask the individual whether they are satisfied with their support arrangements, it should ensure that it communicates directly

with the individual on a regular basis. For example, a different interpreter may be required if the person wishes to comment on the services of their usual interpreter. Councils should not make assumptions that someone who is not satisfied with the way their support is being delivered cannot manage direct payments. They should seek to ensure that individuals feel able to express reservations about the support they are purchasing, or any other problems they are having in managing their direct payments, without concern that their direct payments will be stopped automatically or arbitrarily.

- 225. Councils should follow existing guidance on carrying out reviews.<sup>37</sup> The fact that the council is making direct payments rather than arranging services itself does not affect its responsibility to review an individual's care package at regular intervals. Whether someone directs their own support or receives support directly from their council, the projected timing of the first review should be set at the outset. The purpose of the review remains to establish whether the objectives set in the original care plan are being met. It should therefore cover whether the person's needs have changed, whether the use of direct payments is meeting their assessed needs and supporting the person to achieve their outcomes, and how they are managing direct payments.
- 226. The frequency of monitoring will be dictated by the length of time the person has managed direct payments (either alone or with help) and their particular circumstances. Once a council is satisfied that a person is managing the direct payments satisfactorily, reviews should be conducted at the same intervals as for other people receiving services provided or arranged directly by the council. For example, people with fluctuating conditions might need monitoring every few months, rather than once or twice a year. For children identified as needing services under section 17 of the 1989 Act, reviews may be necessary more often so that the council remains satisfied that the direct payments promote and safeguard the welfare of the child. *Framework for the Assessment of Children in Need and their Families* reminds councils that it is good practice to review plans for children in need in the community at least every six months.<sup>38</sup>

# Reviews for adults who lack capacity

227. The Regulations provide for regular reviews as well as specifying circumstances in which a council must review the arrangements for direct payments for someone lacking capacity, in view of the position of trust held by the suitable person. Councils should review arrangements within the first year of direct payments to the suitable person commencing,

 <sup>&</sup>lt;sup>37</sup> Department of Health, Fair Access to Care Services: Guidance on eligibility criteria for adult social care (2003)
<sup>38</sup> Department of Health, Framework for the Assessment of Children in Need and their Families www.dh.gov.uk/en/ Publicationsandstatistics/Publications/PublicationsPolicyandGuidance/DH\_4003256

and at regular intervals thereafter, at least annually. Suitable persons should be made aware that they can be required by the council to provide information relating to the spending of the direct payments at any time.

- 228. Adults lacking capacity are likely to need more frequent monitoring arrangements than other direct payment recipients. They may be less able to communicate their needs and wishes and there may be issues around fluctuating capacity. If the suitable person has not been involved in the provision of care prior to taking up the direct payments, reviews may be required more often to establish that they are sufficiently capable and supported to carry out their role. Councils should be satisfied at all times that the suitable person is using the direct payments in a way that protects the best interests of the service recipient.
- 229. In addition, councils should be prepared to review arrangements for a person lacking capacity if either the suitable person or someone else comes forward with relevant information. It might be that they believe the beneficiary of the direct payments has gained or regained capacity, in which case that person should be enabled to take control of the direct payments themselves. Councils should also carry out a review if notified by anyone that the suitable person may be having difficulties managing the direct payments or if they are not spending it in a way that supports the outcomes identified in the care plan.

# Financial monitoring

- 230. Each council should set up financial monitoring arrangements for audit purposes. This will fulfil the council's responsibility to ensure that public funds are spent to produce the intended outcomes. CIPFA issues up-todate guidance for councils on this point and councils should ensure that this advice is being applied.<sup>39</sup> Before people decide to accept direct payments, councils should discuss with them the information they will be expected to provide and the way in which monitoring will be carried out.
- 231. Councils should pay particular attention to ensuring that audit arrangements are as simple and easy to understand as possible. Complicated paperwork can be a significant disincentive for people considering direct payments. It is worth taking time to discuss with individuals what is required so as to avoid being needlessly intrusive.
- 232. In order to audit direct payments, it is important for people to be able to identify the direct payment money separately from any other money used for similar purposes. For example, people may use their direct payments to employ a personal assistant, and then pay the assistant to work additional

<sup>&</sup>lt;sup>39</sup> CIPFA, Direct Payments and Individual Budgets: Managing the Finances (2007)

hours from their own resources or using funding from the Independent Living Fund (ILF). A single bank account for direct payment and ILF money (and other money related to personal assistance) can meet this requirement, and is consistent with the CIPFA guidance. It is not appropriate to ask the individual to have a second bank account for non-recurrent expenditure such as a short-term need.

233. Monitoring arrangements to ensure that a person's needs can continue to be met and that finances are properly managed need to be co-ordinated. If they are not to be carried out by the same person, councils should ensure that information is exchanged. All those involved should understand the purpose of direct payments and the role that the council's monitoring plays in the successful operation of the policy.

# Monitoring local implementation

- 234. As well as monitoring how well direct payments are meeting the needs of individuals, it is anticipated that councils will wish to monitor how direct payments are working overall. In doing so, councils should actively seek the comments and suggestions of people who receive direct payments or who have considered receiving them. Councils should pay attention to the views of those who have been discouraged from using them. Councils may also wish to monitor the effectiveness of direct payment support services, again involving the views of people who use such services, to identify where improvements can be made.
- 235. As part of that process, councils should also monitor take-up of direct payments across different groups, to ensure that policy and practice is encouraging equal access to, for example, black and minority ethnic groups, older people, people with mental health problems (including those subject to mental health legislation provisions), people with learning difficulties, people who lack capacity, parents with disabled children and young disabled people.

# Troubleshooting

# When difficulties arise

236. If a council becomes aware that someone is or will be unable to meet their needs through their own arrangements, either temporarily or in the longer term, then the council will need to take steps to meet its responsibility to provide or arrange for the provision of services for that person. If the person receiving direct payments temporarily loses capacity to consent, the council may look to another person to receive and manage the direct payments on that person's behalf (on a temporary basis) if they are willing to do so and provided the service provider agrees to accept payment from the other person instead (see paragraph 256 below).

### Example 31: Temporary loss of capacity to consent

Barbara is an older woman who has been using direct payments to pay two personal assistants to help her at home and to get out and about. This arrangement has worked well for a number of years. However, a urinary tract infection causes her temporary confusion over a period of a few weeks. She is uncertain about where she is and does not always recognise her personal assistants. She temporarily loses her capacity to make decisions and her daughter, who visits her regularly, speaks to the local council. It is agreed that while Barbara is unwell, her daughter will manage the direct payments and other financial matters for her. However, once Barbara has been treated with antibiotics, her confusion clears and she is able to take control of her own financial affairs again, including the direct payments.

237. Councils should make people aware that they should plan for the unexpected and discuss with each person what arrangements they will make for emergencies, to ensure that the person receives the care they need when the usual arrangements break down (e.g. through the sickness of one of the person's personal assistants). The council will need to be prepared to respond in these circumstances just as it would with any other person using a service. It may decide to step in and arrange services where this is necessary to meet its responsibilities. The council could also explore other ways of providing assistance to enable the person to continue to manage their own care using direct payments, particularly if the difficulty is temporary or unforeseen.

- 238. Councils may also wish to make people aware that, in planning for the unexpected, they might consider giving someone a lasting power of attorney to manage their affairs relating to personal welfare, in the event that they lose capacity and are unable to do so themselves. This person, for example a close relative or friend already involved in the provision of their care, could then continue to manage the direct payments to purchase services on their behalf.
- 239. Difficulties can be minimised by good assessments, clarity (e.g. about what the money can be used for), monitoring and effective support arrangements. Discussing potential areas of difficulty and how they will be handled with the individual before direct payments begin is important. Reviews should be carried out regularly and not just when difficulties arise.

#### Example 32: Supporting people when difficulties arise

Miss Bright has been receiving mental health services for many years, and has a long history of hospital admissions. She has been supported by numerous services, including a consultant psychiatrist, social worker, community psychiatric nurse, occupational therapist, community support staff, day service workers, outreach services and telephone support.

During that time Miss Bright has felt deskilled and lacked confidence. The experience of drafting the job description and person specification for a personal assistant allows her to recognise that she understands her own needs, focusing on her strengths and qualities. The process of moving to direct payments enables her to gain control over decisions about her support and make choices about how it should work, rather than deferring such judgements to professionals.

Initially things go well. With her personal assistant, Miss Bright is able to socialise in places where she would not have done previously, and she begins to realise how well she can cope in unfamiliar situations.

Some weeks into the plan Miss Bright begins to experience some problems with her personal assistant. With some support, she becomes more assertive in her role as employer, and discusses issues of concern with her. Miss Bright quickly realises she no longer needs the level of support she has been getting. The process of employing her own staff, and then gaining the confidence to sort out the problems with her assistant, help her recovery and enable her to resume control of her life without support. The direct payment scheme provides Miss Bright with the opportunity to identify her own strengths and to utilise them in dealing with her mental health issues. She continues to have limited support from the community psychiatric nurse and ongoing contact with her consultant, but she has moved on.

- 240. Examples of contingency plans that people who receive direct payments might make include making arrangements with independent agencies for emergency cover, or recruiting personal assistants who are prepared to work additional shifts at short notice when necessary. However, it remains possible that difficulties will arise that have not been anticipated and that cannot be covered by the arrangements the individual has made. In these circumstances, the direct payment recipient should know that they can contact a named individual in the council or support service for help.
- 241. If the council's monitoring or review process reveals that the person's needs are not being met, or they contact the council to seek emergency assistance, the council will need to consider what action it should take. Good communication between the different parts of the council involved will be very important at this stage. This may mean helping people to make other arrangements, or it may mean arranging services directly until they are able to make their own arrangements once more.

# Questions to ask

242. If difficulties arise, a council might find it useful to ask the following questions:

- *Have the person's needs changed?* If so, the person's needs should be reassessed and the level of direct payments should be reviewed.
- Has the person regained or lost capacity to consent to the direct payments? If this appears to be the case, arrangements should be reviewed. If the council is satisfied that someone lacking capacity has now regained it, they should discuss with that person how they might best be supported from now on, whether by means of direct payments to that person rather than to a suitable person, or through direct provision of council services. If it is clear that someone who was managing direct payments by themselves has now lost capacity, the council should make other arrangements for their support. The council should consider whether there is someone who could act as a suitable person on their behalf, so that their direct payments can continue.
- *Is the amount of money reasonable to enable the person to secure the services required?* It may be that experience shows that there are other costs, which were not taken into account in the initial calculations. Alternatively, the anticipated costs may have risen. It may be necessary to review the level of the direct payments.

- Is the person still able to manage direct payments, or can they do so with assistance? Difficulties will not necessarily mean that the person cannot manage. There is inevitably a learning process when people begin to receive direct payments. People may make mistakes but still be capable of managing direct payments in the longer term. Even experienced direct payment recipients can have problems at times, but, with some support, be capable of overcoming them.
- Does the person wish to continue receiving direct payments? As long as there is a duty on the council to make direct payments, it should seek to explore ways of helping people to overcome difficulties and prevent them becoming unduly discouraged when they experience problems. However, if someone has decided that they no longer wish to receive direct payments, then the council should consider alternative ways of securing support, including the use of a notional personal budget controlled by the service user and managed by a third party.
- Has all the money been spent on achieving the outcomes identified in the care plan? If the money has been diverted to other purposes, there may be a case for considering seeking repayment. Before someone begins to receive direct payments, the council should explain the circumstances in which it would seek repayment.
- *Have services for which the individual has paid been received?* If not, then it is the responsibility of the individual to seek a refund from the service provider. They may need support to do this. The council may decide that it would be appropriate to require repayment of the direct payments from the recipient if it has provided services to meet the same needs that the direct payments were intended to meet and the direct payments have consequently not been used to secure the provision of the services to which they relate, or if the services were not received because they were no longer required.
- *Has the money been spent wisely?* If the money has not been spent in a cost-effective way to meet assessed needs as set out in the care plan, the person may need more support to enable them to manage.
- Is the suitable person acting in the best interests of the person lacking capacity? If the council has any reason to believe that someone acting as a suitable person is not acting in the best interests of the person lacking capacity, spending the money in the way agreed in the care plan or capable of managing the direct payments, then arrangements should be reviewed immediately. It may be that the suitable person needs more support to enable them to manage, but there may also be circumstances where it is in the best interests of the person lacking capacity for the council to cease the direct payments.

243. Some councils have concerns that they might be liable for the actions of the service recipient (e.g. the way in which the service recipient treats their employees). Councils should arrange their direct payment schemes in the light of legal advice about their liabilities. This should not be used as a reason to refuse people direct payments.

# When to seek repayment

- 244. Councils are able to require some or all of the money they have paid out to be repaid if they are satisfied that it has not been used to secure the provision of the service to which it relates. They may also require repayment if the person has not met any condition that the council has imposed. Councils that decide to require repayment by someone who they know is also receiving payments from the Independent Living Fund (ILF) should inform the ILF as soon as possible and should seek to agree, if possible, a common approach if the ILF is also seeking recovery. Councils will need to comply with their responsibilities under the Data Protection Act 1998 and should advise users of the circumstances in which the ILF will be contacted.
- 245. It is up to the council to decide when it is appropriate to seek recovery. Councils should bear in mind that repayment should be aimed at recovering money that has been diverted from the purpose for which it was intended or that has simply not been spent at all, or where services have been obtained from someone who is ineligible to provide them. It should not be used to penalise honest mistakes, nor should repayment be sought where the individual has been the victim of fraud.
- 246. Councils are able to seek repayment where a suitable person has been responsible for managing direct payments on behalf of someone lacking capacity if they are satisfied that:
  - the suitable person has not used the direct payments to secure the services for which they were intended; or
  - the suitable person has not met a condition properly imposed by the council.

In such situations, councils should seek repayment from the suitable person, not the person lacking capacity for whose care and support the direct payments were made. Before commencing the making of direct payments to a suitable person, therefore, councils should inform the suitable person from the outset of their responsibilities for ensuring appropriate use of the money.

247. A council should be satisfied, before it begins to make payments, that the potential recipient of that payment understands all of the conditions that they will be required to meet. The council should also discuss with potential

recipients of direct payments the circumstances in which it might wish to consider seeking repayment. Councils may wish to take into account hardship considerations in deciding whether to seek repayments. Councils should also bear in mind that there might be legitimate reasons for unspent funds. There may be outstanding legal liabilities necessitating a direct payment recipient to build up an apparent surplus (for example to pay their employees' quarterly PAYE, or to pay outstanding bills from a care agency).

# **Discontinuing direct payments**

#### Reasons for discontinuing direct payments

- 248. A person to whom direct payments are made, whether to purchase support for themselves or on behalf of someone else, may decide at any time that they no longer wish to continue receiving direct payments. The Regulations provide that a council shall cease making direct payments if the person no longer appears to the council to be capable of managing the direct payments or of managing them with help.
- 249. The Regulations also state that a council must stop making direct payments if it is not satisfied that the person's needs can be met by using direct payments or if the direct payments are not safeguarding or promoting the child's welfare where the payments relate to services under section 17 of the 1989 Act.
- 250. Direct payments should be discontinued when a person no longer needs the support for which the direct payments are made. This might happen in situations where the direct payments are for short-term packages when leaving residential care or hospital. Direct payments might be varied if the person's needs call for the provision of different levels of support at different times.
- 251. There may be circumstances in which the council discontinues direct payments temporarily. An example might be when an individual does not require assistance for a short period because their condition improves and they do not require the services that the direct payments are intended to secure. The council will need to discuss with the individual how best to manage this. The person should be allowed to resume responsibility for their own care after the interruption, if that remains their wish, unless there has been a change of circumstances which means that there is no duty on the council to make direct payments, or, in certain exceptional circumstances, the council decides not to exercise the power to make direct payments.
- 252. The council might also discontinue payments if the person fails to comply with a condition to which the direct payments are subject or if for some reason the council no longer believes it is appropriate to make the direct

payments. For example, the council might discontinue the direct payments if it is apparent that they have not been used to achieve the outcomes of the care plan.

- 253. Direct payments must be discontinued where the recipient is placed by the courts under a condition or requirement relating to a drug and/or alcohol dependency (see Annex C). Councils will also have discretion to discontinue direct payments in respect of particular services if the person in question becomes obliged to receive that service as a result of certain provisions of mental health legislation (see the section on direct payments to people subject to mental health legislation, page 73, and Annex B). This decision should be taken in consultation with the service user and any other appropriate parties, including the relevant mental health practitioner, and the reasons for any decision should be communicated to the direct payment recipient. Where direct payments are discontinued as a result of mental health or criminal justice legislative provisions, the council should make timely arrangements for services to be provided in lieu of the direct payments, to ensure continuity of support.
- 254. Councils should also consider how to recover unspent direct payments if the recipient dies. For example, if someone wishes to pay an agency in advance for its services, the council should bear in mind that it may be difficult to recover money paid for services that were not in fact delivered. Councils should also consider, if the direct payment recipient does leave unspent funds to be recovered, that before their death the direct payment recipient may have incurred liabilities that should legitimately be paid for using the direct payments (for example, they received services for which payment had not been made at the time of death). Councils may need to consider any redundancy costs payable to personal assistants and be prepared to provide advice on how these might be met.

#### Discontinuing direct payments in the case of persons with capacity to consent

- 255. Where someone with capacity was receiving direct payments but then loses capacity to consent, the council should discontinue direct payments to that person and consider making payments to a suitable person instead. In the interim, the council should make alternative arrangements to ensure continuity of support for the person concerned.
- 256. If the council believes the loss of capacity to consent to be temporary, it may continue to make payments if there is someone else who is willing to manage payments on the person's behalf and the service provider agrees to accept payment from this person instead. This situation should be treated as strictly temporary and closely monitored to ensure that, once the person has regained capacity, they are able to exercise overall control

over the direct payments as before. If the person's loss of capacity to consent becomes prolonged, then the council should consider making more formal arrangements for a suitable person to take over receipt of the direct payments on that person's behalf.

#### Discontinuing direct payments in the case of persons lacking capacity to consent

- 257. Direct payments must be discontinued if the council is no longer satisfied for whatever reason that the suitable person is acting in the best interests of the beneficiary, within the meaning of the 2005 Act. The council might also wish to discontinue the direct payments if it has sufficient reason to believe that the conditions imposed on the suitable person are not being met. The council may wish to consider if someone else can act as a suitable person for the person lacking capacity, or whether it will have to arrange services for them in place of the direct payments.
- 258. Direct payments must be discontinued where the council has reason to believe that someone who had lacked capacity to consent to direct payments has now regained that capacity on a long-term or permanent basis. Councils should not terminate direct payments to the suitable person before beginning to make direct payments to the service recipient themselves or to arrange services for them, according to their wishes. If the council is satisfied that the regaining of capacity will only be temporary, then it can continue to make direct payments to the suitable person on the basis that, as far as possible, the beneficiary should control how the direct payments are used (see the section on fluctuating capacity, page 24).

#### How to discontinue direct payments

- 259. In all cases, as soon as possible the council should discuss with individuals, their carers and any suitable person managing the direct payments if it is considering discontinuing direct payments to them, in order to explore all available options before making the final decision to terminate the direct payments. For example, if ability to manage is an issue, the individual should be given an opportunity to demonstrate that they can continue to manage direct payments, albeit with greater support if appropriate. The council should not automatically assume when problems arise that the only solution is to discontinue or end direct payments.
- 260. If the council does decide to withdraw direct payments, it will need to arrange the relevant services instead, unless the withdrawal was following a reassessment after which the council concluded that the services were no longer needed. A minimum period of notice should be established that will normally be given before direct payments are discontinued. This should be included in the information to be provided to people who are considering receiving direct payments. It will be extremely unlikely that a council will

discontinue direct payments without giving notice. Councils should explain to people, before they begin to receive direct payments, the exceptional circumstances in which this might occur and discuss with them the implications this has for the arrangements that individuals might make.

- 261. The council may also need to keep in touch with the ILF and share information where appropriate (and preferably with the service user's permission) in cases where the individual is also receiving ILF funding.
- 262. If direct payments are discontinued, some people may find themselves with ongoing contractual responsibilities or having to terminate contracts for services (including possibly making employees redundant). Councils should take reasonable steps to make people aware of the potential consequences if direct payments end.

# Annexes

# Annex A: Care plan for direct payments – an example

- What are the person's needs, as identified in the assessment?
- What is important to the person? What outcomes would the person like to achieve through meeting their identified needs?
- Can these outcomes be met by means of direct payments?
- How will the person use the direct payments to arrange for their support?
- What variations to the way in which the direct payments are used does the council expect to be asked in advance to approve?
- What support (if any) does the user need to manage their direct payments?
- How will this support be made available to the person?
- What arrangements has the person made to cover emergencies?
- How much money does the council consider is reasonable to secure the necessary support to meet the person's needs?
- How much of this total will the council contribute in direct payments, and how much is the person expected to contribute?
- Will payments be made gross or net of the person's contribution?
- How often and in what form will payments be made?
- What arrangements does the council propose for monitoring? What information should the person provide? What access will be required to the person's home?
- Where relevant, how will the council be satisfied that the direct payments are purchasing services which safeguard and promote the welfare of the disabled child/young person?
- Where relevant, how will the council be satisfied that the direct payments are purchasing services which promote the best interests of the person lacking capacity?
- What information does the council require for audit purposes, and when?
- What, if any, other conditions are attached to the direct payments?
- When will the next review take place?

- What should the person do if they want to stop receiving direct payments?
- In what circumstances will the council consider discontinuing direct payments (permanently or temporarily)?
- How will the council and user handle any temporary gap in direct payments being made?
- How much notice will normally be given if the council decides to discontinue direct payments?
- How will any outstanding commitments be handled if direct payments are discontinued?
- In what circumstances would direct payments be withdrawn with no notice?
- In what circumstances would the council seek repayment?

# Annex B: Power to make direct payments

The new Regulations give councils a power (but not a duty) to make direct payments where someone has been conditionally discharged from hospital under the Mental Health Act 1983 or section 193(7) of the Mental Health (Care and Treatment) (Scotland) Act 2003. See the Community Care, Services for Carers and Children's Services (Direct Payments) (England) Regulations 2009 – Regulations 7(1)(b) and 8(4)(b).

Where someone is compelled to receive a service as a result of any of the following legislative provisions relating to mental disorder, councils have a power (but not a duty) to make direct payments to them in respect of that service. The provisions in question are:

- supervised community treatment, guardianship or on leave of absence from a hospital in which they are detained under the 1983 Act;
- the supervision of a social worker or the Probation Service as a result of a supervision order made under the Criminal Procedure (Insanity) Act 1964;
- an offender released on licence under the Criminal Justice Act 1991, which includes a requirement to accept treatment for a mental health condition;
- an offender on a community rehabilitation order under the Powers of Criminal Courts (Sentencing) Act 2000, which includes a requirement to accept treatment for a mental health condition;

- an offender on a community order or serving a suspended prison sentence under the Criminal Justice Act 2003, which includes a requirement to accept treatment for a mental health condition; and
- the equivalent of any of the above under Scottish legislation.

Where a relevant service is one that has not been imposed by a condition under any of the above provisions, councils have a duty to make direct payments to the person concerned to meet their needs for that service.

Reference should be made to the Regulations for full details of the circumstances in which a power, rather than a duty, to make direct payments applies. See the Community Care, Services for Carers and Children's Services (Direct Payments) (England) Regulations 2009 – Regulations 7(1)(a) and (b) and 8(4)(a) and (b) and Schedule 2.

# Annex C: Exclusions to direct payments

Direct payments may not be made in respect of certain people who have been placed under certain conditions or requirements by the courts in relation to drug and/or alcohol dependencies, as listed below:

- offenders on a community order, or serving a suspended prison sentence, under the Criminal Justice Act 2003, which includes a requirement to accept treatment for drug or alcohol dependency;
- an offender on a community rehabilitation order or a community punishment and rehabilitation order under the Powers of Criminal Courts (Sentencing) Act 2000, which includes a requirement to accept treatment for drug or alcohol dependency;
- offenders released from prison on licence under the Criminal Justice Act 1991, the Criminal Justice Act 2003 or the Crime (Sentences) Act 1997 subject to an additional requirement to undergo treatment for drug or alcohol dependency; and
- people subject to equivalent provisions under Scottish criminal justice legislation.

Reference should be made to the Regulations for full details of people excluded from direct payments. See the Community Care, Services for Carers and Children's Services (Direct Payments) (England) Regulations 2009 – Regulations 2(c) and 4(c) and Schedule 1.

# Annex D: Further information

## National Centre for Independent Living publications

The National Centre for Independent Living (NCIL) is a source of information and expertise.

Unit 3.40, Canterbury Court, 1–3 Brixton Road, London SW9 6DE Tel: 020 7587 1663 Fax: 020 7582 2469 Textphone: 020 7587 1177 Website: www.ncil.org.uk Email: info@ncil.org.uk

- NCIL, Everything you need to know about direct payments (2008)
- Independent Living Institute, *The Rough Guide to Managing Personal Assistants*, Sian Vasey (2000)
- NCIL DVD, *Direct Payments: a beginner's guide* a 30-minute DVD which covers the essential aspects of managing a PA set-up, including recruitment, supervision and contracts
- NCIL, Direct Payments for Mental Health Service Users/Survivors: a guide to some key issues, Pauline Heslop (2007)
- National Youth Agency and West of England Centre for Inclusive Living, Creating Independence and Inclusion – Youth Personal Assistance Support Scheme, Rowen Jade (2003)

## Values into Action (VIA) publications

VIA, Oxford House, Derbyshire Street, London E2 6HG Tel: 020 7729 5436 Fax: 020 7729 7797 Website: www.viauk.org Email: general@viauk.org

- Pointers to Control, Catherine Bewley with Andrew Holman (2nd edition, 2002) – information on direct payment issues such as consent, control, money management, employment and eligibility
- Funding Freedom 2000: people with learning difficulties using direct payments, Andrew Holman with Catherine Bewley (1999) supporting the use of direct payments by people with learning difficulties
- Making Decisions: best practice and new ideas for supporting people with high support needs to make decisions, Stephanie Beamer with Mark Brooks (2001)
- *Trusting Independence: a practical guide to independent living trusts,* Andrew Holman and Catherine Bewley (2001)
- *Helping Ourselves*, Catherine Bewley and Linsay McCulloch (2004) findings of a study into the importance, availability and quality of peer support for people using direct payments

 Mission Possible – DVD and booklet about the Mental Capacity Act 2005 made by and for people with learning difficulties (2007) – accessible storybased information about making your own choices and decisions

# Department of Health publications

Department of Health, Richmond House, 79 Whitehall, London SW1A 2NS Tel: 020 7210 4850

Website: www.dh.gov.uk Email: dhmail@dh.gsi.gov.uk

- A guide to receiving direct payments from your local council: a route to independent living (2008)
- Direct Payments Solution Set (2007) online resource to share what works in promoting and developing direct payment schemes – www.kc.csip.org.uk/ solutionset.php?grp=601
- Direct payments for people with mental health problems: a guide to action (2006)
- Direct Choices: what councils need to make direct payments happen for people with learning disabilities (2004)
- Independence, choice and risk: a guide to best practice in supported decision making (2007)
- Putting People First: a shared vision and commitment to the transformation of adult social care (2007)
- Personalisation toolkit (2008) online resource to support councils to begin to plan and deliver the transformation of their social care systems, as set out in Putting People First – www.dhcarenetworks.org.uk/Personalisation/Topics/
- Valuing People Now resource pack (2009) raising awareness and supporting good practice for people with learning disabilities

# Department for Children, Schools and Families publications

Department for Children, Schools and Families, Sanctuary Buildings, Great Smith Street, London SW1P 3BT

Tel: 0870 000 2288 Textphone: 01928 794274 Website: www.dcsf.gov.uk Email: info@dcsf.gsi.gov.uk

- A Parent's Guide to Direct Payments (2006)
- Transition: moving on well (2008) a good practice guide on effective transition from children's to adult services for young people with complex health needs published by the Department of Health and the Department for Schools, Children and Families – www.everychildmatters.gov.uk/resourcesand-practice/IG00322

 A Transition Guide for all Services (2007) – provides an overarching view of all the services that need to work together to ensure appropriate support for disabled children throughout each stage of their life – www. everychildmatters.gov.uk/resources-and-practice/IG00322

## Scope publications

Scope, 6 Market Road, London N7 9PW **Tel:** 020 7619 7100 for switchboard, or 0808 800 3333 for Scope Response, which offers confidential advice and information **Website:** www.scope.org.uk **Email:** response@scope.org.uk **Text:** SCOPE, plus your message to 80039

- My money, my way: a young person's guide to direct payments (2004)
- *In the driving seat: direct payments for your child* (2004)
- Good Practice Guide for Support Workers and Personal Assistants Working with Disabled People with Communication Impairments (2002)
- A Lot to Say! A guide for social workers, personal advisors and others working with disabled children and young people with communication impairments (2002)

# Joseph Rowntree Foundation publications

Joseph Rowntree Foundation, The Homestead, 40 Water End, York YO30 6WP Tel: 01904 629241 Minicom: 01904 615910 Website: www.jrf.org.uk Email: info@jrf.org.uk

- *Making Direct Payments Work: identifying and overcoming barriers to implementation*, Frances Hasler with Angela Stuart (2004)
- *'It Pays Dividends': direct payments and older people*, Heather Clark, Helen Gough and Ann Macfarlane (2004)
- *Direct Payments and Mental Health: new directions*, Karen Newbigging with Janice Lowe (2005)

## Other resources

- Users with queries about being an employer may find it helpful to consult HM Revenue and Customs' **New Employer Helpline** on 0845 60 70 143. Calls are charged at the local rate.
- *Mental Capacity Act 2005 Code of Practice (2007)*
- Commission for Social Care Inspection, *Direct Payments: what are the barriers?* (2004)
- Policy Press, *Developments in Direct Payments*, Janet Leece and Joanna Bornat (eds) (2006)
- King's Fund, *Direct Payments and Older People*, Teresa Poole (2006)

# **Annex E: Contacts**

### Age Concern

Astral House 1268 London Road London SW16 4ER Helpline: 0800 00 99 66 Website: www.ace.org.uk

## Alzheimer's Society

Devon House 58 St Katharine's Way London E1W 1JX Tel: 020 7423 3500 Fax: 020 7423 3501 Website: www.alzheimers.org.uk Email: enquiries@alzheimers.org.uk

## **Carers UK**

20 Great Dover Street London SE1 4LX Tel: 020 7378 4999 Fax: 020 7378 9781 Website: www.carersuk.org Email: info@carersuk.org

## Chartered Institute of Public Finance and Accountancy (CIPFA)

3 Robert Street London WC2N 6RL Tel: 020 7543 5600 Fax: 020 7543 5700 Website: www.cipfa.org.uk

## Children's Society

Edward Rudolf House Margery Street London WC1X OJL **Tel:** 0845 300 1128 **Website:** www.childrenssociety.org.uk **Email:** supporteraction@childrenssociety.org.uk

#### **Contact a Family**

209–211 City Road London EC1V 1JN Helpline: 0808 808 3555 Tel: 020 7608 8700 Textphone: 0808 808 3556 Fax: 020 7608 8701 Website: www.cafamily.org.uk Email: info@cafamily.org.uk, helpline@cafamily.org.uk

#### Crossroads

10 Regent Place Rugby CV21 2PN Helpline: 0845 450 0350 Website: www.crossroads.org.uk

### Help the Aged

York House 207–221 Pentonville Road London N1 9UZ Tel: 020 7278 1114 Fax: 020 7278 1116 Website: www.helptheaged.org.uk Email: info@helptheaged.org.uk

#### Mencap

123 Golden Lane London EC1Y ORT Tel: 020 7454 0454 Fax: 020 7608 3254 Website: www.mencap.org.uk Email: help@mencap.org.uk

#### Mind

15–19 Broadway Stratford London E15 4BQ Tel: 0845 766 0163 Website: www.mind.org.uk Email: contact@mind.org.uk

#### National Children's Bureau

8 Wakley Street London EC1V 7QE Tel: 020 7843 6000 Fax: 020 7278 9512 Website: www.ncb.org.uk Email: websupport@ncb.org.uk

## Office of the Public Guardian

Customer Services – The Office of the Public Guardian and the Court of Protection PO Box 15118 Birmingham B16 6GX Tel: 0845 330 2900 Textphone: 020 7664 7755 Fax: 020 7664 7551 Website: www.publicguardian.gov.uk Email: customerservices@publicguardian.gsi.gov.uk

## Princess Royal Trust for Carers

Unit 14, Bourne Court Southend Road Woodford Green Essex IG8 8HD Tel: 0844 800 4361 Fax: 0844 800 4362 Website: www.carers.org Email: info@carers.org

## Scope

6 Market Road London N7 9PW Tel: 0808 800 3333 Website: www.scope.org.uk Email: response@scope.org.uk

## United Kingdom Disabled People's Council (UKDPC)

DIAL House Hamilton Place Chester CH1 2BH **Tel:** 01773 746698 **Website:** www.ukdpc.net **Email:** general@UKSDPC.org

# Annex F: Glossary

**Advocate** – a person who acts on behalf of and in the interests of a service user/direct payment recipient who feels unable to represent themselves when dealing with professionals. An **independent advocate** has no vested interest in the service or legal system, solely represents the individual, and is not a relative, friend or professional, thus avoiding conflicts of interest. **Self-advocates** are trained and supported to represent their own views.

**Arbitration** – settlement of a dispute by an independent person/body appointed by both parties in the dispute.

**Assessment** – collection and interpretation of data to determine an individual's need for health, personal and social care and support services, undertaken in partnership with the individual, their representative/advocate and relevant professionals.

**Capable of managing a direct payment** – able (with or without support) to use a direct payment in a way that will meet the outcomes set out in the beneficiary's care plan.

**Capacity** – for the purposes of the Mental Capacity Act 2005, a person lacks capacity in relation to a matter if at the material time they are unable to make a decision for themselves in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain. It does not matter whether the impairment or disturbance is permanent or temporary. A lack of capacity cannot be established merely by reference to a person's age or appearance or to a condition they may have, or an aspect of their behaviour that might lead others to make unjustified assumptions about their capacity.

In the context of this guidance, the decision in question is the decision whether to consent to the making of direct payments.

Certain principles apply under the 2005 Act. These are that:

- a person must be assumed to have capacity unless it is established that they lack capacity;
- a person is not to be treated as unable to make a decision unless all practicable steps to help them to do so have been taken without success; and
- a person is not to be treated as unable to make a decision merely because they make an unwise decision.

**Close relative** – someone related to the direct payment beneficiary in one of the following ways: parent, parent-in-law, aunt, uncle, grandparent, son, daughter, son-in-law, daughter-in-law, step son or daughter, brother or sister.

**Consent** – the legal agreement to a choice or action (i.e. to take on a direct payment) freely made by an individual without coercion, and with acceptance of the responsibilities associated with that choice or action. In a legal context, the individual must be 'mentally capable' of giving consent before it is valid.

**Control** – having autonomy and power over your own life and what happens to you, regardless of how much support you need to put your choices into action. Having self-determination.

**Decision making** – the process of making choices that lead to decisions and action. The word 'decision' is also used in legal contexts. Some people require support (e.g. communication support or advocacy) to consider and make decisions.

**Mixed package** – a direct payment plus a directly provided social care service.

**Parental responsibility** – in the Children Act 'parental responsibility' means all the rights, duties, powers, responsibilities and authority of parents in relation to the child and their property. People other than parents, for example grandparents or guardians, can have parental responsibility for a child. Further guidance on parental responsibility can be found in *The Children Act 1989: Court Orders: Guidance and Regulations: Volume 1.* 

**Personal budget** – the amount of money that a local authority agrees needs to be spent to meet an individual's needs. A direct payment is one way in which the individual can choose to take that money in order to meet their needs, but personal budgets do not have to involve a cash exchange with the service user. Personal budget holders can still choose to receive services provided by their council. Alternatively, the budget can be held by a third party acting on behalf of the service user – such as an individual carer, provider, trust or specialist broker. However the personal budget is deployed, the same principles remain:

- The individual has been informed about a clear, upfront allocation of funding.
- There is an agreed care plan making clear what outcomes are to be achieved with that money.
- The individual can use the money in ways and at times of their choosing.

**Power of attorney** – authority given by one person to another to act on their behalf. The Mental Capacity Act 2005 replaced enduring powers of attorney (EPAs) with lasting powers of attorney (LPAs) from 1 October 2007. As of this date it is no longer possible to create a new EPA. Existing but unregistered EPAs can continue to be registered after 1 October 2007. LPAs were introduced by the Mental Capacity Act 2005 from 1 October 2007. They allow individuals to appoint an attorney to make decisions about their property and financial affairs (or specified property and affairs) and/or to make decisions about their personal welfare (or specified matters concerning their personal welfare). Such attorneys may continue to make these decisions when the person who appointed them lacks the capacity to make these decisions themselves.

**Self-directed support** – an overarching term that encompasses a variety of tools to give disabled and older people greater levels of control over how their support needs are met, including personal budgets and direct payments.

**User-controlled trust** – a legal arrangement whereby a third party/agent helps the direct payment recipient to manage the direct payments, for example by receiving and handling the money. The user's choices and preferences direct the decision-making and, where the user has the capacity to consent to direct payments, the user retains control of and is accountable for the arrangements.

Find us online at:

www.dh.gov.uk/en/SocialCare/Socialcarereform/Personalisation/Directpayments/ index.htm



© Crown copyright 2009 296235 1p 4k Sep09 (RE) Produced by COI for the Department of Health www.dh.gov.uk/publications



