

Direct payments for health care

Information for pilot sites

DH INFORMATION I	READER BOX
Policy	Estates
HR / Workforce	Commissioning
Management	IM & T
Planning /	Finance
Clinical	Social Care / Partnership Working
Document Purpose	For Information
Gateway Reference	14565
Title	Direct Payments for Health Care: Information for pilot sites
Author	DH Policy Unit, Personal Health Budgets Team
Publication Date	15 Jul 2010
Target Audience	Medical Directors, Directors of Finance, Allied Health Professionals, GPs, Personal Health Budget Pilot Leads
Circulation List	
Description	Information on direct payments for health care, reflecing the requirements in the National Health Service (Direct Payments) Regulations 2010.
Cross Ref	National Health Service (Direct Payments) Regulations 2010
Superseded Docs	N/A
Action Required	N/A
Timing	N/A
Contact Details	Jonathan Walden Policy Unit Room 602 Richmond House Whitehall, SW1A 2NS 0207 210 2708
For Recipient's Use	

© Crown copyright 2010 First published 15th July 2010 Published to DH website, in electronic PDF format only. http://www.dh.gov.uk/publications

Direct payments for health care

Information for pilot sites

Contents

Contents	5
Executive summary	6
Running the scheme	7
Who could receive a direct payment?	7
Consent	9
Capacity to consent	
Ability to manage direct payments	11
Criminal Justice restrictions	13
Who should the PCT consult when considering whether to make a direct payment?	13
Deciding not to offer a direct payment	15
Nominated persons for people with capacity	16
Representatives	17
Care Planning	
What can a direct payment be spent on?	
Employees	28
Safeguarding	
Paying family carers	31
Setting the amount of a direct payment	32
Managing Risk	33
Receiving a direct payment	41
Monitoring and reviewing direct payments	42
Stopping or reducing a direct payment	
Asking for repayment of a direct payment	46
Pilot Schemes	48
The Evaluation	49
Annex A- Persons excluded from direct payments	50
Annex B- Useful References	

Executive summary

Direct payments for health care are monetary payments made by PCTs to individuals to allow them to purchase the care they need. They are one mechanism for delivering personal health budgets, and are one of a number of tools for making the National Health Service more personalised and patient centred.

The aim of this document is to assist PCTs to meet the requirements of direct payments. It is written to reflect the requirements in the *National Health Service (Direct Payments) Regulations 2010.*¹ It also includes some ideas and information about best practice when delivering direct payments.

At this stage, direct payments, and personal health budgets more widely, are still at a very early stage of development. The pilot programme is designed to explore how many of the operational issues and challenges may be overcome. For these reasons this document cannot be a comprehensive "how to" guide, in some areas it does discuss best practise, in others best practise will only be identified though the piloting process. While it sets out the minimum regulatory requirements, it gives practitioners and professionals the flexibility to test, explore and develop processes and practices which makes sense locally. It is intended to inform local discussions and planning.

While the requirements in the regulations only apply to direct payments, many of the processes, such as care planning, budget setting, and the principles around empowering people to make decisions about their own care, will be familiar to people using and offering notional and third party budgets. Pilot sites will want to build on their existing experience, and continue to share and draw from ideas from across the NHS and social care.

This guidance is primarily for the use of personal health budget pilot sites, but local authorities and providers may also find it useful.

¹ National Health Service (Direct Payments) Regulations 2010 <u>http://www.opsi.gov.uk/si/si2010/uksi_20101000_en_1</u>

Running the scheme

Who could receive a direct payment?

- 1. A direct payment can be made to:
 - anyone who needs health care and could benefit, or
 - anyone who needs NHS aftercare services.
- 2. The person would have to:
 - live in the area of a pilot scheme,
 - have a healthcare need and meet other criteria covered by the pilot scheme.
- 3. The person receiving care must give their consent to receiving direct payments, where they have capacity.
- 4. The person must also be able to manage the direct payment, on their own or with assistance.
- 5. If they lack capacity to consent to receiving a direct payment, a representative could receive it on their behalf (see paragraph 41).
- 6. If they are under 16, the person with parental responsibility for them would normally receive the direct payment on their behalf as a representative.
- 7. If the person was able to give consent, but did not wish to manage the direct payments, they could ask a nominated person to receive it on their behalf (see paragraph 34.).

Example of someone who could benefit from a direct payment

Jessie had to learn to walk again after a benign tumour was discovered in her brain. Following her recovery, she was then diagnosed with multiple sclerosis. This caused her to suffer migraines and feel continually stressed, for which she required medication. Jessie's care plan focused on appointments with a nutritionist to support her diet and general health, a counsellor to help her manage stress and a head massage to reduce migraines. The PCT currently pays for these services, after Jessie passes on invoices from each provider. A direct payment to Jessie would avoid unnecessary paperwork for Jessie and the PCT, and reduce the time between service delivery and payment.

Box one

8. In principle, a direct payment could be given to anyone who needed to receive healthcare funded by the National Health Service.² This includes aftercare services under section 117 of the *Mental Health Act (1983)*. However, we anticipate that direct payments, and personal budgets more generally, might be easier where conditions are more predictable, and where there is a degree of (clinically appropriate) choice available.

Some of the service areas where people believe direct payments could be beneficial:

- NHS continuing healthcare;
- Mental health services, especially for people with complex needs;
- Learning disability services;
- Maternity services;
- End- of- life care; and
- Some long term conditions, especially where there are complex needs or opportunities to focus on preventative interventions.
- Where people have joint health and social care needs, and are receiving a personal budget for social care

Box two

9. At the moment, direct payments are limited to pilot PCTs, who have been authorised to test direct payments for specific conditions in specific geographical areas (see paragraph 148 on pilot sites). Only people living in these areas can be part of the pilot and receive direct payments. However, people living outside pilot sites may still receive other forms of personal health budget, such as notional budgets or budgets held by a third party, which do not involve giving people money.

² The healthcare for which a direct payment may be made is defined in section 12A(2) of the *Health Act (2009)*. Broadly, it is any care or service the Secretary of State must provide or arrange for under sections 2(1) or 3(1), or paragraphs 8 or 9 of Schedule 1 to the *National Health Service Act* (2006).

Consent

- 10. Direct payments can only be given to someone who consents, or who consents to someone receiving direct payments on their behalf. If they do not have the capacity to consent³, direct payments can be given to their representative, if they consent on the person's behalf. This is similar to the process in social care.
- 11. As well as giving people more control and independence, direct payments carry with them greater responsibilities for individuals than traditionally commissioned healthcare. The person receiving the direct payment (the individual themselves if the direct payment is made to them, or if they have one a nominated person or a representative), will be responsible for the way the money is spent. People may also be taking on additional responsibilities as employers or by entering into contracts with people to provide services.
- 12. Therefore, when providing a direct payment, PCTs must be satisfied that the person understands what is involved, and has consented. This is an area where people may need additional support, especially around potential options for different types of personal health budget, information around what they should expect when receiving a direct payment, or access to advocacy services. Obtaining consent might be a process involving a number of discussions, rather than a singe event, and should be closely interlinked with the wider care planning process.
- 13. When offering direct payments, PCTs should make it clear that receiving a direct payment is voluntary. The person may want to use another form of personal health budget, or not be involved in the pilot at all. It is also possible to combine different forms of personal budget in a single care plan, as well as incorporating other health and social care needs, for example social care personal budgets. It may be sensible to include a discussion of the different types of personal health budget during the care planning process.

³ When we refer to people who lack capacity in this document, we mean people who lack capacity to consent to receive a direct payment.

Example of how a PCT can support someone with limited capacity

After Susan's father John had a series of strokes, resulting in vascular dementia, he became immobile and needed 24/7 care. Although his ability to communicate had deteriorated, he had always been clear that he wished to live with his family, rather than in a nursing home. Susan drew up a care plan on behalf of her father, and used a personal health budget to organise flexible nursing care for John at her home. As John's memory deteriorated, Susan felt that he was still aware that he was at home with his daughter, and recognised and liked the people who were caring for him.

Box three

Capacity to consent

- 14. When obtaining consent, PCTs will need to assess whether the person involved has the capacity to consent.
- 15. Broadly speaking, 'mental capacity' means the ability to make a specific decision at the relevant time. Under the *Mental Capacity Act (2005)* a person lacks capacity if they are unable to make a decision because of an impairment of, or a disturbance in the functioning of the mind or brain.⁴
- 16. 'Mental Capacity' should always be assessed on an individual basis, and in relation to the specific decision to be made. Assumptions should not be made that someone will lack mental capacity simply because they have a particular condition, such as dementia or mental illness. When assessing someone's capacity to make a decision for themselves, people should use a two stage test of capacity:
 - Does the person have an impairment of the mind or brain, or is there some disturbance in the functioning of their mind or brain? (It does not matter whether this 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?

⁴ Section 2(1) of the *Mental Capacity Act 2005* (c.9)

17. As far as possible, people should be supported to make decisions which affect them. The Mental Capacity Act requires that a person should not be treated as unable to make a decision unless all practicable steps to support them have been taken without success. Therefore, before deciding that someone lacks capacity, PCTs should satisfy themselves that they have taken all practicable steps to try and help the person to reach a decision by themselves. This is similar to the process in social care.

Assessing capacity to make a decision

When assessing capacity to make a decision, professionals should consider:

- Does the person have a general understanding of the 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 close family member, carer or advocate)?
- Is there a need for a more thorough assessment (perhaps involving a doctor or other professional expert)?

From Guidance on Direct Payments p.23

Box four

Ability to manage direct payments

- 18. PCTs should only give someone a direct payment if they are satisfied that they have the ability to manage it, on their own or with the assistance available to them. This is similar to the process in social care.
- 19. PCTs should not confuse whether someone has the ability to manage direct payments with whether they have the capacity to consent to receiving them. It does not

necessarily follow that if someone has the capacity to consent to receive a direct payment, they are also able to manage one.

- 20. When deciding whether or not someone has the ability, PCTs should especially consider:
 - a. whether they would be able to make choices about, and manage, the services they wish to purchase;
 - b. whether they have been unable to manage either a health care or social care direct payment in the past, and if their circumstances have changed; and
 - c. whether they are able to prevent a fraudulent use of the direct payment.
- 21. If a representative receives a direct payment on someone's behalf, or the person receiving care chooses to nominate someone to manage the direct payment on their behalf (see paragraphs 34 and 41), then the PCT should be confident that the representative or nominee is able to manage the direct payment on the person's behalf.

Advice on making decisions about the ability to manage

If a professional is concerned that a person who wishes to receive direct payments may not be able to manage them, they should consider:

- the person's understanding of direct payments, including the actions required on their part;
- whether the person understands the implications of receiving or not receiving direct payments;
- what kind of support the person might need to manage a direct payment;
- what help is available to the person; and
- what arrangements the person could make to obtain the necessary support.

Box five

22. A judgement by a PCT that someone is unable to manage a direct payment should be on an individual basis, taking into account the views of the individual, and the help available to them. PCTs should not make blanket assumptions that groups of people will or will not be capable of managing direct payments. For example, they should not assume that people with learning difficulties will automatically be incapable of managing a direct payment, alone or with support.

- 23. When considering whether someone is capable of managing a direct payment, the PCT should take into account the support available to that person, and should consider whether providing additional support would enable them to receive a direct payment (see paragraph 115 on information, advice and support).
- 24. If the PCT concludes that someone would not, even with assistance, be able to manage direct payments, it is important to discuss this with them, and if appropriate with family and friends.
- 25. If a PCT decides that someone is not suitable for a direct payment, they should consider other means of personalising that person's care, including through a notional budget held by the PCT or through a third party budget. People should not be disadvantaged by not being able to manage a direct payment.

Criminal Justice restrictions

26. If the person is subject to certain criminal justice orders for alcohol or drug misuse, then they may not receive a direct payment. However, they might be able to use another form of personal health budget to personalise their care. A full list of these orders is attached in annex A. This list is similar to the exclusions for direct payments in social care.

Who should the PCT consult when considering whether to make a direct payment?

27. When considering whether to make a direct payment, the PCT may consult a range of people to establish whether or not a person is suitable to receive a direct payment and would be able to manage one. A PCT is not required to consult all the people on the list in box six, but should do if they believe the people may have information relevant to the decision to make direct payments.

Who could the PCT consult?

The PCT may consult:

- anyone identified by the person involved as someone to be consulted;
- if the person is aged between 16 and 18, the individual with parental responsibility for them;
- the individual primarily involved in the person's care (e.g. a personal assistant, community mental health nurse);
- anyone else who provides care for the person (e.g. a occupational therapist or community matron);
- an independent mental capacity advocate or an independent mental health advocate appointed for the person;
- any health professional or other professional individual who provides healthcare to the person (e.g. a GP);
- the person's social care team; and
- anyone who the PCT thinks is able to provide relevant information about the person. PCTs should be particularly aware that carers will have particular insights, and should be seen as partners in care wherever possible.

Box six

- 28. The PCT may also ask the person receiving care to provide information about:
 - a. Their overall health, and
 - b. The details of the condition they are receive a direct payment for.
- 29. If the person lacks capacity, the PCT may consult people in box six to establish whether or not that person would want to receive direct payments, if they had capacity to consent.

Who could the PCT consult when making payments to a representative?

If the PCT intends to make a direct payment to a representative of the person receiving care (see paragraph 41) they may also consult:

a. the person receiving care;

- any other deputy appointed by the Court of Protection under the *Mental Capacity Act*, but who lacks the authority to make decisions in relation to the direct payment;
- c. any donee of lasting power of attorney appointed under the *Mental Capacity Act,* but who lacks the authority to make decisions in relations to the direct payment;
- d. anyone named by the person receiving care, when they had capacity, as a person to be consulted in these circumstances; and
- e. anyone appropriate in box six.

Box seven

30. When the PCT intends to make a direct payment to a nominee on behalf of the person receiving care, they may consult anyone listed in box six or box seven (see paragraph 34 on nominees).

Deciding not to offer a direct payment

- 31. A PCT may decide not to provide someone with direct payments if the PCT does not think that the person would be able to manage them, if the person's condition is not suitable, if the PCT thinks the direct payment will be abused, or if the person do not meet the local pilot criteria.
- 32. If a PCT decides not to give someone a direct payment, they must inform the person, and any nominee or representative, in writing, and give their reasons. This should be in an appropriate format for the people involved to understand.
- 33. Even if someone is not suitable to receive a direct payment, they may still benefit from more personalised care. The PCT should, where possible, also consider whether other forms of personal health budget, such as a notional budget or a budget held by a third party, might be suitable for their needs, or how else their care could be personalised.

Nominated persons for people with capacity

- 34. If the person receiving care has capacity, but does not wish (for whatever reason) to receive a direct payment themselves, they may nominate someone else to receive it on their behalf.
- 35. A representative (see paragraph 41) may also choose to nominate someone to hold and manage the direct payment on their behalf.

What is a nominee?

A nominee is responsible for managing the direct payment on behalf of the person receiving care. They are responsible for fulfilling all the responsibilities of someone receiving direct payments. These include:

- a. acting as the principal person for all contracts and agreements with care providers, employees, etc;
- b. using the direct payment in line with the agreed care plan (see paragraph 55); and
- c. complying with any other requirement that would normally be undertaken by the person receiving care (e.g. review, providing financial information).

Box eight

- 36. Before receiving a direct payment, the nominee must give their consent. As with all forms of consent, the PCT must be satisfied that the person understands what is involved, and has provided their consent, before going ahead and providing a direct payment. This is an area where people may particularly welcome advice, support and information around what they should expect when managing a direct payment on someone else's behalf.
- 37. Before the nominee receives the direct payment, the PCT must also give their consent. PCTs should, in particular, consider whether the person is competent and able to manage a direct payment, on their own or with whatever assistance is available to them.

- 38. If the nominated person is not a close family member (see box eighteen) or a friend involved in the person's care, then the PCT must require the nominee to apply for an enhanced criminal record bureau certificate (a CRB check) before giving their consent.
- 39. If the person is a friend or close family member, the PCT may request they apply for an enhanced criminal record certificate. PCTs should judge whether this is reasonable, based on the relationship between the nominee and the person receiving the care.
- 40. The person may withdraw or change a nomination by writing to the PCT. If this occurs, the PCT must consider whether to stop paying the direct payment, consider paying it to the person directly, or paying it to another nominee; and they should review the direct payment and care plan as soon as reasonably possible.

Who might be a good nominee?

Marie is a young woman with a severe and enduring mental health problem. Her care plan includes taking part in a vocational floristry course, to improve her chances of finding employment. Marie would like to pay for the course, and the transport to and from college, via a direct payment but recognises she has had problems with managing money in the past. Marie has suggested that her mother, who is very supportive, manages the direct payment on her behalf.

Box Nine

Representatives

- 41. If someone does not have the capacity to consent to a direct payment, then they cannot receive one themselves. However, a representative may receive a direct payment on the person's behalf, if the person meets the criteria in paragraphs 1 and 2. This is similar to the process in social care.
- 42. When deciding whether or not to make a direct payment to a representative, the PCT should, in particular, consider:
 - a. whether the person receiving care had, when they had capacity, expressed a wish to receive direct payments, or have someone receive them on their behalf;

- b. whether the person's beliefs or values would have influenced them to have consented or not consented to receiving a direct payment;
- c. any other factors that would be likely to influence their decision to consent or not to receiving direct payments; and
- d. as far as possible, the person's current wishes and feelings.

What is the role of the representative?

A representative is responsible for managing the direct payment on behalf of the person receiving care. They must:

- a. act on behalf of the person, e.g. to help develop care plans and to hold the direct payment;
- b. act in the best interests of the person when securing the provision of services;
- c. be the principal person for all contracts and agreements, e.g. as an employer;
- d. use the direct payment in line with the agreed care plan (see paragraph 55;
- e. comply with any other requirement that would normally be undertaken by the person (e.g. review, providing information).

Box ten

- 43. A representative is someone empowered to act on behalf of the person receiving care. They should always act in their best interests (see box twelve).⁵
- 44. In a similar way to a nominated person, the representative is responsible for managing the direct payment, and will be responsible for fulfilling all the relevant requirements for receiving direct payments. In addition, the representative should notify the PCT as soon as they believe the person has regained capacity.

Who could be a representative?

A representative could be:

a. a deputy appointed by the Court of Protection⁶ to make decisions relevant to

⁵ under the definition in the *Mental Capacity Act (2005) (c.9)*

healthcare and direct payments;

- b. a donee with lasting power of attorney⁷ with the power to make the relevant decisions;
- c. an attorney with enduring power of attorney⁸ with the power to make the relevant decisions;
- d. the person with parental responsibility, if the patient is a child⁹;
- e. the person with parental responsibility, if the patient is over 16 and lacks capacity; or
- f. someone appointed by the PCT to receive and manage a direct payment on behalf of a person, other than a child, who lacks capacity.

Box eleven

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 try to 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 best 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 any 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

⁶ under section 16(2)(b) of the Mental Capacity Act (2005)

⁷ see section 9 of the *Mental Capacity Act (2005)*

⁸ see schedule 4 of the *Mental Capacity Act (2005)*

⁹ defined as anyone under 16.

the best interests of that person.

From Guidance on direct payments for community care, services for carers and children's services: England 2009 pg.69¹⁰

Box twelve

- 45. When assessing someone's suitability to receive direct payments, if the PCT believes that they do not have capacity, they should establish whether someone could act as the person's representative (based on the criteria above). Before someone can be a representative, they must give their consent to managing the direct payment. Like all decisions involving consent, PCTs should ensure that people are fully informed, and provided with sufficient advice and support when making their decision. In a similar way to the process for appointing nominated persons, the PCT should also consider whether the person is competent and able to manage a direct payment, on their own or with whatever assistance is available to them.
- 46. When considering whether a representative is suitable, the PCT should be aware of the terms under which someone has been given power of attorney or the power to act as a deputy. The person's powers must cover making decisions about healthcare and about securing services on the person's behalf to meet their care needs; as power of attorney can cover a range of matters, including both personal welfare and property and affairs decisions, and can include a range of exclusions and restrictions. If a deputy or person with power of attorney lacks suitable powers, they will not be able to manage the direct payment, unless specifically appointed as a representative by the PCT.

Whom should a PCT consult?

When considering whether to appoint a representative, the PCT may also consult:

- a. the person receiving care;
- b. any other deputy appointed by the Court of Protection under the *Mental* Capacity Act, but who lacks the authority to make decisions in relation to the direct payment;

¹⁰ Guidance on direct payments for community care, services for carers and children's services: England 2009 (Department of Health 2009)

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_104840

- c. any donee of lasting power of attorney appointed under the *Mental Capacity Act,* but who lacks the authority to make decisions in relations to the direct payment;
 - d. anyone named by the person receiving care, when they had capacity, as a person to be consulted in these circumstances; and
 - e. anyone in box six or box seven above.

Box thirteen

PCTs appointing representatives

- 47. In some cases, it may be appropriate for the PCT to appoint someone to act as a representative on someone's behalf. This should occur if the person receiving care would benefit from a direct payment, and there is no-one else who is able to act as a representative (i.e. no-one falling into categories (a)-(e) in box eleven).
- 48. An appointed representative could be anyone deemed suitable by the PCT. However, it will be important for PCTs to take into account the past expressed wishes of the patient, and as far as possible their current wishes and feelings. Where possible, PCTs should consider appointing someone with a close relationship to the person, for example a close family member or a friend. As far as is reasonably practicable, the PCT should also take into account the views of the people in box thirteen before appointing someone as a representative.
- 49. Once appointed, a representative appointed by the PCT has the same duties and responsibilities as a representative appointed by another route (see box ten).

Fluctuating Capacity

50. There may be situations where someone's capacity to consent fluctuates, for example someone may have psychotic episodes, during which their capacity to make decisions is impaired. During these periods, it is important that there should be continuity of care, and any disruption should be as minimal as possible. PCTs may find it helpful to work with people with fluctuating conditions to draw up advanced directives and contingency plans to ensure that their care in a crisis better meets their wishes.

- 51. If someone was receiving direct payments and lost their capacity to consent to receiving them, they may no longer receive a direct payment. However, if the PCT is content that this will be temporary, a representative may be appointed to receive direct payments on their behalf, or an existing nominated person may continue to receive them. In these circumstances, their role will be similar to that of a representative for someone who permanently lacks capacity.
- 52. If someone has fluctuating capacity, the representative or nominee must allow the person to manage the direct payment themselves for any period when the person has capacity, if they wish to (they may, of course, leave it to the representative or nominee to continue to manage it).
- 53. When a person gains or regains their capacity to consent, they must give their consent to the direct payment and the care plan continuing. If they wish for the representative or nominee to continue to manage the direct payment, both they and the nominee must also give their consent (as for all nominees- see paragraph 34). If they withdraw their consent, the direct payment must stop. As in all circumstances when direct payments stop, alternative provision should be made to ensure continuity of care.
- 54. If someone regains capacity, the PCT must, as soon as is reasonably possible, review the direct payment and the care plan, to ensure it fully meets the person's needs.

Care Planning

- 55. Before a direct payment can be made, the PCT must develop a care plan.¹¹ This must set out:
 - a. the health needs and outcomes to be met by the services in the care plan;
 - b. the services that the direct payment will be used to purchase (see paragraph 64);
 - c. the size of the direct payment, and how often it will be paid (see paragraph 85);
 - d. an agreed procedure for managing significant potential risk (see paragraph 91);

¹¹ Also known as a support plan, or by other names-, it is important that it contains all the elements listed in paragraph 55.

- e. the name of the care co-ordinator responsible for managing the care plan (see paragraph 112);
- f. who will be responsible for monitoring the patient's health condition (see paragraph 112);
- g. the anticipated date of the first review, and how it is to be carried out (see paragraph 122); and
- h. the period of notice that will apply if the PCT decides to reduce the amount of the direct payment (see paragraph 133);

56. When agreeing the care plan, the PCT must be satisfied that:

- a. the health needs of the patient will be met by the services in the care plan; and
- b. the amount of money in the care plan will be sufficient to cover the full costs of the services in the care plan.
- 57. The individual, nominee or representative must also agree that:
 - a. the person's care needs can be met by the services agreed in the care plan;
 - b. the amount of the direct payment is sufficient to cover the full cost of the care plan; and
 - c. the person receiving care will be part of the review, and their needs may be reassessed as part of that.
- 58. The care plan is the key document setting out the agreement between the person and the PCT about what money they will receive, and what it will be spent on. Drawing up the care plan should be at the heart of the care planning process, and we envisage that it should involve a series of discussions between the patient, their care co-ordinator, and a range of health and social care professionals. A good care plan should be outcome focused, and will be the result of discussions about the person's needs and wishes, as well as the services which will be purchased to meet those needs.
- 59. Where possible, PCTs should work with local authorities and other healthcare providers to ensure that a person has a single care plan covering their health and wellbeing needs across both the NHS and social care. This could include outcomes and services to be addressed through commissioning mechanisms other than direct payments, for example through notional budgets or traditionally commissioned services. However, the

regulations and this guidance only applies to the part of the care plan related to services to be purchased by healthcare direct payments, although the principles are applicable to all care planning.¹²

60. The care plan is an agreement between the PCT and the person receiving direct payments, and includes responsibilities on both sides. It is therefore vital that people are supported throughout the care planning process, to ensure that they are able to make informed decisions in their best interests, and to ensure they do not find the process overly burdensome or overwhelming. This support could take many forms, for example providing information, advocacy or brokerage services. Different PCTs may take different approaches (see box twenty) but each PCT should ensure that they make appropriate arrangements to meet each individual's needs.

More information on care planning

More information on care planning is available from:

- the personal health budget learning network¹³;
- Supporting People with Long Term Conditions: Commissioning Personalised Care Planning: A guide for commissioners¹⁴; and
- Personalised Care Planning for People with a Long Term Condition who have a Personal Health Budget. A Discussion Paper¹⁵.

Box fourteen

61. As a result of the care planning discussion, each care plan should clearly set out the health needs that the direct payment is to address. These may be reasonably broad, but it should be clear to both the PCT and the people involved what the direct payments are meant to achieve.

¹² For ease, in this document, whenever 'care plan' is used, it refers only to the direct payment element, if it is part of a wider care plan.

¹³ http://www.dhcarenetworks.org.uk/PHBLN/

¹⁴ Supporting People with Long Term Conditions: Commissioning Personalised Care Planning: A guide for commissioners (Department of Health 2009)

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_093354

- 62. Having set out the health needs, the care plan should also set out the intended outcomes that the plan is intended to address. These may relate to both health and 'well-being' outcomes. PCTs have broad powers to address people's health and well-being needs, and a good care plan should address people's needs holistically. PCTs may also want to consider developing joint care plans with social care, covering both health and social care needs.
- 63. The care plan should be open to revision and alteration as necessary, and should be reviewed at clinically appropriate intervals. It must be reviewed within the first three months, and then at least annually (see paragraph 123). It is important to note that if someone's condition changes, the care plan should be adapted to meet their changing needs. No-one should ever be denied the care they need because it is not included in their care plan, especially in the case of urgent or emergency care.

What can a direct payment be spent on?

- 64. Tied to the discussion around outcomes, there must be a discussion about the goods and services the person wants to purchase.¹⁶ As far as possible, the person, with support from professionals, carers and others, should make these choices. It may also be helpful to involve service brokers and advocates at this stage.
- 65. A direct payment may only be spent on services agreed in the care plan. The care plan must be agreed by both the PCT and the person receiving care, or their representative or nominee. Before signing off the care plan, the PCT must be reasonably satisfied that the health needs of the patient will be met by the services in the care plan.
- 66. A direct payment may be spent on anything (with a few exceptions) that the person believes will meet their heath and well-being needs, and which is agreed by the PCT. PCTs should be careful not to exclude unusual requests without examining the proposal on a case- by- case basis- these may have significant benefits for people's health and wellbeing.

¹⁵ Available from the personal health budgets learning network

¹⁶ For brevity, we have used 'services' throughout this document, although it refers to anything that can be bought and which will meet someone's health needs.

67. In some cases, it may be sensible for a PCT to agree a service which would normally be funded by Social Care, or another funding stream. If that service is likely to meet someone's agreed health and wellbeing outcomes PCTs should not refuse to purchase this because it has been traditionally commissioned elsewhere.

What could a direct payment can be spent on?

Mary has complex health needs, is ventilator dependent, and was being supported by staff funded by NHS continuing healthcare through a nursing agency. Unfortunately this means Mary is unable to travel to visit her family, as the nursing staff were not allowed to work outside the county. Using a personal health budget, Mary uses a direct payment to employ personal assistants to support her, which means that she is able to travel to see her family and stay overnight if she want to. She is also able to use her assistants in a much more flexible way and choose who comes to support her and when.

Susan has a complex lung condition and had a CPAP machine to help her breathe at night but each time she needed the setting changed she had to travel up to a London hospital to get this done. With a direct payment, Susan bought a variable rate CPAP that automatically adjusted to her breathing and a local supplier was contracted to service this device. This meant that Susan was able to enjoy her "well" hours rather than spend the time travelling to and from hospital.

Box fifteen

- 68. There are a few restrictions on what a direct payment may be spent on. A direct payment cannot be used to purchase alcohol or tobacco, cannot be used for gambling, and cannot be used to repay a debt other than for a service agreed in the care plan.
- 69. A direct payment should also not be used to purchase primary medical services provided by GPs, such as diagnostic tests, basic medical treatment or vaccinations. The Government does not wish to undermine services provided by GPs as part of the registration based, holistic service they currently provide. We do not believe that the vast majority of GP services are suitable for inclusion in direct payments. However,

some, more specialist, services, such as counselling services or nursing services currently organised or managed by GPs, may be suitable for inclusion.

- 70. A direct payment is also not suitable to cover urgent or emergency treatment services, such as unplanned in- patient admissions to hospital. Generally, PCTs should avoid including services in the care plan which require unplanned emergency access. However, they may want to develop advanced directives or crisis planning to ensure that people's wishes are taken into account.
- 71. No service should be included in the care plan if the PCT believes that the benefits are outweighed by the possible damage to someone's health. It is also important to note that direct payments do not circumvent existing guidance, for example relating to NICE approval. Where NICE has concluded that a treatment is not cost effective, PCTs should apply their existing exceptions process before agreeing to such a service. However, where NICE has not ruled on the cost effectiveness or otherwise of a specific treatment, PCTs should not use this as a barrier to people purchasing such services, if it may meet their health and well-being needs.
- 72. When agreeing a care plan, PCTs should also bear in mind their obligations to safeguard public money. Services should not be purchased which are unlikely to meet the agreed outcomes, or where the cost is substantially disproportionate to the potential benefit. PCTs should also not agree services which would reasonably appear to be a misuse of public money or inappropriate for the state to fund.
- 73. If a PCT decides to refuse a service as part of the care plan, the person, representative or nominee may request the PCT to explain why. The person can also ask the PCT to reconsider their decision. If requested, the PCT must inform them of their reasons, in terms the person will understand. This may be a useful part of the process for exploring suitable options during the care planning process. If there is still a dispute, the PCT should discuss any process for resolution, or refer the person to the complaints procedure (see paragraph 106).

Employees

- 74. People may wish to used their direct payment to employ staff as care workers. PCTs should support them to do so whenever possible, while ensuring that there are appropriate safeguards in place.
- 75. For some people receiving direct payments, it may be their first experience of being an employer, and it will be vital to provide them with support, if they want it. This may be especially relevant during the recruitment process, whether they intend to employ a personal assistant, hire a self- employed assistant, or contract with an agency.
- 76. Individuals should be made aware of their legal responsibilities as employers. If someone is employing someone paid for via direct payments, they are legally that person's employer, and so have certain legal responsibilities. PCTs should ensure that individuals are fully aware of the their responsibilities, and are supported to meet them. More information, and a list of responsibilities, is available from annex A of *A guide to receiving direct payments from your local council: A route to independent living*¹⁷. The responsibilities are similar to those on people employing staff using a social care direct payment.
- 77. Concern about becoming an employer should not discourage people who would otherwise be willing and able to manage a direct payment and use this to employ someone. The aim should be to inform the potential recipients 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 PCT fail to make recipients aware of what is involved.
- 78. There will also be costs associated with employing a member of staff directly, such as national insurance, training, and insurance costs and emergency cover. When setting

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4097397 Information is also available from the Directgov website at http://www.direct.gov.uk/en/DisabledPeople/FinancialSupport/Introductiontofinancialsupport/DG_10016128

¹⁷A guide to receiving direct payments from your local council: A route to independent living (Department of Health 2009)

the budget and agreeing the care plan, PCTs should ensure that the full cost of employing someone is included, and people must not be expected to bear any of these costs themselves.

79. As one of a range of support services, individuals or PCTs may wish to include payroll services, which will take responsibility for administering wages, tax and National Insurance for direct payment recipients. If it is agreed that this should be paid for via the direct payment, the cost should be factored in when setting the budget.

Safeguarding

- 80. When deciding whether or not to employ someone, people should follow best practice in relation to safeguarding, vetting and barring. PCTs should follow the requirements set out in the *Safeguarding Vulnerable Groups* legislation, and the procedure laid out by the Independent Safeguarding Authority. This is still developing, and so PCTs should ensure they are aware of their current obligations and best practice.
- 81. When employing or contracting with someone known to the person receiving care (e.g. a friend or family member), it will be at the person's discretion whether or not to require them to undertake an enhanced CRB check. If the person is known to the representative or nominee, but not the person receiving the care, an enhanced CRB check will be required.
- 82. The PCT should ensure that anyone else involved in the management or delivery of care has undertaken an enhanced CRB check, and should ensure the person, or their nominee or representative, is aware of the results.

Advice about employing someone using direct payments

When giving information to people, it may be helpful to suggest that they should:

- Make a list of the things they want to ask a potential employee.
- Be suitably cautious. If they 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 them, for example about smoking and eating habits or what their hobbies are. If they are employing someone to look after their child, they need to find out where the child might be taken, and any other individuals the child might have contact with when being cared for.
- Get a friend, parent or someone they trust to spend some time with them and their new personal assistant initially.
- Make sure that the personal assistant has their support and welfare, or that of their child, as their priority.
- If they are unhappy with the person caring for them, 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 the person chooses to ask for a criminal records check, they should ensure that such a check has been completed recently.
- They should take notes and listen to everything that their 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 their 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.

More information is available from A parent's guide to direct payments.¹⁸

In the case of a representative employing someone on behalf of an adult who lacks capacity:

• Again, if the person chooses to ask for a criminal records check or if one is required,

¹⁸ A parent's guide to direct payments at http://www.dcsf.gov.uk/everychildmatters/resources-and-practice/IG00321/

ensure that such a check has been completed recently.

- 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.

Box sixteen

Paying family carers

- 83. A direct payment should only be used to pay a close family carer (see box seventeen for a definition of a 'close family carer') living in the same household when "it is necessary to meet satisfactorily the patient's need for that service; or to promote the welfare of a patient who is a child". As a general principle, direct payments should only be used to pay family carers living in the same household in exceptional circumstances, for example if there is no other reasonable way of providing someone's care. PCTs will need to make these judgements on a case by case basis. Similar restrictions apply in relation to social care direct payments.
- 84. These restrictions are not intended to prevent people from using their direct payments to employ a live-in personal assistant, provided 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 case. In order to recognise the contribution of carers, the Government has put in place separate means of support for carers, including support to help them build their state pension entitlement.

Who is a close family member?

A person's close family members are described in the regulations as:

- a. The spouse or civil partner of the person receiving care;
- b. Someone who lives with the person as their spouse or civil partner;

- c. Their parent or parent-in-law;
- d. Their son or daughter;
- e. Son- in- law or daughter- in- law;
- f. Stepson or stepdaughter;
- g. Brother or sister;
- h. Aunt or uncle;
- i. Grandparent; or
- j. The spouse or civil partners of (c)- (i), or someone who lives with them as their spouse or civil partner.

Box seventeen

Setting the amount of a direct payment

- 85. Direct payments must be set at a level sufficient to cover the full cost of each of the services agreed in the care plan. If it is not set at a suitable level, it must be reviewed and adjusted. PCTs may wish to consider including a contingency fund, either for the individual or as part of a collective risk pool, to ensure that the budget is available to fully fund the care plan.
- 86. During the pilot phase of the personal health budget pilot programme, the Government does not intend to issue guidance to PCTs around different methods of budget setting. While information is available from the Personal Health Budget learning network¹⁹, this is an area of emerging practice, and it is too early to set out a comprehensive or national approach in guidance.
- 87. Pilot sites should ensure that when calculating the budget, they recognise the additional, 'hidden' costs, for example around ensuring that if someone is employing an assistant, there is also funding available to cover the cost of national insurance, emergency cover and so on.
- 88. The PCT may increase or decrease the size of the direct payment at any time, if they are satisfied that the new amount is sufficient to cover the full cost of the current care

¹⁹ Personal health budget learning network: <u>http://www.dhcarenetworks.org.uk/PHBLN/</u>

plan. If reducing the size of the direct payment, the PCT must notify the person and follow the process in set out in paragraph 133.

- 89. If money has accumulated, the PCT may reduce subsequent direct payments to offset this surplus. However, they should notify the person in advance that this will occur.
- 90. It should be noted that direct payments do not circumvent existing government policy around additional private care. In no circumstances should the budget be set at a level where someone is expected to pay for care privately in order to meet their agreed health needs. If someone wishes to purchase additional care privately, they may do so, so long as it is additional to their assessed needs, and it is a separate episode of care, with clearly separate lines of clinical accountability and governance.

Managing Risk

- 91. During the care planning process, the PCT should have a detailed discussion with the patient, representative or nominee about potential risks, and how they can be managed. This should be part of an ongoing dialogue between people and the PCT about how to manage risk.
- 92. The care plan must contain details of any proportionate means of mitigating the risks, and this should be informed by a discussion of the significant potential risks and their consequences. The PCT must also agree with the individual, nominee or representative the procedure for managing significant potential risk, and must include this in the care plan.
- 93. The risks included in this discussion may include:
 - a. the risks to the person's health;
 - b. the health risks of different treatments;
 - c. risk around employing members of staff;
 - d. purchasing services without appropriate indemnity cover;
 - e. purchasing services lacking complaints procedures; and
 - f. the direct payment being misspent.

This is not an exhaustive list, and PCTs should ensure that they adequately address potential risks on a case by case basis.

94. Any discussion about risk should be realistic and aimed at enabling people to make the decisions that are right for them. This may require balancing potential risks and consequences with the benefits associated with any particular decisions. There is a delicate balance between empowerment and safeguarding, choice and risk. *Independence, Choice and Risk: A guide to best practice in supported decision making* suggests that, whatever the setting:

"the governing principle behind good approaches to choice and risk is that people have the right to live their lives to the full as long as that does not stop others from doing the same"²⁰

Positive Risk Management

Best Practice in Managing Risk: Principles and evidence for best practice in the assessment and management of risk to self and others in mental health services²¹ proposed the concept of 'positive risk management', which may be a helpful starting point for PCTs considering how to develop approaches to risk. Key concepts include:

- Working with the person to identify what is likely to work;
- Paying attention to the views of carers and others when deciding a plan of action;
- Weighing up the potential benefits and harms of choosing one action over another;
- Being willing to take a decision that involves an element of risk because the positive benefits outweighed the risk;

²⁰ Independence, Choice and Risk: A guide to best practice in supported decision making (Department of Health 2007) <u>http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_074773</u>
²¹ Best Practice in Managing Risk: Principles and evidence for best practice in the assessment and management

of risk to self and others in mental health services (Department of Health 2007) www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_076511

- Being clear to all involved about the potential benefits and potential risks; and
- Developing plans and actions that support the positive potentials and priorities of the person while minimising the potential risks.

Box eighteen

- 95. The balance between risks and benefits will be different for different conditions, for different groups, and for different individuals. PCTs should ensure that they do not impose blanket prohibitions, and are sufficiently flexible to tailor their risk management processes to the needs of different people. Best practice guidance is available for some areas, such as mental health, and PCTs may find this to be useful.
- 96. During the process of discussing risk with individuals, PCTs should ensure that everyone has the opportunity to contribute. PCTs should ensure the individual is always involved in these discussions, and if appropriate, someone's family or carers. It will also be important to gain the input of a range of healthcare professionals and the people involved in the person's care, for example social workers or care workers. PCTs should consider how best to strike a balance between the views of individuals and healthcare professionals, maximising choice and control as far as possible, while also ensuring clinical needs are met.
- 97. The discussion in the care plan should be part of an ongoing discussion about risk and benefit between the individual and the PCT. As people's circumstances and condition change, the balance between risk and benefit may change. At each review, the identified risks, and the agreed means of mitigating them, should be discussed, to ensure the decisions made are still relevant and appropriate.

Indemnity

98. People may, if they wish, buy services from providers who have limited or no indemnity or insurance cover. For example, it is unlikely that an acupuncturist will have a similar level of indemnity to a service covered by the NHS Indemnity Scheme. So long as the person buying the service is aware of this, and of the potential risks and implications, limited or no indemnity should not automatically be a bar to purchasing from a provider. This should be included in the discussion around risks when developing the care plan.

- 99. In the first instance, it will be the responsibility of the person buying the service to check the indemnity cover of the provider from which they are buying services. They must make enquiries to ascertain whether the provider has indemnity or insurance, and if so, whether it is proportionate to the risks involved, and otherwise appropriate. For example, a physiotherapist would be required to have a different degree of insurance cover than someone who ran a small dance class.
- 100. If the person buying the service asks the PCT to undertake these checks on their behalf, the PCT must do so. PCTs should also ensure that people are aware that this is an option, and may wish to offer this as part of the risk assessment and care planning process.
- 101. Regardless of who carries out the initial check, the PCT should review this as part of the first review, to ensure the checks have been made and are appropriate.

Registration

- 102. If someone wishes to buy a service which is a regulated activity²², they will need to inquire as to whether their preferred provider is appropriately registered with the Care Quality Commission. If someone wishes to use a direct payment to purchase a service which is not a regulated activity, they may do so.
- 103. A direct payment cannot be used to purchase a regulated activity from a nonregistered service provider. Where a person employs a care worker directly, without the involvement of an agency or employer, the employee does not need to register with CQC.
- 104. In some circumstances, the provider may also need to be a registered member of a professional body affiliated with the Council for Healthcare Regulatory Excellence. A

²² see the Health and Social Care Act 2008 (Regulated Activities) Regulations 2010, S.I 2010/781
direct payment should not be used to purchase care from someone who is unregistered if they are required to be.

Which are the professional registration bodies?

- The General Chiropratic Council (GCC) regulates chiropractors;
- The General Dental Council (GDC) regulates dentists, dental nurses, dental technicians, dental hygienists, dental therapists, clinical dental technicians and orthodontic therapists;
- The General Medical Council (GMC) regulates doctors;
- The General Optical Council (GOC) regulates optometrists, dispensing opticians, student opticians and optical businesses;
- The General Osteopathic Council (GOsC) regulates osteopaths;
- The Health Professions Council (HPC) regulates the members of 15 health professions: arts therapists, biomedical scientists, chiropodists/podiatrists, clinical scientists, dietitians, hearing aid dispensers, occupational therapists, operating department practitioners, orthoptists, paramedics, physiotherapists, practitioner psychologists, prosthetists/orthotists, radiographers, speech and language therapists;
- The Nursing and Midwifery Council (NMC) regulates nurses and midwives; and
- The Pharmaceutical Society of Great Britain (RPSGB) regulates pharmacists in England, Wales and Scotland

Box nineteen

105. In the first instance it will be the responsibility of the person buying the service to check whether the provider they are purchasing from is appropriately registered. They can request the PCT to investigate this, and if they ask the PCT must do so. As with

indemnity cover, the PCT must also review this as part of their assessment as to whether the direct payment is being effectively managed.

106. While some providers, for example aromatherapists, are not required to be registered, there is an established voluntary register for the sector, the Complementary and Natural Healthcare Council (CNHC). The CNHC holds a register of practitioners who have been independently assessed as meeting national standards of competence and practice. However, if a provider is not registered with CNHC this should not automatically be a bar to purchasing from that provider. This should be included in the discussion around risks when developing the care plan.

Complaints

- 107. As part of the discussion around the care plan, there should be a discussion around how people can make complaints if something goes wrong.
- 108. The NHS complaints procedure will continue to apply to any decision made by the PCT. PCTs should ensure that people are aware of the process for accessing that procedure.
- 109. For complaints relating to providers, people will be need to use the provider's complaints procedure. A complaints process is a requirement for services registered with CQC, and people should contact the provider to explore how to use that process. PCTs should consider how best to support people who wish to make a complaint about their provider, and may wish to work with both parties to resolve disputes.
- 110. In some circumstances, providers will not have a complaints procedure (for example, if they are a small organisation that is not registered with CQC). This should not necessarily be a barrier for people to purchase services from them, though the implications should be discussed as part of the discussion around risk.
- 111. The Health Service Ombudsman may investigate complaints about any service purchased by a direct payment. The PCT should ensure that if someone has a

complaint and wishes to escalate it to the Ombudsman, they should be informed how to do so. Generally, other mechanisms to resolve complaints should be explored and exhausted before appealing to the Ombudsman. The Ombudsman will be concerned to ensure that the actions of PCTs and providers are reasonable, and PCTs should ensure that proper records of decisions are kept, including explanations for their decisions.

Care co-ordinator

- 112. For each person receiving a direct payment, the PCT must name a care coordinator, and this must be recorded in the care plan. The care co-ordinator is responsible for:
 - Managing the assessment of the health needs of the person receiving care, for the care plan;
 - b. Ensuring that both the individual, representative or nominee and the PCT have agreed the care plan;
 - c. Undertaking or arranging for the monitoring and review of the direct payment, the care plan and the health of the person; and
 - d. Liaising between the PCT and the person receiving the direct payment.
- 113. The care co-ordinator should normally be someone who has regular contact with the person, and a representative or nominee if they have one. While they may not have care co-ordinator in their job title, the important thing is that they are fulfilling the responsibilities above. While they are able to arrange with others to undertake actions, such as monitoring or review, the care co-ordinator should be the primary point of contact between the person and the PCT. This is a similar role to that of care co-ordinator in many mental health services, or community matrons for Continuing Healthcare..
- 114. It will be the responsibility of PCTs to decide who is best placed in their organisations to take up the role of care co-ordinator. Different services already have best practice guidance around the role of the care co-ordinator, such as for Mental Health services, and there is experience from local authorities which PCTs may find it helpful to build on.

Information, advice and support

- 115. PCTs must make arrangements to provide the person (and if they have one, their representative or nominee) with information, advice and other support. This can be provided either directly or by another organisation working in partnership with the PCT. The PCT should ensure that the person receives adequate information and support at every stage of the process, including during the discussion about whether to receive a direct payment, and during care planning discussions.
- 116. At this stage, PCTs are exploring a number of different ways of providing information, advice and support, and the regulations do not specify either the type of support or information they must provide, as there are a number of possible options available. PCTs should ensure that the support they give is relevant, up-to-date, and accessible. This may include using different forms of media, and different formats or languages, depending on the groups they are aimed at.
- 117. Many local authorities have already commissioned support services for people with social care direct payments, and PCTs may find it helpful to work with them to develop joint or integrated support services. PCTs may also want to consider consulting with and using the expertise of voluntary, user led, community, carers or peer support organisations when discussing or developing their ideas.

What types of support might people need?

- Information in a variety of formats, including on video or in translation to languages other than English;
- Expert patient programmes;
- Advocacy services, for example assistance from a peer or a specially trained advocate;

- Peer support services;
- Commissioning brokerage services; or
- Payroll, training or other employment services to help people manage their employees.

Box twenty

118. While support may be provided directly by the PCT, it may also be appropriate for people to purchase their own support, for example purchasing a payroll service to help when employing a care worker. Money may be included in the care plan to allow the person to do this, but it must be costed and agreed, in the same way as any other service.

Receiving a direct payment

- 119. The person receiving direct payments (the patient, nominee or representative) must have a bank account for them to be paid into. This should be separate from that person's other money, and it should only be used for purchasing care. The bank account should only be accessible by people agreed by the PCT, which should normally be limited to the person purchasing care.
- 120. The bank account may also be used to receive money for other care or services provided by the Government. These include direct payments for social care, payments made by the Independent Living Fund and money paid to disabled people under the "right to control" being piloted by the Office for Disability Issues.²³ This includes money for Access to Work, Disabled Living Fund, Work Choice, and housing related support (also known as Supporting People).
- 121. When receiving direct payments, the person holding the account should keep a record of the money going in and record where it is spent, for example through keeping bank statements and receipts. Where different funding streams are being paid into a single account, this may require taking copies of statements, as different funding

²³More information on the 'Right to Control' is available from <u>www.odi.gov.uk/working/right-to-control.phb</u>

streams may have different monitoring and review processes. As far as possible, PCTs should endeavour to join up with other statutory services, to ensure that monitoring is not onerous and to limit the amount of duplication.

Monitoring and reviewing direct payments

- 122. The PCT must undertake ongoing monitoring of how the direct payment is being used and the health condition of the person. This should be ongoing, and worked into best practice and local processes around delivering care.
- 123. The PCT will also have to undertake more formal reviews at an appropriate frequency. The care plan must be reviewed within three months of the person first receiving a direct payment. Following this, reviews should be at appropriate intervals, but at least yearly. A review should consider:
 - a. Whether the care plan adequately addresses the health needs of the person.
 This includes considering whether their health needs have changed, and if so whether the care plan is still appropriate;
 - b. whether the direct payment has been used effectively;
 - c. whether the direct payment is sufficient to cover the full cost of each of the services;
 - d. whether the person, or their representative or nominee, has used the direct payment appropriately and fulfilled their obligations;
 - e. whether the risks have changed, and whether the risk management is still effective;
 - f. If it is the first review, or if a service has been changed, reassesses indemnity and registration; and
 - g. whether the person's outcomes have been met.
- 124. When carrying out a review, the PCT may:
 - a. re-assess the health needs of the person;
 - b. consult anyone mentioned in box six, and where relevant box seven;
 - c. review receipts, bank statements and other information relating to the use of direct payments; and

- d. consider evidence around whether direct payments have been effectively managed, including evidence as to whether service providers have or had appropriate indemnity and registration.
- 125. Reviews should be light- touch, and should place as few burdens on people, representatives and nominees as possible. PCTs should consider working with local authorities, or other statutory services, to develop joint approaches to reviews, in order to minimise duplication and to reduce the burden on individuals.
- 126. During the care planning discussion, there should be discussion about what the review will look at, and the information that will need to be provided by the person, the representative or the nominee. Information must be:
 - a. legible;
 - b. accompanied with authorisation for the PCT to make copies or take extracts;
 - c. if requested by the PCT, accompanied with an explanation of the information provided;
 - d. if requested, accompanied with a statement informing the PCT where information is held which the person has been unable to provide.
- 127. If a PCT becomes aware, or is notified, that the health of the person has changed significantly, the PCT must consider whether it is appropriate to carry out a review. Whether or not to carry out a review will be informed by local or national best practice for that condition.
- 128. If the PCT becomes aware, or is notified that the direct payment has been insufficient to purchase the services agreed in the care plan, they must carry out a review (see paragraph 122) as soon as possible.
- 129. The person, the representative or nominee may request that the PCT undertakes a review at any time. If this happens, the PCT must decide whether or not to undertake this review, taking into account local practices and circumstances.
- 130. Following a review, the PCT may:
 - a. amend the care plan;

- b. decide to pay the direct payment to the person receiving care, rather than the representative or nominee;
- c. decide to pay the direct payment to a representative or nominee rather than the person;
- d. increase, maintain or reduce the size of the direct payment;
- e. require that a direct payment is not used to purchase a service from a particular individual;
- f. require that the person, representative or nominee provide additional information;
- g. take any other action the PCT considers appropriate. This should normally be to ensure the safe and effective running of the direct payment or care plan, or to protect public money if there is a significant risk of abuse.
- 131. If the PCT decides to reduce the direct payment, they must give the person, representative or nominee reasonable notice in writing (see p.43), stating the reasons for their decision and when it will take effect. On receiving that notice, the person, representative or nominee may request the PCT review that decision, and may provide information or evidence for the PCT to consider. The PCT must then review their decision, and give written notice of the outcome of this second review, stating the reasons for their judgement.

Stopping or reducing a direct payment

- 132. A PCT must stop paying direct payments if:
 - a. the person, who has capacity to consent, withdraws their consent to receiving direct payments (see paragraph 10);
 - b. someone has recovered their capacity to consent, and has withdrawn their consent to continuing to receive direct payments (see paragraph 50); or
 - c. the representative withdraws their consent to receiving direct payments and no other representative has been appointed.
- 133. A PCT may stop making a direct payment if they are satisfied that it is appropriate to do so, for example if:
 - a. the person no longer needs care;

- b. direct payments are no longer a suitable way of providing someone with care;
- c. the PCT no longer thinks the representative or nominee is suitable to receive direct payments, and no-one else has been appointed (paragraphs 34 and 41);
- d. the nominee withdraws their consent;
- e. the person has withdrawn their consent to the nominee receiving direct payments on their behalf;
- f. the direct payment has been used otherwise than to purchase services agreed in the care plan;
- g. fraud, theft or an abuse in connection with the direct payment has taken place; or
- h. the person has died.
- 134. During the care planning process, the PCT should agree with the person receiving the direct payment a reasonable period of notice if the PCT decides to reduce or stop the direct payment. This should be based on the period of notice required for altering or ending contracts with service providers, and should give sufficient time to allow alternative provision to be made to ensure continuity of care. Normally, this will be between one and three months. In some circumstances, it may be appropriate to agree a staggered timeline for reducing the direct payment, as notice periods may differ for different services in the care plan.
- 135. If, for whatever reason, the person receiving care is no longer able or willing to manage the direct payment, the PCT will be responsible for fulfilling the contractual obligations the person has entered into. After a direct payment is stopped, all rights and liabilities acquired or incurred as a result of a service purchased by direct payments will transfer to the PCT.
- 136. In some cases, it may be necessary to stop the direct payment immediately, for example if fraud or theft has occurred. In these cases, 'reasonable notice' may include immediate termination of the direct payment. In these circumstances, the PCT should endeavour to protect public money as far as possible, but should also be mindful of its continued duty to provide care, and should try to ensure the person involved continues to receive appropriate services via other mechanisms.

- 137. Whenever a direct payment is reduced or stopped, the PCT must ensure that the person receiving the direct payment is notified, and reasons for the PCT's decision are explained. This must be in writing, and should be accessible and understandable to the person involved.
- 138. Even if the PCT chooses, for whatever reason, to stop the direct payment, they are still under a duty to provide healthcare if someone requires it. No-one should ever be denied the care they need. Where possible, PCTs should also endeavour to continue to provide a personalised service and maintain continuity of care. For example an independent user trust could be established to manage the budget or the PCT could directly commission the services agreed in the care plan.

Asking for repayment of a direct payment

- 139. In some circumstances, the PCT may ask for all, or part, of the direct payment to be repaid. The decision to seek repayment, and the amount of money to be reclaimed, is at the discretion of the PCT. PCTs may choose to waive reclaiming all or part of the direct payment.
- 140. Direct payments may be reclaimed if:
 - a. the direct payments have been used otherwise than to purchase a service not agreed in the care plan;
 - b. Theft, fraud or other offences may have occurred;
 - c. The patient has died, leaving part of the direct payment unspent;
 - d. The care plan has changed substantially, and there are excess funds as a result;
 - e. The individual's circumstances have changed substantially, for example as a result of being hospitalised and so they are not using their direct payment to purchase care; or
 - f. A significant proportion of the direct payment has not been used to secure the services specified in the care plan and so money has accumulated.

- 141. The pilots and people involved are part of a learning process, and honest errors may occur. The power to reclaim direct payments should not be used to penalise people for making mistakes, nor should it be used when the individual has been the victim of fraud.
- 142. If a substantial amount of money has accumulated in the individual's account due to an under spend, for whatever reason, the PCT should consider whether it is appropriate to reclaim that money. In some circumstances, it may be more appropriate to simply reduce subsequent direct payments, factoring in the existing surplus. However, PCTs should also be aware that a surplus may indicate that someone is not receiving the care they need or too much money has been allocated, and so as part of the review process they should establish why any surplus has built up.
- 143. When reclaiming money from someone with a representative or nominee, the PCT should approach the representative or nominee holding the money, rather than the individual receiving care. However, the PCT should also ensure that, as far as possible, the person receiving care is also aware of the PCTs intentions, and their reasons for this.
- 144. When reclaiming money from the estate of someone who has died, the PCT must approach the personal representatives of the individual to seek repayment. They should do so sensitively, and may wish to leave a period of grace to allow the executors of the will to ensure the estate is in order.
- 145. In some cases, the person may also be being approached by the Local Authority and Independent Living Fund (ILF) seeking to reclaim money, for example in cases where someone has a joint care plan. In these circumstances, the PCT should coordinate with the Local Authority (LA) and ILF to agree a common approach. PCTs should be aware of their responsibilities under the Data Protection Act (1998) and should inform the relevant individuals before contacting the LA or ILF.
- 146. If the PCT has decided to seek repayment, they must give the relevant person reasonable notice in writing, stating:

- a. The reasons for their decision;
- b. The amount to be repaid;
- c. The time in which the money must be repaid; and
- d. Identifying who will be responsible for repayment.
- 147. On receipt of notice from the PCT, the person, representative or nominee may request the PCT to reconsider their decision. They may also provide additional evidence or relevant information to inform that decision. The PCT must reconsider their decision in the light of any new evidence, and then notify and explain the outcome of their deliberation in writing.
- 148. If the PCT is seeking to reclaim money as a result of theft, fraud or another criminal offence, the PCT may seek for that sum to be summarily reclaimed as a civil debt. In these circumstances, PCTs should seek legal advice. This power does not affect any other method of recovery, for example under the *Proceeds of Crime Act* (2002).

Pilot Schemes

- 149. The power to grant direct payments is limited to pilot PCTs authorised by the Secretary of State. When a PCT has been authorised, it will receive a letter from the Department of Health, setting out:
 - a. the PCT(s) involved, and if there is more than one PCT involved, the lead PCT;
 - b. the geographical area in which the power will operate;
 - c. the health needs for which a direct payment may be offered;
 - d. whether direct payments can be offered for aftercare services²⁴;
 - e. any other criteria identifying the people who may be offered direct payments;
 - f. the period of the pilot scheme (up to three years); and
 - g. any other provisions that are required.
- 150. Authorisation will be based on the PCT's application to join the personal health budgets pilot programme, and will follow their completion of the progress check and

²⁴ under section 117 of the Mental Health Act 1983 (c.20)

submission of their project initiation documents. More information on the process for joining the programme, including details around applying for direct payment powers, is available from http://www.dhcarenetworks.org.uk/PHBLN/.

- 151. If pilot sites wish to expand their proposals, they will need to notify the Department of their plans, and they may need to provide additional information before their authorisation is extended.
- 152. The Secretary of State may also write to pilot sites to amend their authorisation. This could include extending period of the pilot programme (up to five years), or imposing additional restrictions or obligations. The Secretary of State may also require pilot PCTs to notify him of their intended arrangements to provide continuity of care on the expiry of the pilot scheme.
- 153. The Secretary of State may revoke a pilot scheme by notice in writing, if he considers that to do so is in the interests of the NHS.

The Evaluation

154. The Department has commissioned an independent evaluation team to carry out a review of the pilot schemes. More information is available from <u>www.phbe.org.uk</u> Authorised pilot PCTs must provide the evaluation team with information that they require for the review, and must cooperate with the evaluation team.

Annex A- Persons excluded from direct payments

A person is unable to receive a direct payment if they are-

- a. subject to a drug rehabilitation requirement, as defined by section 209 of the Criminal Justice Act 2003 (drug rehabilitation requirement)²⁵, imposed by a community order within the meaning of section 177 (community orders) of that Act,²⁶ or by a suspended sentence of imprisonment within the meaning of section 189 of that Act (suspended sentences of imprisonment)²⁷;
- b. subject to an alcohol treatment requirement as defined by section 212 of the Criminal Justice Act 2003 (alcohol treatment requirement), imposed by a community order, within the meaning of section 177 of that Act, or by a suspended sentence of imprisonment, within the meaning of section 189 of that Act;
- c. released on licence under Part 2 of the Criminal Justice Act 1991 (early release of prisoners)²⁸, Chapter 6 of Part 12 of the Criminal Justice Act 2003 (release on licence) or Chapter 2 of the Crime (Sentences) Act 1997 (life sentences)²⁹ subject to a non-standard licence condition requiring the offender to undertake offending behaviour work to address drug or alcohol related behaviour;
- required to submit to treatment for their drug or alcohol dependency by virtue of a community rehabilitation order within the meaning of section 41 of the Powers of Criminal Courts (Sentencing) Act 2000 (community rehabilitation orders) or a

²⁵ 2003 c. 44. Section 209 was amended by paragraph 88 of Schedule 4 to the Criminal Justice and Immigration Act 2008 (c. 4) and by S.I. 2008/912)

²⁶ Section 177 was amended by paragraph 82 of Part 1 of Schedule 4 to the Criminal Justice and Immigration Act 2008 (c. 4).

²⁷ Section 189 was amended by S.I. 2005/643.

²⁸ 1991 c. 53.

²⁹ 1997 c. 43.

community punishment and rehabilitation order within the meaning of section 51 of that Act (community punishment and rehabilitation orders)³⁰;

- e. subject to a drug treatment and testing order imposed under section 52 of the Powers of Criminal Courts (Sentencing) Act 2000 (drug treatment and testing orders)³¹;
- f. subject to a youth rehabilitation order imposed in accordance with paragraph 22 (drug treatment requirement) of Schedule 1 to the Criminal Justice and Immigration Act 2008³² ("the 2008 Act") which requires the person to submit to treatment pursuant to a drug treatment requirement;
- g. subject to a youth rehabilitation order imposed in accordance with paragraph 23 of Schedule 1 to the 2008 Act (drug testing requirement) which includes a drug testing requirement;
- h. subject to a youth rehabilitation order imposed in accordance with paragraph 24 of Schedule 1 to the 2008 Act (intoxicating substance treatment requirement) which requires the person to submit to treatment pursuant to an intoxicating substance treatment requirement
- required to submit to treatment for their drug or alcohol dependency by virtue of a requirement of a probation order within the meaning of sections 228 to 230 of the Criminal Procedure (Scotland) Act 1995 (probation orders) or subject to a drug treatment and testing order within the meaning of section 234B of that Act (drug treatment and testing order)³³; or

³² 2008 c. 4

 ³⁰ 2000 c. 6. Sections 41 and 51 were repealed, with savings, by Schedule 37 to the Criminal Justice Act 2003 (c. 44) ("the 2003 Act").
 ³¹ Section 52 was repealed, with savings, by Schedule 37 to the 2003 Act.

³³ 1995 c. 46 Section 228 was amended by paragraph 21 of Schedule 1 to the Crime and Punishment (Scotland) Act 1997 (c.48), by paragraph 1 of Schedule 6 to the Crime and Disorder Act 1998 (c.37) by paragraph 122 of Schedule 7 to the Criminal Justice and Court Services Act 2000(c.43), by sections 42(11) and 89 of the Criminal Justice (Scotland) Act 2003 (asp 7) and by S.I. 1998/2327, S.I. 2001/919, S.I. 2001/1149, S.I. 2003/288 and S.I. 2008/912. Section 229 was amended by section 49(4) of the Criminal Proceedings etc. (Reform) (Scotland) Act 2007 (asp 6). Section 229A was inserted by sections 12(2) and 24 of the Management of Offenders etc (Scotland) Act 2005 (asp 14) ("MOSA") and amended by S.S.I. 2006/48. Section 230 was amended by Schedule 6 to the Adults with Incapacity (Scotland) Act 2000 (asp 4), by sections 135, 331 and 333 and paragraph 8 of Schedule 4 and Part 1 of Schedule 5 to the Mental Health (Care and Treatment) Scotland Act 2003 (asp 13) and by S.S.I.

j. released on licence under section 22 (release on licence of persons serving determinate sentences) or section 26 of the Prisons (Scotland) Act 1989 (release on licence of persons sentenced to imprisonment for life, etc.)³⁴ or under section 1 (release of short-term, long term and life prisoners) or section 1AA of the Prisoners and Criminal Proceedings (Scotland) Act 1993 (release of certain sexual offenders)³⁵ and subject to a condition that they submit to treatment for their drug or alcohol dependency.

^{2005/161} and S.I. 2009/1182. Section 234B was inserted by section 89 of the Crime and Disorder Act 1998 and amended by S.I. 1998/2327. ³⁴1989 c.45. Sections 22 and 26 were repealed, with savings, by Schedule 7 to the Prisoners and Criminal

³⁴1989 c.45. Sections 22 and 26 were repealed, with savings, by Schedule 7 to the Prisoners and Criminal Proceedings (Scotland) Act 1993 (c.9).

³⁵ 1993 c.9. Section 1 was amended by paragraph 98 of Schedule 8 to the Crime and Disorder Act 1998, by section 1(2) of the Convention Rights (Compliance) (Scotland) Act 2001 (asp 7) and by section 15(2) of MOSA. Section 1AA was inserted by section 15(3) of MOSA.

Annex B- Useful References

Legislation and Statutory Instruments

National Health Service (Direct Payments) Regulations 2010

Health Act (2009) (c.21)

Mental Capacity Act (2005) (c.9)

Health and Social Care Act 2008 (Regulated Activities) Regulations 2010, S.I 2010/781

Other documents

Guidance on direct payments for community care, services for carers and children's services: England 2009 (Department of Health 2009)

Supporting People with Long Term Conditions: Commissioning Personalised Care Planning: A guide for commissioners (Department of Health 2009)

Personalised Care Planning for People with a Long Term Condition who have a Personal Health Budget. A Discussion Paper

A guide to receiving direct payments from your local council: A route to independent living (Department of Health 2009)

Independence, Choice and Risk: A guide to best practice in supported decision making (Department of Health 2007)

Best Practice in Managing Risk: Principles and evidence for best practice in the assessment and management of risk to self and others in mental health services (Department of Health 2007)

A parent's guide to direct payments

http://www.opsi.gov.uk/si/si2010/uksi_20101 000_en_1

http://www.opsi.gov.uk/acts/acts2009/ukpga_ 20090021_en_1 http://www.opsi.gov.uk/acts/acts2005/ukpga_ 20050009_en_1

www.opsi.gov.uk/si/si2010/uksi_20100781_e n_1

http://www.dh.gov.uk/en/Publicationsandstati stics/Publications/PublicationsPolicyAndGuid ance/DH_104840

http://www.dh.gov.uk/en/Publicationsandstati stics/Publications/PublicationsPolicyAndGuid ance/DH_093354

Available from http://www.dhcarenetworks.org.uk/PHBLN/

http://www.dh.gov.uk/en/Publicationsandstati stics/Publications/PublicationsPolicyAndGuid ance/DH_4097397

http://www.dh.gov.uk/en/Publicationsandstati stics/Publications/PublicationsPolicyAndGuid ance/DH_074773

www.dh.gov.uk/en/Publicationsandstatistics/ Publications/PublicationsPolicyAndGuidance /DH_076511

http://www.dcsf.gov.uk/everychildmatters/res ources-and-practice/IG00321/

Websites

Personal health budget learning network Right to Control Website

Directgov website

http://www.dhcarenetworks.org.uk/PHBLN/ www.odi.gov.uk/working/right-to-control.phb

http://www.direct.gov.uk/en/DisabledPeople/ FinancialSupport/Introductiontofinancialsupp ort/DG_10016128