



Direct Payments Guidance

**Community Care, Services for Carers and
Children's Services (Direct Payments) Guidance
England 2003**

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Children's Services (Direct Payments) Guidance
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www.doh.gov.uk/directpayments/

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Foreword

The purpose of direct payments is to give recipients control over their own life by providing an alternative to social care services provided by a local council. A financial payment gives the person flexibility to look beyond 'off-the-peg' service solutions for certain housing, employment, education and leisure activities as well as for personal assistance to meet their assessed needs. This will help increase opportunities for independence, social inclusion and enhanced self-esteem. Direct payment schemes can facilitate this by building links with local health, housing, education, learning and skills councils and other agencies.

What some recipients say:

"I am a man in my late seventies who is a full time wheelchair user and is partially sighted."

"Direct payments have given me control of my life. My personal assistants help me with all my care needs, which enables me to live as independent a life as possible. At the same time I can live in my home, which is what I want to do. I have lived here for fifty years, since I married. My wife died three years ago. My relationship with my son and his family who live nearby is good. Now that I am not so dependent on them we have more to talk about."

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

Introduction

Aim of this guidance

1. The aim of this guidance is to assist local councils in making direct payments. Together with the Annexes, it also provides guidance on how local councils might manage and administer direct payments. This guidance replaces:
 - the *Community Care (Direct Payments) Act 1996 Policy and Practice Guidance* which was issued in 2000
 - the *Carers and Disabled Children Act 2000 Direct Payments for young disabled people Policy and Practice Guidance* which was issued in 2001, and
 - the passages on direct payments contained in the *Carers and Disabled Children Act 2000 Carers and people with parental responsibility for disabled children Policy and Practice Guidance*, which was issued in 2001
2. Direct payments are a different way of delivering certain existing social services responsibilities. Generic policy and practice guidance on those social services which are the subject of direct payments also applies.
3. This guidance has been written to reflect the changes introduced chiefly by s 57 of the Health and Social Care Act 2001 ('the 2001 Act'), section 17A of the Children Act 1989 ('the 1989 Act') and by the Community Care, Services for Carers and Children's Services (Direct Payments) (England) Regulations 2003 ('the Regulations'). From 8 April 2003, the broad effect of this legislation ('the direct payments legislation') is that instead of a local council providing certain social care services, they are required, in certain circumstances, to make direct payments to enable a person to obtain for themselves the services that they are assessed as needing. The Community Care (Direct Payments) Act 1996 was repealed (in relation to England) by the 2001 Act.
4. Not all social care services are included in the direct payments legislation, although a great many of the services for which local councils are responsible are. The Regulations provide that the duty to make direct payments applies to:
 - a community care service within the meaning of section 46 of the National Health Service and Community Care Act 1990; or
 - a service under section 2 of the Carers and Disabled Children Act 2000; or
 - a service which local councils may provide under section 17 of the 1989 Act (provision of services for children in need, their families and others).

Wherever a person is assessed as needing social care services, a council should check whether there is a duty to make a direct payment in respect of that service.

5. In implementing the changes made by the direct payments legislation, the Government is concerned to increase the number of people who receive direct payments and to ensure that people from all client groups have access to the choice that direct payments bring. This is equally important whether the person assessed as needing services is an older person, a disabled adult of working age, a carer, or a disabled child. In respect of the services to which direct payments apply, direct payments should, therefore, always be considered when deciding how to meet a person's care needs. If the conditions are met, a council has a duty to make a direct payment. Payments may only be made if the person agrees, and they have a choice of whether to receive services provided by the council. Recipients of services should not be unfairly influenced in their choices one way or the other. The Government, however, expects to see a substantial increase in the number of direct payment recipients – particularly among older people – and will be monitoring local councils' progress in achieving this goal.
6. This guidance has been written primarily for the use of local councils, but also the NHS and others who want information on the setting-up and operation of local council direct payments schemes might find it useful to refer to it. Individual direct payments users will often find it more convenient to consult user guides for information which they need in order to manage their own direct payments package. The Department of Health (DH) and others publish user guides. Information about the DH guides can be found on the Department's website. Other guides are referenced at the end of this document.
7. Direct payments are monetary payments by local councils direct to individuals, who have been assessed as needing certain services, including those that find themselves caring for others. Direct payments help people who want to manage their own support to improve their quality of life. They promote independence, choice and inclusion by enabling people to purchase the assistance or services that the council would otherwise provide in order to live in their own homes, be fully involved in family and community life, and to engage in work, education and leisure.
8. Day-to-day control of the money and care package passes to the person who has the strongest incentive to ensure that it is spent properly on the necessary services, and who is best placed to judge how to match available resources to needs.
9. When setting up a direct payments scheme, local councils are encouraged to actively consider how to include people with different kinds of impairment, people from different ethnic backgrounds and people of different ages. When considering whether a person's needs for a service can be met by means of a direct payment, local councils should consider the provision of direct payments for both intensive packages and lower level services, long and short-term provision, and they are also encouraged to think about how direct payments can be assimilated into preventative and rehabilitative strategies.
10. The Government wants to see more extensive use of direct payments, in particular, by those groups that have not made wide use of them up to now. For that reason, local councils now have not just a power, but a duty to make direct payments in certain circumstances. This has important implications for the way that local councils undertake assessment and care planning discussions with individuals, and for local councils' own commissioning procedures and planning. For some staff/professionals, direct payments may require a significant change from current ways of working with people needing services. However, those staff who have made the 'cultural leap' have discovered that they experience the great satisfaction that comes from expanding individuals' lifestyle choices.

11. **What some social workers/care managers have said:**

“People have a voice when they’re in control of something...I just feel keeping people more in control gives them a better quality of life”¹

“It’s great way to take hold of your own life”²

“It’s so exciting ! There’s a massive sense of satisfaction”³

12. People may ask carers or other people to *help* them manage direct payments, for example, by helping them to secure the services to which the payments relate. Someone assisting in this way may be the person who also receives and handles the money. Except for children under 16, the person using the service should remain in control, and is accountable for the way in which the direct payments are used. Unless the person using the service is a child aged under 16, payments made to other people wholly *on behalf* of the user are not direct payments within the meaning of the Regulations.

Context

13. The Government’s aim, in promoting direct payments, is to increase individuals’ independence and choice by giving them control over the way the services they are assessed as needing are delivered. The local council makes the payment or payments *instead* of providing or arranging for the provision of the services. The person then uses the payment to secure for him or herself the relevant services. In the case of disabled children, a person with parental responsibility for a disabled child, which is frequently the parent, secures services to meet the needs of their child or the child’s family.
14. As a general principle, local councils should aim to leave choice in the hands of the individual by allowing people to address their own needs as they consider best, whilst satisfying themselves that the agreed outcomes are being achieved. Where a child is assessed as needing services under section 17 of the 1989 Act, the local council also has to be satisfied that the direct payment will ‘safeguard and promote’ the welfare of the child for whom the service is needed.

Scope of the direct payments legislation

15. Where a local council makes a direct payment, it retains its functions with respect to overall provision of the service under the applicable social services legislation. However, so long as the council is satisfied that the person’s needs for a particular service will be met through the arrangements he or she makes using the direct payment, the council is not obliged to provide or arrange those services for that person.
16. Direct payments *must* be made to all individuals who are eligible to receive them and who want them. This might include those people in the groups listed below who have been assessed as needing relevant services.

1 *It Pays Dividends. Direct payments and older people*, Dr Heather Clark, Helen Gough and Ann Macfarlane, 2003.

2 *ibid.*

3 *ibid.*

17. There are some persons to whom the duty to make direct payments does not apply. Examples of the relatively few exceptions to this are people listed in Annex C. Broadly, these are certain people whose liberty to arrange their care is restricted by certain mental health or criminal justice legislation. People in these groups are required to receive specific services. A local council retains its existing functions as respects the provision of services even though it is not under a duty to make a direct payment to a person in this group.
18. Each eligible individual should be offered the choice of having their needs for a relevant service met through direct payments rather than through services provided or arranged by the council as part of the care planning process. The Fair Access to Care Services guidance offers advice about care planning and how direct payments should be offered as part of this process.
19. If individuals wish, local councils can arrange mixed packages for individuals with some directly provided services and direct payments for other needs. This can, for example, give somebody the opportunity to familiarise him/herself with the business of using a direct payment before taking on responsibility for arranging services to meet all their needs.
20. The following groups of people may be eligible to receive direct payments:
 - **Older and disabled people aged 16 and over**
This includes in particular older people who, despite being the largest single group of people using community care services, have been the least likely to be offered and to get a direct payment. This may also include disabled adults and disabled young people aged 16 or 17.
 - **A person with parental responsibility for a child**
This may include a parent or others, such as a grandparent, with parental responsibility for a disabled child. It may also include , a disabled person with parental responsibility for a child.
 - **Carers aged 16 and over**
People whom the council decides need services because they provide or intend to provide a substantial amount of care on a regular basis for someone aged 18 or over. Carers (but not employees, persons working under contract or for a voluntary organisation) may obtain direct payments in respect of their own needs for services but not for services in respect of the needs of the person they care for.

Developing direct payment services locally

Consultation

If local councils are to enhance local involvement in community care services, it is important that local councils consider ways of making direct payment services more responsive to the needs and wishes of individuals using services, including arrangements to consult local people about how direct payments schemes are set up. The best direct payments schemes have been developed by councils and people needing support working together to draw up a scheme that meets local needs. Councils should avoid focusing on one group of potential recipients to the exclusion of other groups. They should not make the assumption that organised groups necessarily represent all individuals and their carers in the locality who might benefit from the flexibility offered by direct payments.

21. Care should be taken to include people with different kinds of impairment, people from different ethnic backgrounds and people of different ages in this process. In particular, local councils should consider how best to consult older people who have previously found it difficult to access schemes. Councils may wish to seek views on the types of scheme older people would like, and also the views of people with impairments that have not yet been fully encompassed within many schemes. Examples include people with learning disabilities, sensory impairments or mental health problems. It is also important that the lines of communication remain open, so that the council is responsive to users' views over time.

Example 1: Promoting direct payments

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

Commissioning

22. Councils should take care to ensure financial planning systems and commissioning arrangements take account of changing patterns of demand, including increases in demand for direct payments.

Example 2: Developing a flexible commissioning strategy

Council B recently revised its commissioning strategy for older people. Over a long period the council had built up a pattern of commissioning typified by cost and volume and block contracts. This proved economical in terms of transaction costs and also enabled the council jointly to plan and invest with providers in ways that encouraged improvements in quality of services as well as supporting innovation and diversification. In many ways this had proved successful and surveys of user satisfaction indicated year-on-year improvements, particularly in relation to flexibility of service and continuity of care.

However, a population needs analysis undertaken to inform the development of the commissioning strategy raised a number of significant issues including:

- Low numbers of older people using direct payments
- An under representation of older people from black and minority ethnic groups in all services
- A lack of development of low level preventative services
- Poor usage of leisure facilities by older people
- A steep decrease in the numbers of older people using day centre facilities

In response the council decided to top-slice the budget for older people. An amount was ring-fenced to develop an information, advice and support service for older people wishing to know more about direct payments. Money was also reallocated away from that which was to have been used to increase the amount of services purchased through block contracts to cash budgets for each area to use for direct payments. In addition the budget was then allocated in a way that specifically attempted to redress the balance in relation to black elders. Local councillors have agreed the council's scrutiny committee will monitor the implementation and impact of the new strategy. Adjustments to budgets will be made as necessary as rising numbers of older people use direct payments.

23. Problems with internal budget management procedures may not be used as a reason to refuse or delay the offering or start of a direct payment to a person to whom there is a duty to make a direct payment.

Support services

24. When discussing direct payments with people, local councils will wish, wherever possible, to offer the option for them to be put in touch with a support group or local centre for independent living, or a peer support group of people who already manage direct payments.
25. Experience has shown that developing support services is a key element of successful implementation of direct payment schemes. Councils are encouraged to consider ways in which they can offer support in connection with direct payments. Councils might decide that they can provide a support service directly, in partnership with a local voluntary organisation, or by some other means. Support provided through voluntary/recipient-run organisations has been shown to be particularly effective and valued by recipients.

26. The experience of existing recipients of direct payments is that they find it easier to seek advice from someone who is independent of the council. People receiving direct payments who have been involved with setting up their local scheme often act as advocates for and mentors of those who follow. They can be a valuable source of emotional support, understanding and advice, and offer positive role models to others. Parents of disabled children often have informal networks with other parents with disabled children. Strengthening such local schemes and networks could be the most effective way of providing advice and support to parents. It also aids the rapid expansion of the scheme and ensures that a council's investment in start-up costs provides good value for money.
27. A support service helps to produce better outcomes for both individuals and local councils. When establishing and reviewing support services, local councils should seek to ensure that the range of support provided reflects the needs of local people requiring services and their carers. A good support service can make direct payments an accessible and attractive option for a wide range of people. Councils should seek to ensure that people who express an interest in direct payments do not have to wait unduly for advice about direct payments.

Example 3: Providing support in connection with direct payments

A voluntary organisation in Council C provides support and assistance to users of direct payments. The Outreach and Advice Worker has developed a peer support network which, via email, shares information on good and not so good practice among recipients of direct payments. The network has developed a database of good reliable personal assistants, and in addition enables participants to share information on spare capacity of good personal assistants. This scheme offers a practical solution to some of the workforce issues highlighted as being experienced by disabled people.

28. Support services might include training and practical assistance in addition to providing information, advice and peer support. Examples of the range of areas in which support might be welcomed are:
- a list of local provider agencies
 - support and advice in setting up and maintaining a direct payments scheme including financial management
 - help for people to draft advertisements, job descriptions and contracts
 - help in explaining the safeguards needed in the employment of people to work with children or adults
 - rooms for interviews and assistance with interviewing
 - an address for responses to advertisements
 - support and advice about the legal responsibilities of being an employer
 - support and advice about being a good manager of staff
 - information about income tax and national insurance
 - a payroll service
 - advice on health and safety issues, including moving and handling
 - regular training, for example, on assertiveness, budgeting skills, etc.
 - some emergency cover support
 - signposting to other services such as welfare benefits advocacy
 - advice about user-controlled trusts.

29. People who receive direct payments may need particular support when they first take on responsibility for managing their own or their child's care, or become employers for the first time.
30. Councils should also have regard to the reasonable needs and expectations of support scheme users, and to the need to comply with their legal obligations, for example, under the Disability Discrimination Act 1995. Information about direct payments should be published in 'Better Care, Higher Standards' long-term care charters.
31. Councils will wish to ensure that local support services are sufficiently accessible to everyone eligible to receive direct payments. Skills and knowledge are required to work with people with particular support needs, especially where there are issues of consent and the ability to manage. This might include people with learning disabilities, communication difficulties, mental health problems or older people with dementia.
32. It can often be important for the person with parental responsibility for the disabled 16- or 17-year-old also to have access to support services. This may be particularly important if the 16- or 17-year-old is receiving help from their parent to manage the direct payment, or if they are receiving a package of care where some elements are managed by the parent and some managed by the young person. People with parental responsibility for a disabled 16- or 17-year-old may also find it useful to meet disabled adults who receive direct payments. The community and voluntary sector is often able to promote links between families with disabled children, both for parents and for children and young people.
33. Support services may need to contract-in people with specialist skills as appropriate. As the number and variety of direct payments recipients expands, local councils should review the support services they provide, or arrange to ensure that people from different backgrounds have sufficient access to peer support and other services to match their particular needs and that the aims of the service continue to be met.
34. The Government has produced a national guide for people who receive direct payments.⁴ Councils may find it helpful to supplement this with local information. Local councils should also allow for differing communication requirements, for example, for non-English speakers, British sign language, communication methods for deaf/blind people, large print, audio, Braille, and email.
35. People in receipt of Independent Living Fund (ILF) awards often require the same advice as people using direct payments. Councils are encouraged to consider the needs of ILF recipients when setting up and reviewing local support services. In addition, other people such as carers of people who are receiving direct payments may also need advice about how direct payments work. This is particularly important if they are assisting their friend or relative with managing the payments. People who are self-funding their services may also welcome the advice of a support service.

Advocacy

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

⁴ *A Guide to Receiving Direct Payments from Your Local Council*, Department of Health, May 2003.

Support for young disabled people

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

Example 4: Providing support and advocacy

Martin, who has profound and complex disabilities with high-level support needs, began to use direct payments when he became 17 years old. Although at first some professionals involved expressed lots of concerns, Martin and his family persevered, supported by his Circle of Support.

There have been plenty of ups and downs with recruiting and retaining personal assistants, but receiving direct payments has made a big difference to Martin's daily life. He is no longer totally dependent on his parents to organise interesting things to do each day, or support him to do them. He has help to do ordinary everyday activities such as shopping, visits to interactive museums, swimming, eating out and going out with his friends. Most exciting for Martin, he has support during the family holiday, giving him freedom to choose when to go out, and not having to rely on the rest of the family. For the first time ever, Martin now spends weekends in his own home without his parents, supported by two friends who act as personal assistants, giving him all the support and attention he needs.

38. Where there is a difference of views between parents and disabled young people aged 16 or 17, the duty to make direct payments might mean that local councils should give precedence to the views of the young person. It follows that there may be situations where it would be right for a young person to receive a direct payment whether the parents agree or not, although, it is important that local councils consider the welfare of the young person in such circumstances.

Example 5: Differences of opinion

Jennifer is a 17-year-old with a physical disability who wishes to move away from home to go to college. To help her do this she wants to engage her own personal assistant to help her get ready for college in the mornings, rather than rely on the local council domiciliary service. Her parents were unhappy at the decision as they felt that she would be unable to manage her needs independently. In addition they are reluctant to have her leave home. The local council has worked closely with the local support and advocacy services. Jennifer's parents have accessed separate advice and information and now fully support her decision.

39. There will be situations where disabled young people aged 16 or 17 will express their wish to manage a direct payment but their parents and the local council believe that they are not at the moment capable of managing a direct payment by themselves or with help. When the young person does not agree with the council's judgement, they should have access to advocacy and the opportunity for discussions with the council to ensure that their arguments are properly considered. The council's complaints procedure should also be open to the young person.

Complaints procedure

40. Councils are required to operate a procedure for considering any representations (including any complaints) which are made to them with respect to the discharge of their social services functions or about any failure to discharge those functions. The making of direct payments is a social services function within the meaning of section 1A of the Local Authority Social Services Act 1970. People who receive, or consider that they should receive, direct payments are entitled to have access to this procedure in the same way as someone who receives services provided or arranged by the local council.
41. There is also a complaints procedure under section 26 of the 1989 which may be used to complain about direct payments made under section 17A of that Act.

Using direct payments

Consent

42. Councils may make direct payments only with the consent of the person concerned, or, for disabled children aged under 16, with the consent of a person with parental responsibility, usually a parent. Whilst a direct payment can be made to a nominee and someone else can help the person to manage the direct payment, the person eligible to receive direct payments must be able to consent to the making of the payment.
43. As well as giving users greater control and independence, a direct payment carries with it responsibilities. The individual is accountable to the local council for the way in which the money is spent. Users also take on responsibility for obtaining the services they need through their own arrangements, which may involve legal responsibilities.
44. Councils should establish that there is an understanding of what is involved in managing the direct payment. This is an area where people may particularly welcome support. Obtaining consent might be a process involving continuing discussion, rather than a single event.
45. The council should also make clear that a person does not have to agree to a direct payment and that it would arrange services in the normal way if someone decides not to accept direct payments. They should also discuss with people who are to receive direct payments what they should do if they no longer wish to receive direct payments.
46. Situations may arise where people will refuse to accept direct payments because they object to a specific aspect of the terms on which the payments are offered, for example, the amount or the conditions attached. In such cases, the individual should have access to the same procedures outlined above for those who have been refused a direct payment.

Ability to manage

47. If the person consents, local councils are under a duty to make direct payments to anyone who appears to the council to be able to manage them (either alone or with help). This is, of course, provided they are not prevented from doing so for other reasons specified in the Regulations, or, for example, because the local council is not satisfied that the person's needs for the service can be met using a direct payment.
48. Councils should not make blanket assumptions that whole groups of people will or will not be capable of managing direct payments. A council is not under a duty to make a direct payment if it does not appear to it that the person is capable of managing the payment, or to do so with assistance. However, very many people will be able to do so, in particular, if they have access to help and support. Where a council makes a judgement that someone is unable to manage, this should be made on an individual basis, taking into account the views of the individual and the help that may be available to him or her. Where an individual does not agree with the council's judgement, they should have access to advocacy and, if available, arbitration, to ensure that their arguments are properly considered, or access to the council's complaints procedure.

49. Councils should give the person information and support as early in the process as possible about what receiving direct payment will involve. In order to make an informed decision, people need to understand what is involved in managing direct payments. Managing direct payments is not simply about handling money. A direct payment also involves people making their own arrangements, with assistance if necessary, to obtain the services which the council would otherwise have arranged or provided.

Advice on making decisions about the ability to manage

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

- the person's understanding of direct payments, including the actions required on their part;
- whether the person understands the implications of taking or not taking on direct payments;
- what help is available to the person;
- the nature of the services the person is assessed as needing;
- what arrangements the person would make to obtain services.

50. If the person who is deciding whether to accept direct payments does not already have a service in place, for example, if they have been newly assessed, the council may need to provide a service in the interim. Where the individual is expressing doubt about their ability to manage, this might mean that they are experiencing some difficulties, but this may not mean that they are incapable of managing the payment altogether. It may be appropriate to offer a mixed package of direct payments and council-arranged services to give him/her experience of operating direct payments. This may be particularly useful for those people used to receiving direct services, such as older people, and who may need to increase their confidence.
51. Some people may need help with managing the money. The payment may be made to a third party (nominee) for the recipient and day-to-day management of finances may be delegated in this way. However, the person to whom the direct payment is made must have control over how services are delivered. Direct payments may also be provided through someone with power of attorney for the individual or a user-controlled trust. Values into Action's Report *Trusting Independence* is a good guide to arranging a user-controlled trust.⁵ Before direct payments begin councils should satisfy themselves that the relationship between the individual and the agent will honour the spirit of independent living.
52. Where someone needs assistance to manage direct payments, the council might wish to explore ways of delivering this so that adequate help is available over a sustained period, not just for the set-up period. Recipients may choose to ask family or friends, or advocacy or support groups to help them in this way. They might also choose to buy in assistance, for example, with keeping records, management of day-to-day relationships with staff or using a payroll service.
53. In certain circumstances a trust may take on the employment of staff and the financial management of the payment (see above). In such cases, local councils should seek to establish that there is an understanding by those appointed to manage the administration of the payment of what is involved before making direct payments.

⁵ Holman and Bewley, VIA, 2001.

54. If the local council concludes that someone is not, even with assistance, able to manage direct payments, it is important to discuss with him or her and, in appropriate circumstances, with any family or friends the reasons for the decision. Where an individual does not agree, they should have access to advocacy and, if available, to arbitration to ensure that their arguments are properly considered. The council should also make the individual aware that they can use the complaints procedure to challenge the local council's decision not to offer direct payments.

Long-term considerations

55. Many people with an episodic condition can manage direct payments very adequately. Nevertheless, some people may be better able to cope with direct payments if a friend, relative or some other third party is willing to provide greater assistance when their condition worsens. Advance statements should be used as part of the process of managing a fluctuating condition.
56. Provided it appears to the council that a person is currently capable of managing a direct payment, or managing the payment with help, there may still be duty to make a direct payment even if it is known that the person is likely to lose the ability to manage in the future. The council should make suitable arrangements to ensure that direct payments do not continue if appropriate support cannot be arranged to enable such people to continue to manage or if their condition deteriorates so they become incapable of managing the payment, even with help. People whose condition is likely to fluctuate or deteriorate permanently should be given an opportunity to explore any worries they may have about their ongoing ability to manage direct payments.
57. Where individuals are worried about dementia or other cognitive impairment local councils may wish to direct them to the appropriate voluntary sector organisations (see Appendix F). It is important that the needs of people with dementia and their carers are properly considered, and direct payments should not be discontinued if the person needing services is able to manage with appropriate support.

Enduring power of attorney

58. A person with legal capacity can make an enduring power of attorney (EPA). He or she makes the EPA in the expectation that if they lose capacity the person appointed as attorney will lawfully be able to continue to deal with his or her property and affairs once the power is registered. If a person receives direct payments, then the attorney under the EPA could continue to receive payments on his or her behalf.
59. However, this relies on the person having previously consented to receiving direct payments at a time when they had the capacity to do so. An attorney acting under an enduring power cannot give consent on the person's behalf. If a person, to the knowledge of the council, becomes permanently incapable of managing a direct payment, whether alone or with help, the council is required by the Regulations to terminate the making of direct payments, and provide or arrange for the provision of services instead. Currently, such an attorney cannot make decisions about a person's health care or personal welfare. If it becomes appropriate for the person to receive different services, such an attorney cannot consent to direct payments for such services. This guidance will be reviewed in light of any changes to the law made as a result of the Mental Incapacity Bill. The draft Bill currently includes provision for a "lasting power of attorney" so that important decisions can be made about a person's welfare in addition to decisions about their property and affairs.

Support for people with communication difficulties

60. People with learning disabilities may have little real knowledge about their current services, how they operate, who pays for the services or who controls the spending. Information about direct payments may be meaningless if people do not understand the system they are replacing. In addition, people with learning disabilities may have little control over their current services and may not even be aware that they have choices. *Valuing People*, the Government's White Paper on learning disabilities, highlighted the importance of direct payments for people with learning disabilities. The guidance accompanying *Valuing People* requires Learning Disability Partnership Boards to foster the development of good support services and schemes so that more people with learning disabilities and their families can benefit from direct payments. Direct payments are a priority work area for the Valuing People Support Team in the help they give to Partnership Boards. The Valuing People support team website is www.doh.gov.uk/vpst.
61. Councils will need to think carefully about how to best present information about services including direct payments to people with learning disabilities and other cognitive impairments so as to maximise the potential for people to make informed decisions. Supporting people in making choices about how they want their needs to be met should be an integral part of the assessment and review process.
62. If it is not obvious initially how an individual communicates choices, care should be taken to involve in the process people who know the service user well and understand how they express their preferences. This will help build up a picture of the type of service response which would best meet the individual's needs, desires and aspirations. For further information on how to make direct payments work for people with learning disabilities, local councils may wish to consult with Values into Action, who produce a range of guidance on this subject. Details of some of their publications can be found in Annex E.

Example 6: Making direct payments work for people with learning disabilities

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

Miss O'Leary decides she would like to spend more time swimming, doing voluntary work and socialising with friends in the evenings and cut down her attendance at the centre to one day per week instead of five. The local council agrees to fund a direct payment of £200 per week and her social worker makes an application to the ILV to increase the payment to £400 per week, which the ILF agree to fund. She decides that rather than appoint someone to manage the direct payment she would prefer a trust arrangement. Her brother, a social worker, an advocate and a friend agree to become trustees and an independent living trust is set up to manage the payments on her behalf. The trust employs Miss O'Leary's personal assistants and manages all the financial matters associated with the direct payment. Decisions are made inclusively and she is helped to recruit people she enjoys working with and review her timetable periodically. After a short time she is clearly more expressive and extrovert and the symptoms of withdrawal subside. (See Values into Action's report on user controlled trusts, *Trusting Independence*, VIA, 2001.)

Setting up direct payments

63. In order to ensure that the person's assessed needs for the relevant service can be met by means of a direct payment, each local council should consider the person's needs and also discuss with anyone to whom it proposes to offer direct payments how he or she intends to secure the services. Councils will want to be satisfied that the person's assessed needs can and will be met, and that the money is being spent appropriately in securing services to meet those needs. In the case of services for children in need, a local council is required to satisfy itself that child's welfare will be safeguarded and promoted using the direct payment. Councils may set reasonable conditions on the direct payment, but need to bear in mind when doing so that the aim of a direct payment is to give people more choice and control over the services they are assessed as needing. For example, individual choice and control would not be delivered were a condition set that someone who receives direct payments may only use certain providers. Conditions should be proportionate and no more extensive, in terms or number, than is reasonably necessary. Councils should avoid setting up disproportionately intensive monitoring procedures. Financial payments should not begin until the recipient has agreed to any conditions that the local council considers are necessary in connection with the direct payment.
64. Some people may already have ideas about how they would use direct payments, and may have discussed these with the care manager or social worker at the assessment stage. Other people may need advice or advocacy to help them think through the implications or alternatives. A local support group can be invaluable in assisting with this. If there is a local register of approved providers of services to direct payment recipients who are willing for their details to be passed on, the council could bring the register to the attention of the individual. Councils should not *require* the individual only to contract with providers from the register, and will also need to think carefully about setting up and maintaining a register, including the potential legal implications.
65. In considering whether the person's needs for the relevant service will be met by the person's own arrangements, local councils should not be constrained by existing patterns of service provision. By exploring innovative and creative options, people should be encouraged to identify alternatives that meet their needs more effectively. Where the user's needs fluctuate over time, it will be important to discuss in advance how the direct payments will be used to secure a package of assistance which varies according to need.
66. Many people will prefer to use direct payments to take on their own personal assistants as employees. This option gives them the most direct control over the assistance they receive, but it also carries the most responsibility (e.g. to pay tax, National Insurance contributions and statutory sick and maternity pay). Others may choose to contract with independent agencies and not to employ personal assistants themselves or to contract with self-employed individuals.
67. The Government has implemented a scheme of regulation in domiciliary care. Councils will be required, when making arrangements for domiciliary care under their community care responsibilities, to place contracts only with registered domiciliary care providers. Direct payments users need not restrict themselves to registered domiciliary care providers, but should be aware of the scheme.

Example 7: Getting started with direct payments

As part of a Community Care Assessment or Children in Need Assessment in Council D, the assessor discusses with the individual the option of using a direct payment. If the person decides she or he is interested in a direct payment, the assessor completes a referral form and sends it to the Direct Payment Project Manager who liaises with the Direct Payments Support Scheme (DPSS) to arrange a joint visit.

The Project Manager produces a start-up pack for each person which explains how much their direct payment is, what date it starts from, how much their contribution is, and so on. It also contains copies of the financial monitoring form and timesheets as well as two copies of the agreement. This is taken to the individual by the DPSS who go through the paperwork and monitoring requirements. People are asked to forward a copy of their direct payment bank account statement, financial monitoring form, timesheets and invoices to the Project Manager each month.

The DPSS organises a well-attended Direct Payments User Group every three months and produces a newsletter containing the minutes of the meeting as well as topical issues.

Assessment and care plans

68. Detailed policy and practice guidance on assessment (including risk assessment) already exists, and should be followed whether or not the person being assessed is likely to receive services provided by the local council or direct payments.⁶ There is no difference in the assessment of a person's needs for services, although under the Regulations a local council must also be satisfied that the person's needs for services can be met by means of a direct payment. It is important that the needs-led focus of the assessment is retained.
69. If encouraged, many individuals will already have clear views about the activities with which they need assistance. Existing direct payment schemes have enabled people to secure assistance with personal and domestic tasks inside and outside the home. This might include daily activities like getting in and out of bed, dressing, having a bath, preparing a meal, doing housework and laundry, going shopping, going to college, and more complex needs such as enabling a deaf/blind person to secure the services of a guide-communicator. Direct payments for children with enduring disabilities will usually be a long term commitment, but frequent review will be needed as the needs of the child change with age.

⁶ Guidance on assessment of adults is contained in the guidance on the *Single Assessment Process*, published in January 2002, and in the *Fair Access to Care Services* guidance, published in May 2002. Guidance on assessment of children is contained in the *Framework for the Assessment of Children in Need and Their Families*, and requires a holistic assessment of the needs of the disabled child as well as the parents and any siblings.

Example 8: Working together to promote non-institutional care

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

70. Councils should also consider how direct payments might promote preventive and rehabilitative strategies. Good assessment can result in timely provision of a direct payment and forestall the need for a more extensive provision of services in the future.
71. Councils are reminded that there should always be a care plan, a written copy of which should be given to the individual. This advice applies equally where direct payments are provided in place of services provided or arranged by the local council. Annex B contains a checklist of points which should be sorted out before direct payments start and which should be covered in the care plan.

Example 9: Using direct payments to meet a range of assessed needs

In Council E, direct payments have been used to create a variety of innovative care packages that meet individuals' assessed needs in the most appropriate way at no extra cost to the council. For example:

- Miss Lee is 79 and assessed as needing one day a week of day care to combat social isolation and depression. She does not want to go to a day centre as it means getting up early to get ready and it is too long a day. She receives a direct payment instead of day care provided by the local council and engages an agency carer for three hours a week. The carer collects her at 11.00am and takes her to the library. She then goes to the post office to collect her own pension and to the local shops for light shopping. The carer then takes her back home and cooks lunch, leaving at around 2.00pm.
- Mrs Watts is 56 with severe MS. She was unhappy with traditional services so her husband provided the majority of her care. When she fell at home and broke her leg they realised he could not manage any longer. A referral was made to the Direct Payment Project Manager, who visited Mrs Watts in hospital to discuss direct payments. Her husband set up the bank account and an agency was found to provide the service. Mrs Watts was able to be discharged from hospital after a week and is still very happy with her care provider.
- Miss Dunn is 19 and has a physical disability. Her parents are separated and her father does not live locally. She has a direct payment to provide her home care but does not visit her father as often as she would like. The Direct Payment Support Scheme contacted an agency in the council where her father lives and Miss Dunn now goes regularly for the weekend using her direct payment to pay the local agency.
- Mr Singh is an older Indian gentleman who was assessed as requiring day care in order to give his carer a break and for him to be more involved in his community. He uses his direct payment for a personal assistant to take him to the Sikh Temple instead of attending a day centre.

Short-term needs

72. For people whose needs are short term, direct payments can support their return to independence. In such instances it will be important to discuss at the outset how the ending of the direct payment will be managed. Consideration should also be given to looking at how people could use a direct payment to regain or retain their independence, and live in their own home, for as long as possible. When setting up direct payments schemes, local councils should particularly consider how to make the administration of direct payments sufficiently fast and flexible to use for hospital discharge or intermediate care.

Example 10: Using direct payments to meet short-term needs

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

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

Example 11: Short breaks for disabled children using direct payments

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

Short term care in a care home

74. Direct payments may not pay for adults to live for the longterm in a care home. They may be made to enable people to purchase for themselves short stays in care homes, but this cannot be for more than a four-week period in any twelve-months. Where two successive periods of such care are less than four weeks apart, they are added together to make a cumulative total which may not exceed four weeks. If the two periods are more than four weeks apart they are not added together. It is unlikely that direct payments will be appropriate for emergency (unplanned) residential care.
75. People can receive additional weeks in a care home once they have reached the four-week maximum. They cannot purchase the stay using their direct payments, but if the council considers that a longer stay is needed, it can still arrange and fund stays for the person itself in the normal way. There is no restriction on the length of time for which the council may arrange such accommodation for someone.

76. A direct payment also cannot be made in relation to the provision of residential accommodation for a disabled child or disabled young person for any single period in excess of four weeks, and for more than 120 days in any period of twelve months. The time limit is imposed to avoid inappropriate use of residential accommodation.

People in residential care

77. Direct payments may also be used to enable people who are living in care homes to have temporary access to direct payments to try out independent living arrangements before making a commitment to moving out of their care home. Direct payments can also be used by people living in care homes to buy a day service place or engage in an alternative day time activity, and this can be particularly enabling for young people at transition stage.

Equipment

78. Councils may make direct payments to enable people to purchase for themselves equipment that would otherwise have been provided by the social services department. Direct payments may also be made to enable people to pay for adaptations which would otherwise have been provided or arranged by the social services department
79. Direct payments cannot be used to purchase services or equipment for which the council is not responsible, for example, services that the NHS provides. Direct payments are not a substitute for disabled facilities grants.
80. If making a direct payment for the purchase of items of equipment, local councils will need to satisfy themselves that the person's needs for the service will be met by the user's own arrangements. In particular, local councils will wish to ensure that the direct payment recipient is adequately supported by specialist expertise. This is particularly true in the case of major items, when advice may be needed to ensure that equipment purchased is safe and appropriate.
81. Where a council makes a direct payment for equipment, it needs to clarify with the individual at the outset (just as it should where it arranges for the provision of equipment itself) where ownership lies as well as who has responsibility for ongoing care and maintenance. As direct payments mean that the individual will secure for themselves the equipment they are assessed as needing, a council will need to consider what conditions, if any, should be attached to the payment, for example, concerning what will happen to the equipment if the individual no longer requires the services for which the equipment was purchased. Equipment can be purchased as part of making a package cost effective, for example, supplying pagers or mobile phones to personal assistants.

Calculating the amount of a direct payment

82. It is up to the council to decide on the amount of a direct payment. However, the direct payments legislation provides that it must be equivalent to the council's estimate of the reasonable cost of securing the provision of the service concerned, subject to any sum paid by the recipient. This means that the direct payment should be sufficient to enable the recipient lawfully to secure a service of a standard that the council considers is reasonable to fulfil the needs for the service to which the payment relates. There is no limit on the maximum or minimum amount of a direct payment either in the amount of care it is intended to purchase or on the value of the direct payment.

83. In estimating the reasonable cost of securing the provision of the service concerned, local councils should include associated costs that are necessarily incurred in securing provision, without which the service could not be provided, or could not lawfully be provided. The particular costs involved will vary depending upon the way in which the service is secured, but such costs might include recruitment costs, National Insurance, statutory holiday pay, sick pay, maternity pay, employers' liability insurance, public liability insurance and VAT.
84. The council is not obliged to fund the particular costs associated with the individual's preferred method of securing the service if, taking into account the user's assessed contribution, the costs exceed the council's estimate of the reasonable cost of securing it and the service can in fact be secured more cost effectively (but still to the required standard) in another way. The local council is also not obliged to fund particular costs that are incurred by the individual on a discretionary basis, for example, non-statutory liabilities such as an ex gratia bonus payment. The council might decide that they are able to increase the amount nevertheless so as to enable the person to secure his or her preferred service if it is satisfied that the benefits of doing so outweigh the costs and that it still represents best value. Direct payments recipients can use their own resources to purchase additional, or better quality, services if they wish to do so.
85. There may be cases where an individual thinks that the total value of the direct payment should be greater than the council proposes, and/or that his or her contribution or the amount they are asked to pay by way of reimbursement should be less than the council proposes. Where these cases cannot be resolved through discussion, local councils should advise the individual that he or she can pursue the matter through the council's complaints procedure.
86. The council should give individuals as much notice as possible of the value of a direct payment, and the contribution or repayment they will be expected to make to the cost of their care package. This should be done before the payment begins, or its level is changed, to provide the opportunity for any dispute over the level to be resolved before the payment begins or the change takes effect. If that is not possible, whilst any complaint is being considered, individuals may choose either to manage on the amount of direct payments being offered or refuse to accept the direct payments. If a person does not agree to a direct payment, the council remains responsible for providing or arranging the provision of the services they are assessed as needing.
87. A preventive strategy may necessitate a higher investment to achieve long-term benefits and savings. Provision of direct payments that allow a person to remain in their own home may represent long-term savings if that person does not then require hospital or residential care. Similarly the provision of direct payments to a person in need of rehabilitative care may result in a more sensitive and individualised service which may in turn ease a person's recovery.

Charging

88. In considering whether to ask recipients of direct payments to make a financial contribution to the cost of their care package, the Regulations provide that the local council shall determine, having regard to the recipient's means, what amount or amounts (if any) it is reasonably practicable to pay towards the cost. For people assessed as needing community care services or carer services, the relevant guidance is *Fairer Charging Policies for Home Care and Other Non-residential Social Services*.
89. There are two ways in which an individual may make a financial contribution to the cost of his or her care. The council may make a direct payment that is equivalent to their estimate of the reasonable cost of the service and subsequently seek reimbursement (gross payment). Alternatively, the local council may deduct from their estimate the assessed charge before the payment is made and make direct payments

net of the amount that the individual is expected to make (net payment). Councils should take into account the views of users when producing their policy on charging, allowing sufficient flexibility to respond to individual circumstances.

90. Councils are reminded that they do not have power to charge for services provided under section 117 of the Mental Health Act 1983 (after-care). Accordingly, where local councils make direct payments instead of providing services under section 117 of the Act, they may not seek payment, whether by way of reimbursement or a contribution. Where the need for services arises under section 17 of the 1989 Act and payments are made to person with parental responsibility for a child aged 16 or 17, or to a person in receipt of certain benefits, the same restrictions on charging apply.

Making payments

91. It is up to local councils to decide how frequently payments should be made. In considering what procedures to put in place, local councils should bear in mind the possible effect of different alternatives on the circumstances of people who are likely to receive direct payments. People need to be in a position to pay for services when payment is due. The arrangements for making direct payments should be reliable, as late or incorrect payments may put at risk people's ability to secure the services they need. The council may also need to set up procedures for making additional payments in emergencies, for example, if needs change or regular payments go astray. Councils should tell recipients, before direct payments begin, how and when the payments will be made, and the procedures for additional payments in an emergency.

Example 12: Using direct payment monies flexibly

Mr Williams is an older man living alone who has become blind, lost confidence and has few social contacts. He is not gregarious and does not want to go to a day centre. He feels stressed and anxious trying to cope with everyday tasks. At his assessment it is agreed that his needs are to reduce his anxiety, prepare food safely, shop, regain social activity, manage his finances, build 'mental maps' of his outdoor environment and have emotional support to help regain his independence. A direct payment package of 17 hours a week enables him to employ a personal assistant to do these things.

As Mr Williams's confidence returns, he becomes more ambitious in his activities. He is able to manage his direct payment hours to 'bank' some time. He uses the time to travel with his personal assistant to visit his grand daughter in London, a trip he has not made before. The banked hours also pay for the assistant's travel. He pays his own train fare.

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

92. The flexibility inherent in direct payments means that individuals can adjust the amount they use week to week and 'bank' any spare money to use as and when extra needs arise. So long as the overall the payments are being used to secure the services they are for and the care plan objectives are met, the actual pattern of 'service' does not need to be predetermined.

Example 13: Making lump sum payments for occasional or fluctuating use

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

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

Social services have agreed funding to enable a suitable level of support to be purchased for up to 28 days per year, to be deployed as and when Mrs Awousu wishes to use it. This has been set at a rate that allows her to employ a personal assistant whom she knows and who is willing to work at the times she wants. She is there in the evenings to prepare a meal and help Mrs Awousu to bed, and she sleeps over in case any further attention is needed in the night.

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

Transfer to direct payments from direct provision

93. People who are already receiving services may wish to switch to direct payments. They may also wish to combine a package of services and direct payments. They may not raise these possibilities themselves, so the council should raise it at, or between, a person's review. This guidance applies equally to people with whom the council is undertaking an assessment for the first time, and existing service users with whom the council is discussing a switch to direct payments.

Specific delivery issues

Close relatives

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

Health and safety

96. Councils will wish to consider the health and safety implications of direct payments, both for themselves and for recipients. As a general principle, local councils should avoid laying down health and safety policies for individual direct payment recipients. Individuals should accept that they have a responsibility for their own health and safety, including the assessment and management of risk. They should be encouraged to develop strategies on lifting and handling and other tasks both in the home and outside it where lifting equipment, for example, may not be available.⁸
97. As part of the process of informed choice, local councils will wish to take appropriate steps to satisfy themselves that recipients and potential recipients are aware of health and safety issues that affect them as individuals, anyone they employ, and anyone else affected by the manner in which their support is delivered.
98. As part of this process, local councils should give the recipients and potential recipients the results of any risk assessments which were carried out as part of the care assessment. Such risk assessments are necessary so that health and safety issues can be taken into account. This allows the individual to share the assessment with the care agency or the employee who provides the service. They can therefore take reasonable steps to minimise the risks to the health and safety of any staff they employ. (The recipient or potential recipient has a common law duty of care towards the person they employ.)

⁸ For further information councils should refer to the recently published guidance from the Health and Safety Executive (HSE) on lifting and handling entitled *Handling Home Care*. Councils should note in particular the HSE's advice that "implementation of policy and practice on lifting and handling should not place any unreasonable restrictions on client's rights to autonomy, privacy or dignity".

Direct payment recipients as employers

99. For people who receive direct payments it may be their first experience of being an employer, and they may welcome support through the recruitment process whether they intend to employ a personal assistant, or hire a self-employed assistant or an agency to provide services. It is important that the information and help provided is clear and concise and not offered in such a way as to dissuade them from accepting a direct payment.
100. Individuals should be made aware of their legal responsibilities in terms of providing a statement of employment particulars, meeting the national minimum wage, taxes and statutory benefits such as sick pay and annual leave. If support services are provided, local councils may wish to include a payroll service which will take responsibility for administering wages, tax and National Insurance for the direct payment recipient. A written contract will help ensure that all those involved have the same understanding about the terms of employment.
101. Concern over becoming an employer should not be allowed to discourage people who would otherwise be willing and able to manage direct payments. The aim should be to inform the potential recipient accurately, responsibly, constructively and supportively. It should not be done in such a way as to put off the recipient, for example, by over-stressing the extent and complexity of these responsibilities, but neither should the council fail to make recipients aware of what is involved. Recipients should be able to make informed choices. In all cases the council remains responsible for continuing assessment and review to ensure the person's assessed needs for services can be met by means of a direct payment.
102. The only contracts which are binding on minors are contracts for 'necessaries', that is, contracts for necessary goods and services. Even then such a beneficial contract will not be enforceable against a minor if it is found to contain unreasonable and onerous terms. This will need to be borne in mind in deciding whether to make a direct payment to a disabled 16- or 17-year-old, and it is suggested that in each case legal advice be obtained.
103. For more detailed information regarding employment issues individuals can refer to the DH's guide on this question.⁹

Employing a suitable person: children and young people

104. The Protection of Children Act 1999 enables a person who is considering employing an individual to care for their child, or a disabled 16- or 17-year-old who is considering employing a care worker themselves to ask the local council to carry out checks under the Protection of Children Act 1999 via the Criminal Records Bureau (CRB). When the person with parental responsibility or the disabled young person requests such a check the local council has a duty to comply.
105. Councils should work in partnership with parents to help them make arrangements that are designed to safeguard and promote the welfare of the child. The majority of parents will be both willing and able to do this, but local councils should only arrange a direct payment for a parent of a disabled child when they are satisfied this is the case.
106. Local councils may want to clarify with those who request a CRB check the council's responsibility for child protection, and the implications should a parent insist on employing an individual who has been found to be unsuitable following such a check. The council's actions must be determined in the light of

9 *A Guide to Receiving Direct Payments from Your Local Council*, Department of Health, 2003.

its duty to safeguard and promote the welfare of children in need. Note that it is an offence under the Criminal Justice and Court Services Act 2000 if an individual knowingly offers work with children to, or procures work with children for, an individual who is disqualified from working with children, or allows such an individual to continue in such work.

107. When the parent or young disabled person has chosen to ask for a CRB check to be carried out, they should be advised that they may wish to continue to receive services from their local council, current provider, or contract with a registered agency for the services they need until the prospective candidate for employment is approved.
108. Local councils may also refer to the Protection of Children Act list a relevant individual the council considers guilty of a misconduct that harmed a child or placed a child at risk of harm. Local councils should make people with parental responsibility aware that the fact that a CRB check reveals no criminal convictions does not necessarily mean that someone is a suitable person to work with children. They should still offer the advice about employing someone using direct payments as outlined above. A relevant individual is one who is or has been employed to provide care to a child and that employment is funded by a direct payment under section 17A of the Children Act.
109. An individual wishing to work with the child will make the application for a CRB check to be carried out. The application will be counter-signed by the local council. A fee is required for each CRB check. The individual making the application for employment will normally be asked to pay the fee. The local council may wish to consider the cost of the check in its estimate of the reasonable cost of securing the provision of the service so that the direct payment user may reimburse successful candidates.

Example 14: Using direct payments where there may be child protection and/or child safety concerns

Mrs Garret cares for her son Kieran, who has Smith Magenis syndrome. Kieran has very limited verbal communication, and needs constant supervision. Social services have organised short break care, so that Kieran is reviewed as a 'looked after child'. He also attends an Out of School club.

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

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

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

110. Currently there is no requirement to carry out criminal records checks for people working with adults. Under the Care Standards Act 2000, the Protection of Vulnerable Adults list will be created to protect vulnerable adults from harm from those employed to care for them. It is hoped to publish the guidance on the vulnerable adults list consultation in the near future.

Advice about employing someone using direct payments

The information should cover the following general advice:

- Be suitably cautious. If you have any doubts about the individual do not take them on.
- Always ask for two references and check them carefully – following up with a telephone call is often advisable.
- Ask all the questions that are important to you, for example about smoking and eating habits or what their hobbies are. If employing someone to look after your child, you need to find out where they might be taken.
- Get a friend, parent or someone you trust to spend some time with you and your new personal assistant initially.
- Make sure that the personal assistant has your support and welfare, or that of your child, as their 6-priority.
- If you are unhappy with the person caring for you, seek advice and try to find someone else.

In addition, in the case of employing someone to look after a child or where the employer is a 16–17-year-old:

- If choosing to ask for a criminal records check, ensure that such check has been completed in the last month.
- Take note and listen to everything that your child is communicating about the care they receive. Especially with non-verbal children note should be taken of unusual or regressive behaviour.
- Try and spend time ensuring that your child is able to settle with the new person.
- Do not employ someone under the age of 16 to undertake a paid caring role as people under 16 may not be mature enough for such a responsibility.
- Information should be clear and straightforward about the risk of child maltreatment without unnecessarily raising anxieties.

Where additional support is required

Parents and children

111. Existing guidance emphasises the importance of:
 - the family as the natural and most appropriate place for children;
 - local councils working in partnership with parents;
 - recognising that children are individuals with their own wishes and feelings; and
 - holistic family assessment, taking account of the needs and views of children and parents.¹⁰
112. Local councils are required to provide information about services available in their area. It will be essential that families have information about the full range of services, including the option of direct payments.¹¹

Direct payments to disabled parents with parental responsibility for a child

113. The Social Services Inspectorate report *A Jigsaw of Services* found that many disabled parents had difficulties accessing appropriate support to enable them to look after their children. Councils should ensure that needs assessments for disabled adults include parenting responsibilities.
114. Disabled people who are parents could be assessed as needing services under both community care legislation and/or the 1989 Act to assist them in their parenting role. This means that direct payments can be used to meet the social care needs of them, their children or their family that arise from their disability. It is important that the needs of the disabled person and their family are looked at holistically, bearing in mind that specific duties may arise under particular legislation. In the interest of the family and to avoid duplication, local councils should ensure the assessment process is streamlined and co-ordinated between adult and children's services and other relevant departments such as education.

Example 15: Using direct payments to support disabled parents

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

¹⁰ See the Assessment Framework, para. 3.32 and vol. 6 of the Children Act 1989 Guidance, para. 6.1.

¹¹ Children Act 1989, section 17, and Schedule 2, Part 1.

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

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

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

Example 16: Supporting parents with mental health problems

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

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

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

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

Direct payments to a parent with parental responsibility for a disabled child

116. In this section, 'parent' and 'parents' refers to those with parental responsibility for a disabled child.
117. Where a parent opts for direct payments, councils retain their responsibilities under the 1989 Act to assess and review the needs of disabled children and their families in the normal way.
118. In considering direct payments some parents will require advice about their child's need for additional support or protection. Other parents need support and sometimes permission to let their disabled child take risks in their everyday lives. This may include allowing their 16- or 17-year-old to manage their own support through a direct payment.
119. Local councils should make clear the steps that people with parental responsibility for a disabled child ought to take to satisfy themselves that the person offering help with the care of their child is a suitable person. (*"The available UK evidence on the extent of abuse among disabled children suggests that disabled children are at increased risk of abuse."*)¹² It is important that people with parental responsibility for disabled children are fully alerted to any risks of abuse and provided with advice to minimise those risks.
120. The responsibilities of people with parental responsibility for disabled children are often made more arduous by the difficulty of accessing mainstream services such as childcare, after school clubs and leisure activities. Families with disabled children may not think existing services provided or commissioned by their local council are suitable for their child and may well be able to make more appropriate arrangements for themselves. Direct payments can enable parents with parental responsibility for a disabled child to make such arrangements.
121. Parents should be encouraged and supported to use direct payments with a view to enabling their disabled children to access the same kinds of opportunities and activities as their non-disabled peers. Direct payments to people with parental responsibility for a disabled child are provided within the framework of Part III of the 1989 Act which requires local councils to provide a range of services to safeguard and promote the welfare of children in need.

Intimate care for a disabled child using direct payments

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

Childminding

123. Local councils may make available the list of registered child minders and other registered providers of childcare in the area. The local council may consider that a direct payments support service is also well placed to provide such information and support.

¹² *Working Together to Safeguard Children*, Department of Health et al., 1999, para. 6.27.

124. Section 79D of the 1989 Act states that anyone caring for a child under eight for over two hours a day and for payment in their own home has to be registered as a childminder. Parents of disabled children should be aware of this requirement, designed to safeguard the welfare of young children, when purchasing support via a direct payment.
125. A checklist such as that available on www.childcarelink.gov.uk that enables parents to select safe childcare may be helpful.

Education

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

Transition

Young person into adulthood

127. Parents often face challenges or problems in supporting and preparing their children for an independent adult life. The transition to financial independence and independent living is not usually a single event, nor does it happen quickly. Families with disabled children often face additional challenges that may delay or limit the children's move towards independence. For any young person (with or without a disability) the process of growing up involves the gradual taking on of more and more responsibility for himself or herself.
128. In some cases the young disabled person at age 16 or 17 may wish, as part of the transition to adulthood, to take control of parts or all of the direct payment that has to date been managed by the person with parental responsibility. This can allow them to gain experience of managing direct payments in a gradual way prior to reaching adulthood.

Example 17: Increasing independence

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

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

129. Whatever decisions are made when the disabled child reaches age 16 or 17, people with parental responsibility for a disabled child may not continue to receive direct payments to purchase services that meet the needs of that child once the child reaches his or her majority. However, if they are going to continue in their caring role, such carers may be entitled to receive direct payments as an alternative to local council directly provided carers' services under section 2 of the Carers and Disabled Children Act (2000). Carers' services would be to support the parent carer in their caring role and to help them maintain their own health and wellbeing.
130. It will be important for local councils to recognise and respect the views of parents who have been managing the delivery of support for their child in setting in place any new arrangements once the young person reaches his or her majority. The parents would, for example, normally be involved in setting up and running a user-controlled trust.
131. Disabled 16- and 17-year-olds are entitled to take advantage of the flexibility of direct payments where this will safeguard and promote their welfare. Direct payments enable them to make more decisions for themselves and to provide opportunities for them to have more control over their lives.
132. Some disabled 16- and 17-year-olds may have previous experience of direct payments because their parents are receiving them to meet the family's needs. However, many disabled 16- and 17-year-olds' parents will have been receiving services direct from their council.
133. A way to develop a young person's ability to manage the direct payment can be to put in place transitional arrangements, initially set up with the young person managing only a proportion of their support with a direct payment. This proportion could increase as the young person matures, with the objective of full management of the support package at age 18.

Example 18: Enabling social inclusion for young people with high support needs

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

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

Example 19: Overcoming disabling barriers with direct payments

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

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

135. The above case study highlights how services and direct payments can be used imaginatively by seeking to overcome disabling barriers that prevent the child from accessing social and leisure opportunities available to non-disabled peers. It also shows the importance of linking the different agencies that support disabled children.¹³

Direct payments for carers

136. Direct payments allow carers to purchase the services they are assessed as needing *as carers* to support them in their caring role and to maintain their own health and wellbeing. Carers (other than those with parental responsibility caring for children) may not receive a direct payment to purchase services to meet the assessed needs of the person they care for.

Example 20: Using direct payments to deliver outcomes that carers want

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

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

¹³ See *Assessing Children in Need and their Families, Practice Guidance*, Department of Health et al., 2000, para 3.70.

Young carers

137. This facility is available to allow for flexibility in the *small* number of circumstances where a 16- or 17-year-old is choosing to undertake a substantial caring role for a disabled adult for a period and where the local council supports that decision. It could in some circumstances be more helpful to the young carer to receive a direct payment, for example, to allow them to arrange for carer services to be delivered in such a way as to minimise any disruption to their education that would result from their decision to care.
138. An example where it might be appropriate for a 16- or 17-year-old to provide assistance is where they are involved in looking after a terminally ill relative. In such a temporary situation, direct payments may provide flexibility, which enables them to have a break from caring.

Example 21: Considering direct payments for 16- and 17-year-old young carers

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

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

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

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

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

Ben and his father have always been close and share an enthusiasm for modern art. Ben has taken a year off to care for his father, but is hoping to go to art college in due course. In lieu of a carers' service to help him engage in leisure activities, which everyone agrees he needs, he opts for direct payments. When Mr Bridges is being cared for by home-carers or nurses (community care services), Ben uses these direct payments for trips to art galleries, all of which he discusses at length with his father on his return.

139. When assessing whether the young carer is willing and able to manage the direct payment the local council should consider the impact of the additional responsibility direct payments will bring. The local council might also consider the variety of ways in which the young person could be supported to manage any direct payment. For instance, the young carer might need to be informed that they might be able to have the payroll aspects of managing a direct payment dealt with by a local payroll service.

Monitoring and reviews

140. When a person chooses to receive direct payments, he or she takes on the responsibility for securing the provision of services to which the direct payment relates. Monitoring arrangements should be consistent both with the requirement for the council to be satisfied that the person's needs for the service can and will be met and with the aim of promoting and increasing choice and independence.
141. Councils should focus on achieving agreed outcomes, rather than on the service being delivered in a certain way. The council should discuss with individuals what steps it intends to take to fulfil its responsibilities, and may also wish to discuss how it might support them in securing adequate quality care. It should be prepared to consider variations to what it proposes.
142. Councils should aim to ensure that the information that the direct payment recipient is asked to provide is as straightforward and the least onerous possible, consistent with monitoring requirements.

Example 22: Adjusting direct payments to meet changing needs

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

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

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

143. Each council will need to establish how it will know if someone is experiencing difficulty with managing their direct payments. It may not be appropriate to rely on someone who has been managing his or her own care for some time to ask for extra help if he or she needs it. It is important, however, that local councils should not assume this is an adequate safeguard, particularly when someone has a fluctuating or deteriorating condition such as HIV/AIDS or Alzheimer's, or when the person begins to receive direct payments for the first time
144. Where a council wishes to ask the individual whether he or she is satisfied with the services he or she is securing, it should ensure that it communicates directly with the individual on a regular basis. For example, a different interpreter may be required if the person wishes to comment on the services of his or her usual interpreter. Councils should not make assumptions that someone who is not receiving services to their satisfaction cannot manage direct payments. They should seek to ensure that individuals feel able to express reservations about the services they are purchasing, or any other problems they are having in managing their direct payments, without concern that their direct payments will be stopped automatically or arbitrarily.
145. Councils should follow existing guidance on carrying out reviews. The fact that the council is making direct payments rather than arranging services itself does not affect its responsibility to review an individual's care package at regular intervals. As with all services, the projected timing of the first review should be set at the outset. The purpose of the review remains to establish whether the objectives set in the original care plan are being met. It should therefore cover whether the person's needs have changed, whether the use of direct payments is meeting assessed needs, and how he or she is managing direct payments.
146. The frequency of monitoring will be dictated by the length of time the person has managed a direct payment (either alone or with help) and their particular circumstances. Once a council is satisfied a person is managing the direct payments satisfactorily, reviews should be at the same intervals as for other people receiving services. For example, people with fluctuating conditions might need monitoring every few months, rather than once or twice a year. For children identified as needing services under section 17 of the 1989 Act, reviews may be necessary more often so that the council remain satisfied that the direct payment promotes and safeguards the welfare of the child. *The Framework for the Assessment of Children in Need and Their Families* reminds councils that it is good practice to review plans for children in need in the community at least every six months.

Financial monitoring

147. Each council should set up financial monitoring arrangements for audit purposes. This will fulfil its responsibility to ensure that public funds are spent to produce the intended outcomes. CIPFA issues up-to-date guidance for local councils on this point and local councils should ensure this advice is being used. Before people decide to accept direct payments, local councils should discuss with them the information they will be expected to provide and the way in which monitoring will be carried out.
148. Councils should pay particular attention to ensuring that audit arrangements are as simple and easy to understand as possible. Complicated paperwork can be a significant disincentive for people considering direct payments. It is worth taking time to discuss with individuals what is required so as to avoid being needlessly intrusive.

149. In order to audit direct payments, it is important for people to be able to identify the direct payments money separately from any other money used for similar purposes. For example, people may use their direct payments to employ a personal assistant, and then pay the assistant to work additional hours from their own resources or using funding from the ILF. A single bank account for direct payment and ILF money (and other money related to personal assistance) can meet this requirement, and is consistent with the CIPFA guidance. It is not appropriate to ask the individual to have second bank account for non-recurrent expenditure such as a short-term need.
150. Monitoring arrangements to ensure that a person's needs can continue to be met and that finances are properly managed need to be co-ordinated. If they are not to be carried out by the same person, local councils should ensure that information is exchanged. All those involved should understand the purpose of direct payments and the role that the council's monitoring plays in the successful operation of the policy.

Monitoring local implementation

151. As well as monitoring how well direct payments are meeting the needs of individuals, it is anticipated that local councils will wish to monitor how direct payments are working overall. In doing so, local councils should actively seek the comments and suggestions of people who receive direct payments or who have considered receiving them. Councils should pay attention to the views of those who have been discouraged from using them.
152. As part of that process, councils should also monitor take-up of direct payments across different groups, to ensure that policy and practice is encouraging equal access to, for example, black and minority ethnic groups, older people, people with mental health problems, people with learning difficulties, parents with disabled children and young disabled people.

Troubleshooting

When difficulties arise

153. If a council becomes aware that someone is or will be unable to secure the services to meet his or her needs through their own arrangements, either temporarily or in the longer term, then the council will need to take steps to meet its responsibility to provide or arrange for the provision of services for that person.
154. Councils should make people aware that they should plan for the unexpected and discuss with each person what arrangements he or she will make for emergencies, to ensure that the person receives the care he or she needs when the usual arrangements break down (e.g. through sickness of one of the person's personal assistants). The council will need to be prepared to respond in these circumstances just as it would with any other person using a service. It may decide to step in and arrange the services where this is necessary to meet its responsibilities. The council could also explore other ways of providing assistance to enable the person to continue to manage his or her own care by using direct payments, particularly if the difficulty is temporary or unforeseen.
155. Difficulties can be minimised by good assessments, clarity (e.g. about what the money can be used for), and monitoring and effective support arrangements. Discussing potential areas of difficulty and how they will be handled with the individual before direct payments begin is important. Reviews should be carried out regularly, not just when difficulties arise.

Example 23: Supporting people when difficulties arise

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

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

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

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

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

Questions to ask

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

- ***Have the person's needs changed?*** If so, the person's needs should be reassessed and the level of direct payment should be reviewed.
- ***Is the amount of money reasonable to enable the person to secure the services concerned?*** It may be that experience shows that there are other costs which were not taken into account in the initial calculations. Alternatively, anticipated costs may have arisen. It may be necessary to review the level of direct payment.
- ***Is the person still able to manage direct payments, or can they do so with assistance?*** Difficulties will not necessarily mean the person cannot manage. There is inevitably a learning process when people begin to receive direct payments. People may make mistakes but still be capable of managing direct payments in the longer term. Even experienced direct payments recipients may have problems at times but, with some support, be capable of overcoming them.
- ***Does the person wish to continue receiving direct payments?*** As long as there is a duty on the council to make direct payments, it should seek to explore ways of helping people to overcome difficulties and prevent them becoming unduly discouraged when they experience problems. However, if someone has decided that he or she no longer wishes to receive direct payments, then the council provide or arrange to provide the services they are assessed as needing.

- ***Has all the money been spent towards achieving the outcomes identified in the care plan?*** If the money has been diverted to other purposes there may be a case for considering seeking repayment. The council should explain before someone begins to receive direct payments the circumstances in which it would seek repayment.
- ***Have services for which the individual has paid been received?*** If not, then it is the responsibility of the individual to seek a refund from the service provider. They may need support to do this. The council may decide that it would be appropriate to require repayment of the direct payment from the recipient if they have provided services to meet the same needs as the direct payment or if the services were not received because they were no longer required.
- ***Has the money been spent wisely?*** If the money has not been spent in a cost-effective way to meet assessed needs as set out in the care plan, the person may need more support to enable him or her to manage.

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

When to seek repayment

160. Councils are able to require some or all of the money they have paid out to be repaid if they are satisfied that it has not been used to secure the provision of the service to which it relates. They may also require repayment if the person has not met any condition that the council has properly imposed. Councils that decide to require repayment by someone who they know is also receiving payments from the ILF should inform the ILF as soon as possible and should seek to agree if possible a common approach if the ILF is also seeking recovery. Councils will need to comply with their responsibilities under the Data Protection Act 1998 and should advise users of the circumstances in which the ILF will be contacted.
161. It is up to the council to decide when it is appropriate to seek recovery. Councils should bear in mind that repayment should be aimed at recovering money which has been diverted from the purpose for which it was intended, or where services have been obtained from someone who is ineligible to provide them, or which has simply not been spent at all. It should not be used to penalise honest mistakes, nor should repayment be sought where the individual has been the victim of fraud.
162. Councils should be satisfied before they start to make payments that people who will receive the direct payment understand all of the conditions they will be required to meet. Councils should also discuss with potential recipients of direct payments the circumstances in which the council might wish to consider seeking repayment. Councils may wish to take into account hardship considerations in deciding whether to seek repayments. Councils should also bear in mind that there might be legitimate reasons for unspent funds. There may be outstanding legal liabilities necessitating a direct payment recipient to build up an apparent surplus (e.g. to pay their employees' quarterly PAYE, or to pay outstanding bills from a care agency).

Discontinuing direct payments

163. A person for whom direct payments are made may decide at any time that they no longer wish to continue with direct payments. The Regulations provide that a council shall cease making direct payments if the person no longer appears to the council to be capable of managing the direct payment or of managing it with help. The council may, however, continue to make direct payments if it is reasonably satisfied that the person's incapability will be temporary, and that there is someone else who is prepared to accept and manage the payments on their behalf. It is also necessary for the council to confirm that the person providing assistance or services agrees to accept payment from the person who steps in to help.
164. The Regulations also state that a council shall also stop making direct payments if it is not satisfied that the person's needs for the service can be met by using a direct payment or if the direct payment is not safeguarding or promoting the child's welfare where the payment relates to services under section 17 of the 1989 Act.
165. The council might also discontinue payments if the person fails to comply with a condition to which the direct payments are subject, for example that the payments must be used to obtain services that the user has been assessed as needing and the council has reasonable reason to fear that further payments may be misspent.
166. The council should discuss with individuals as soon as possible if it is considering discontinuing direct payments to them. They should be given an opportunity to demonstrate that they can continue to manage direct payments, albeit with greater support if appropriate. A minimum period of notice should be established that would normally be given before direct payments are discontinued. This should be included in the information to be provided to people who are considering direct payments. It will be extremely unlikely that a council will discontinue direct payments without giving notice. Councils should explain to people, before they begin to receive direct payments, the *exceptional* circumstances in which this might occur and discuss with them the implications this has for the arrangements that individuals might make. *The council should not automatically assume when problems arise that the only solution is to discontinue or end direct payments.*
167. Direct payments should be discontinued when a person no longer needs the services for which the direct payments are made. This might particularly happen in situations where the direct payment is for short-term packages when leaving residential care or hospital. Direct payments might be varied if the person's needs call for the provision of different services.
168. Other than in exceptional cases, the decision to discontinue should follow discussion with the individual and any carer. The council may also need to keep in touch with the ILF and share information where appropriate (and preferably with the service user's permission) in cases where the individual is also receiving ILF funding. If the council does decide to withdraw direct payments then it will need to arrange the relevant services instead, unless the withdrawal was following a reassessment after which the council concluded that the services were no longer needed.
169. There may be circumstances in which the council discontinues direct payments temporarily. An example might be when an individual does not require assistance for a short period because his or her condition improves and they do not require the services that the direct payment is intended to secure. The council will need to discuss with the individual how best to manage this. The person should be allowed to resume responsibility for his or her own care after the interruption, if that remains his or her wish unless there has been a change of circumstances which means that there is no duty on the council to make a direct payment.

170. If direct payments are discontinued, some people may find themselves with ongoing contractual responsibilities or having to terminate contracts for services (including possibly making employees redundant). Councils should take reasonable steps to make people aware of the potential consequences if direct payments end.

171. Councils should also consider how to recover unspent direct payments if the recipient dies. For example, if someone wishes to pay an agency in advance for its services, the council should bear in mind that it may be difficult to recover money paid for services which were not in fact delivered. Councils should also consider, if the direct payment recipient does leave unspent funds to be recovered, that before his or her death, the direct payment recipient may have incurred liabilities which should legitimately be paid for using the direct payment (e.g. he or she received services for which payment had not been made at the time of death).

Annex A: Setting up a direct payment scheme

Examples of how three local councils have developed schemes

Council X

Council X currently has the largest direct payments scheme in the country, with over 700 users. This has developed from a 'third party' (indirect payments) scheme that in 1996 had 70 users. The key factors in achieving the growth of the scheme since then have been:

- Investing in advocacy – the local Independent Living Advocacy group has a contract to provide advocacy to all prospective direct payments users
- Investing in PA support scheme – the 'PASS' scheme operated by the local coalition of disabled people have a contract to support disabled people using direct payments; payroll, returns, training for personal assistants, etc.
- Strong links – during the community care assessment process, all cases that might be supported by direct payments are routinely referred to the ILA
- Using the expertise of disabled people locally (some had developed great expertise from setting up the third party scheme)
- A generic budget – direct payments support came from the whole community care budget (top slicing) and so was not linked to any one client group
- Setting annual targets for increasing take-up
- Senior management support

Support costs for advocacy and the PASS are offset by savings in care manager time both in planning a package (advocacy leads to better initial assessments) and in managing a package (direct payments produce more sustainable packages, with substantially less call on care managers to deal with renegotiating arrangements).

Council Y

This scheme was set up as a pilot project in 1998, initially as a joint undertaking between the local council and Scope, the national charity. An EC grant supported some of the start-up costs for Scope to employ a project officer, and the County Council seconded a liaison officer to the scheme.

As the scheme developed it was able to demonstrate that care packages could be funded cost effectively under direct payments, and that further resources could be attracted in the form of increased take up of ILF grants. The council demonstrated a commitment to direct payments by encouraging it to grow and providing funding for additional support staff.

Part of Scope's role was to support the formation of a group of disabled people, with a view to setting a local organisation that could assume responsibility for the support scheme. The Independent Living Association (ILA) grew out of this and was established as a new charitable organisation in 2001, when it took over the direction of the direct payments support service from Scope.

The success factors for the scheme have been:

- The development of a local 'user led' support service
- Close working relationships between the social services staff and the DP support team
- Partnership working with other voluntary sector organisations
- A fundamental shift in thinking, from the idea of services being 'planned *for*' to that of being 'planned *by*' disabled people
- An introduction of the concepts of choice, control, empowerment and consumerism into the local disability movement
- Regular reviews of the support service in order to increase its capacity to meet increased demand from disabled people
- A tailored support service to enable all eligible applicants to explore the option of direct payments

Council Z

Council Z ran a pilot direct payment scheme for four service users with a physical disability who had high level support needs. In July 2001 a temporary post of Direct Payment Project Manager was created to widen the scheme to all client groups. A target of 1% of service users over three years was set by their Direct Payment Steering Group.

A tendering process awarded the contract for managing the DPSS to a joint bid by local branches of Scope and Share. Their existing office bases in the north and south of the area, and their knowledge of both physical disabilities and learning difficulties, made them ideal partners. The DPSS employed two part time co-ordinators who each worked 25 hours, and a payroll/administrator to work 10 hours. All three started work on 1 October 2001. Support prior to this date was provided by the Direct Payment Project Manager. The Project Manager took responsibility for the training and updating of all the assessment teams and writing the policy and procedures, public information and publicity.

The scheme was officially launched on 4 July 2001 with an event which attracted an audience of over 100 invited interested parties, including care providers, elected members and service users. The DPSS wrote to all voluntary groups offering to speak at meetings and also organised two information roadshows. A brief information leaflet and invitation was sent to all service users who used the Outreach home care service (for service users between 18 and 65 years old) and also to parents with a disabled child. Although the roadshows were not particularly well attended the mailshot generated a great deal of interest.

Direct payments have been used in lieu of home care, short breaks and day care. The scheme has been successful in all areas, creating care packages that meet assessed need in the most appropriate way but at no extra cost to the department. The support of senior managers has been key in allowing this to flourish.

The post of Direct Payment Project Manager was made permanent in October 2002 and the title changed to Direct Payment Co-ordinator. Plans for the future include increasing the uptake amongst over 65s and service users with learning difficulties and mental health problems.

Annex B: Care plan for direct payments – an example

- What are the person's needs, as identified in the assessment?
- To which of these needs do the direct payments relate?
- Can the person's needs for those services be met by means of a direct payment?
- How will the person secure the appropriate services?
- What variations to the way in which the direct payments are used does the council expect to be asked in advance to approve?
- What support (if any) does the user need to manage their direct payments?
- How will this support be made available to the person?
- What arrangements has the person made to cover emergencies?
- How much money does the council consider is reasonable to secure the appropriate services?
- How much of this total will the council contribute in direct payments, and how much is the person expected to contribute?
- How often and in what form will payments be made?
- What arrangements does the council propose for monitoring? What information should the person provide? What access will be required to the person's home?
- (Where relevant, how will the council be satisfied that the direct payment is purchasing services which safeguard and promote the welfare of the disabled child/young person?)
- What information does the council require for audit purposes, and when?
- What, if any, other conditions are attached to the direct payment?
- When will the next review take place?
- What should the person do if he or she wants to stop receiving direct payments?
- In what circumstances will the council consider discontinuing direct payments (permanently or temporarily)?
- How will the council and user handle any temporary gap in direct payments being made?
- How much notice will normally be given if the council discontinues?
- How will any outstanding commitments be handled if direct payments are discontinued?
- In what circumstances would direct payments be withdrawn with no notice?
- In what circumstances would the council seek repayment?

Annex C: Eligibility restrictions

– examples

Direct payments may not be made to certain people whose liberty to arrange their care is restricted by certain mental health or criminal justice legislation as follows:

- (i) patients detained under mental health legislation who are on leave of absence from hospital;
- (ii) conditionally discharged detained patients subject to Home Office restrictions;
- (iii) patients subject to guardianship under mental health legislation and those covered by the new power of supervised discharge introduced by the Mental Health (Patients in the Community) Act 1995;
- (iv) people who are receiving any form of after-care or community care which constitutes part of a care programme initiated under a compulsory court order;
- (v) offenders serving a probation or combination order subject to an additional requirement to undergo treatment for a mental health condition or for drug or alcohol dependency;
- (vi) offenders released on licence subject to an additional requirement to undergo treatment for a mental health condition or for drug or alcohol dependency; and
- (vii) people subject to equivalent restrictions in Scottish mental health or criminal justice legislation.

Reference should be made to the Regulations for full details of the circumstances in which the duty to make a direct payment does not apply.

Annex D: Further information

Publications

National Centre for Independent Living

The NCIL is a source of information and expertise.

250 Kennington Lane, London SE11 5RD

Tel: 020 7587 1663 Fax: 020 7582 2469 Text: 020 7587 1177

Website: www.ncil.org.uk Email: ncil@ncil.org.uk

Everything You Need to Know about Getting and Using Direct Payments, 2003

Direct Routes to Independence: A guide to local authority implementation and management of direct payments, F Hasler, G Zarb and J Campbell, 1999

The Rough Guide to Managing Personal Assistants, Sian Vasey

Direct Payments: A beginner's guide. A 30-minute video which covers the essential aspects of managing a personal assistant set-up, including recruitment, supervision and contracts

Direct Payments for Mental Health Users/Survivors: A guide to some key issues

Users' Ability to Manage Direct Payments, NCIL and Changing Perspectives. £3.00, cheques payable to BCODEP. A training pack for care managers and others involved in assessment

Creating Independence and Inclusion – Youth Personal Assistance Support Scheme, Rowen Jade, National Youth Agency and WECIL

Values into Action

Oxford House, Derbyshire Street, London E2 6HG

Tel: 020 7729 5435 Fax: 020 7729 7797 Email: general@viauk.org

Website: www.via.org.uk

Pointers to Control, Catherine Bewley et al., 2002. Information on direct payments issues such as consent, control, money management, employment and eligibility

Funding Freedom 2000: People with learning difficulties using direct payment, Andrew Holman and Catherine Bewley, 1999

Making Decisions: Best practice and new ideas for supporting people with high support needs to make decisions, Stephanie Beamer with Mark Brookes, 2001

Trusting Independence: A practical guide to independent living trusts, Catherine Bewley and Andrew Holman, 2001

Direct Payments and People with Learning Difficulties. 8-page leaflet and 14-minute tape making direct payments easier to understand

Department of Health Publications

PO Box 777, London SE1 6XH

Tel: 08701 555455 Email: doh@prolog.uk.com

Website: www.doh.gov.uk/publications

A Guide to Receiving Direct Payments from your Local Council, 2003

An Easy Guide to Direct Payments, in preparation for 2003

A Parent's Guide to Direct Payments, Department of Health and Council for Disabled Children, 2003

Framework for the Assessment of Children in Need and Their Families, The Stationery Office, 2000

Direct Payment, 1996. Cash for services video (BSL version)

Valuing People Support Team – for advice on improving direct payments schemes for people with learning disabilities www.doh.gov.uk/vpst

Scope

6 Market Road, London N7 9PW

Tel: 020 7619 734441 Email: information@scope.org.uk

Good Practice Guide for Support Workers and Personal Assistants Working with Disabled People with Communication Impairments

A Lot to Say: A guide for social workers, personal advisors and others working with disabled children and young people with communication impairments

Joseph Rowntree Foundation

The Homestead, 40 Water End, York, North Yorkshire, YO30 6WP

Tel: +44 (0)1904 629241 Email: info@jrf.org.uk Website: www.jrf.org.uk

Directing Support: Report from a workshop on direct payments and black and minority ethnic disabled people, JRF/YPS, 2000

Independent Successes: Implementing direct payments, Carol Dawson, JRF/YPS, 2000

Users with queries about being an employer may find it helpful to consult the **New Employer's Helpline** on 0845 60 70 143. Calls are charged at the local rate

Other resources

Cashing in on Independence, Gerry Zarb and Pamela Nadash, BCODP, 1994

Devising and Resourcing Personal Care Packages, Flora Gathorne-Hardy, Disablement Income Group

Personal Assistant Employer's Handbook, ILSA, West of England Centre for Inclusive Living 1998

Recruiting and Employing a Care Worker, Disablement Income Group, 1999

User Consultation: Consulting and involving older people with the provision and development of personal social services, M. Davis, RNIB, 1996

Handling Home Care: Achieving safe, efficient and positive outcomes for care workers and clients, HSG225, ISBN 0 7176 2228 2, price £9.50. Available online: <http://www.hsebooks.co.uk/> from HSE Books, PO Box 1999, Sudbury, Suffolk CO10 2WA. Tel: 01787 881165 Fax: 01787 313995

Annex E: Contacts

The following individuals, organisations and councils are willing to be contacted for information about their experiences of offering direct payments.

Local information

Brent Social Services – Mike Bibby
Mahatma Gandhi House
34 Wembley Hill Road
Wembley
Middlesex HA9 8AD
Tel: 020 8937 4625
Fax: 020 8937 4630
Website: www.brent.gov.uk

Cheshire – Janice Skelton
Cheshire County Council
County Offices
Chapel End
Wilmslow FK9 1PU
Tel: 01625 534814
Fax: 01625 534713

Cumbria – For more information and to order the video, please contact
Cumbria Direct Payments Advice and Information Service
c/o Disability Association Carlisle and Eden
Regents Court
Kingmoor Business Park
Kingstown
Carlisle CA6 4SJ
Tel: 0845 1249300
Email: cumbriadp@aol.com.

Derby – Stephen Sadler
Derby City Council SSD
29 St Mary's Gate
Derby
Derbyshire DE1 3NU
Tel: 01332 717 348
Fax: 01332 717 360
Website: www.derby.gov.uk

Essex – Mike Hay - Service Manager- Independent Living, Essex County Council,
Rose House, 1 London Road, Stanway, Colchester, Essex CO3 0NS www.essexcc.gov.uk
Independent Living Advocacy (Essex) - Direct Payments Support Service
Unit 4, Whitelands, Terling Road, Hatfield Peverel, Essex CM3 2AQ www.ilaessex.com

Gateshead – Dawn Docherty
Civic Centre
Regent Street
Gateshead
Tyne and Wear NE8 1HH
Tel: 0191 433 2342
Fax: 0191 478 2224
Website: www.gateshead.gov.uk

Kirklees – Carol Haigh
Briarcourt
28 Occupation Road
Huddersfield
West Yorkshire HD3 3EE
Tel: 01484 226561
Fax: 01484 223549
Email: carol.haigh@kirkleesmc.gov.uk

Oldham – Julie Gittins
Metropolitan House
Hobson Street
Oldham OL1 1TT
Tel: 0161 911 4746
Fax: 0161 911 4804
Email: socs.direct.payments@oldham.gov.uk

Oxford – Alan Sinclair
Yarnton House
Rutten Lane
Yaunton
Kidlington
Oxfordshire OX5 1LP
Tel: 01865 854481
Fax: 01865 884484

Tameside – Bill Kay
Loxley House
Birch House
Dukinfield SK15 5AU
Tel: 0161 368 5832
Fax: 0161 368 2046
Minicom: 0161 368 8416
Email: direct.payments@mail.tameside.gov.uk

Warwickshire – Rowan Organisation

The Rowan Organisation

Rowan House

Lime Tree Courtyard

Main Road

Ratcliffe Culey CV9 3PD

Tel: 01827 718 972

Fax: 01827 718 932

Website: www.therowan.org

West Sussex – Michael Boyd (Independent Living Association)

Barry Ruffell (DP Support Service)

West Sussex Direct Payments Scheme

Independent Living Association

Elm Grove Centre

Elm Grove

Lancing

West Sussex BN15 8QH

Tel: 01903 875950

Fax: 01903 875951

Email: wsdirectpayments@yahoo.co.uk/directpayments@ilawestsussex.org

National Agencies

Age Concern

Age Concern England

Astral House

1268 London Road

London SW16 4ER

Tel: 020 8867 9800

Fax: 020 8679 6069

Website: ww.ace.org.uk

Email: ace@ace.org.uk

Alzheimer's Society

Gordon House

10 Greencoat Place

London SW1P 1PH

Tel: 020 7306 0606

Fax: 020 7306 0808

Website: www.alzheimers.org.uk

Email: enquiries@alzheimers.org.uk

British Council of Disabled People

Litchurch Plaza

Derby DEA 8AA

Tel: 01332 295551

Fax: 01332 295580

Website: www.bcodp.org.uk

Email: bcodp@bcodp.org.uk

Carers UK

20/25 Glasshouse Yard
London E1A 4JT
Tel: 0808 808 7777
Fax: 020 7490 8824
Website: www.carersonline.org.uk
Email: info@ukcarers.org

Chartered Institute of Public Finance and Accountancy

Contact – Terry Brodie
3 Robert Street
London WC2N 6RL
Tel: 020 7543 5600
Fax: 020 7543 5700

The Children’s Society

Edward Rudolf House
Margery Street
London WC1X 0JL
Tel: 020 7841 4400
Fax: 020 7841 4500
Website: www.childrensociety.org.uk
Email: info@childrensociety.org.uk

Contact a Family

209–211 City Road
London EC1V 1JN
Tel: 020 7608 8700
Fax: 020 7608 8701
Text: 0808 808 3555
Website: www.cafamily.org.uk
Email: Info@cafamily.org.uk

Council for Disabled Children, National Children’s Bureau

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

Crossroads – Caring for Carers

10 Regent Place
Rugby CV21 2PN
13–16 Warren Court
London
Tel: 01788 573653
Fax: 01788 565498
Website: www.crossroads.org.uk
Email: association.office@crossroads.org.uk

Help the Aged

207–221 Pentonville Road
London N1 9UZ
Tel: 020 7278 1114
Fax: 020 7278 1116
Website: [www@helptheaged.org.uk](http://www.helptheaged.org.uk)
Email: info@helptheaged.org.uk

MENCAP

Mencap National Centre
123 Golden Lane
London EC1Y 0RT
Tel: 020 7454 0454
Fax: 020 7696 6014
Email: information@mencap.org.uk
Website: www.mencap.org.uk

MIND (The Mental Health Charity)

15–19 Broadway
London E15 4BQ
Tel: 020 8519 2122
Fax: 020 8522 1725
Website: www.mind.org.uk
Email: contact@mind.org.uk

Princess Royal Trust for Carers

142 Minorities
London EC3 1LB
Tel: 020 7480 7788
Fax: 020 7481 4729
Website: www.carers.org
Email: info@carers.org

SCOPE

Cerebral Palsy Helpline
PO Box 833
Milton Keynes MK12 2NY
Tel: 0808 800 3333
Website: www.scope.org.uk
Email: cphelpline@scope.org.uk

Annex F: Glossary

Ability to manage – capacity (with or without support) to arrange a direct payment service to meet an assessed need. The ability to ‘direct’ is more important than the ability to ‘manage’.

Advance statement – a statement made by a person (with, for example, a fluctuating condition) of how they wish their services to be delivered or their payments managed in the event that they are temporarily unable to do this for themselves. Advance statements have no legal status at present.

Advocate – a person who acts on behalf of and in the interests of a service user/direct payments recipient who feels unable to represent him/herself when dealing with professionals. An **independent advocate** has no vested interest in the service or legal system and solely represents the individual, not relatives, friends or professionals, thus avoiding conflicts of interest. **Self advocates** are trained and supported to represent their own views. (Based on *Who’s in Control* [VIA, 2001] and *Care Standards for Adults*.)

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

Assessment – collection and interpretation of data to determine an individual’s need for health, personal and social care and support services, undertaken in partnership with the individual, his/her representative/advocate and relevant professionals. (From *Care Standards for Adults*.)

Best value – a systematic approach to improving local council performance which places a duty on local councils to deliver services to clear standards covering both the quality and efficiency of these service. (Based on Modernising Social Services.)

Capacity – ability to make a decision, with support if needed. Common Law incorporates a presumption of capacity – that is, everyone is presumed to be able to make decisions for themselves until proved otherwise. **Incapacity** is defined in *Making Decisions* (Lord Chancellor’s Department, 1997) as ‘unable by reason of mental disability to make a decision on the matter in question; or unable to communicate a decision on that matter because he or she is unconscious or for any other reason’. (*Incapacity* is a definition taken from VIA, *Who’s in Control*. Guidance only uses the term *capacity*.)

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

Consent – the legal agreement to a choice or action (i.e. to take on a direct payment) freely made by an individual without coercion, as well as acceptance of the responsibilities associated with that choice or action. In a legal context, the individual must be ‘mentally capable’ of giving consent before it is valid. (From VIA, *Who’s in Control*, and *DRC*.)

Control – having autonomy and power over your own life and what happens to you, regardless of how much support you need to put your choices into action. Having self-determination. (From VIA, *Who’s in Control*.)

Decision-making – the process of making choices which lead to decisions and action. The word ‘decision’ is also used in legal contexts. Some people require support (e.g. communication support or advocacy) to consider and make decisions. (Last sentence from *DRC*.)

Indirect payment – payment to someone other than the person with an assessed need (a third party).

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

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

Power of attorney – authority given by one person to another to act on his or her behalf . An **enduring power of attorney** (EPA) is entered into by a person with legal capacity and authorises the appointee to continue to act for him or her in business or legal matters if he or she loses capacity.

User-controlled trust – a legal arrangement by which a third party/agent helps the direct payment recipient to manage the direct payment, for example, by receiving and handling the money, but the user’s choices and preferences direct the decision-making, and the user retains control of and is accountable for the arrangements.



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