



SCOTTISH EXECUTIVE

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4 July 2007

Dear Colleague,

SELF-DIRECTED SUPPORT - NEW NATIONAL GUIDANCE

The attached new national guidance on self-directed support¹ is issued under Section 5(1) of the Social Work (Scotland) Act 1968 and replaces earlier guidance on direct payments issued on 20 June 2003. It is designed to improve take-up of self-directed support and fulfils the recommendation made by the Parliamentary Health Committee at the Care Inquiry into the implementation of the Regulation of Care (Scotland) 2001 and the Health and Community (Scotland) Act 2002.

The guidance is based on best practice recommendations from national working groups, national research work, and the evidence of the Care Inquiry, and takes account of the wealth of helpful responses to a public consultation held from September to December 2006. The specific tasks for local authorities to fund are:

- a local support service which, where possible, should be independent and user-led (para 15)
- early involvement of individuals with the local support service to assist with self-assessment and care planning (paras 17-18)
- other essential training for individuals on self-directed support, and training of personal assistants (PAs) (paras 34, 128)
- all basic costs within a PA employer's package, where appropriate (paras 33 -34)
- designated self-directed support lead officers or teams within each local authority (para 179)
- training on self-directed support for care managers, finance managers and local authority directors (para 128)
- enhanced disclosures for PAs employed by individuals on self-directed support (para 93)

¹ The term direct payments is commonly used interchangeably with self-directed support. The definition is historical and focused on a system of delivery rather than the outcomes for individuals. The new guidance is not bound by a direct payments title that does not fully encompass the range of potential for its usage.



- legal support for PA employers where appropriate e.g. indemnity insurance (para 35)
- packages during PA employers' short stays in hospital, where appropriate (para 105)
- payments for self-directed support on a gross basis and to recover the individual's contribution later (para 39).

Self-directed support is part of the whole range of practical solutions to disabled and older people's meaningful integration into mainstream society. It includes services for children, for those using mental health services and for older people in receipt of free personal care. The flexibility achieved is such that those with complex needs can also have self-directed support using the Adults with Incapacity (Scotland) Act 2000 to safeguard their interests. The guidance strikes a balance of providing the technical information respondents have told us is needed to improve local systems, and innovative practical examples to push the boundaries of what is possible to achieve.

Self-directed support is part of Shifting the Balance of Scotland's health care towards sustaining and improving health and preventing longer term conditions through an emphasis on self-help and support that is continuous, integrated and individualised. It also helps equalise access to educational and employment opportunities. It is a means to build stronger communities in which disabled and older people are able to flourish and to which they can contribute. It is ultimately about promoting confidence and well-being.

Yours sincerely

JEAN MACLELLAN
Assistant Director

National guidance on self-directed support

Primary and Community Care Directorate
Adult Care and Support - Change Team
July 2007



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NATIONAL GUIDANCE ON SELF-DIRECTED SUPPORT

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Preface

This national guidance is based on the findings of three national working groups, the recommendations of the Scottish Parliament's Health Committee Care Inquiry, and a public consultation. It describes simple and effective schemes for self-directed support and is for use by local authority staff, support organisations and service providers. Local authority finance managers will wish to focus on section 9 on the financing of self-directed support.

Some service users, their families and carers may also find the guidance useful. Other publications^{1 2} provide a more accessible introduction for those exploring what self-directed support can deliver and how the day-to-day practicalities work.

A glossary of main terms which appear in bold in the text is provided at **Annex A**. The term **direct payments** is commonly used interchangeably with self-directed support. The definition is historical and focused on a system of delivery rather than the outcomes for individuals. Self-directed support is a way of organising social care so that people can take control of their lives and fulfil their role as citizens. It is not the name of a particular service or provision.

¹ <http://www.scotland.gov.uk/Publications/2002/04/14662/4093>

² <http://www.scl.d.org.uk/pub/default.asp?p=c>

PART 1: THE BASICS OF SELF-DIRECTED SUPPORT FOR CARE MANAGERS

What is self-directed support?

1. **Self-directed support** in Scotland is part of the mainstream of social care delivery, targeted at empowering people. It is part of creating a healthier nation with stronger and safer communities and is key to achieving a fairer and wealthier Scotland. It puts the principles of **independent living**³ into practice and enables people to be **active citizens** in their communities. Like the **social model of disability**⁴, it is about reducing or removing the physical, organisational or attitudinal barriers that people may experience in the world around them. It is about flexibility, choice and **control** and having a decent quality of life. It is ultimately about promoting confidence and wellbeing for those with an assessed need.

2. Self-directed support builds on the platform provided by **direct payments** legislation and the rights enshrined in the Disability Discrimination Act (Scotland) 2003. It is used instead of, or in addition to, support services that the local authority might otherwise have provided. It can buy support for a person to live in their own home, such as having a bath or getting washed and dressed. Out of the home it could be to support an individual in college, or to enjoy leisure pursuits more. It may also be used to pay for someone to provide care and support to enable them to take a short break with the person. A person on self-directed support can buy this from a service provider such as a care agency or voluntary organisation, a local authority such as their own or a neighbouring one, or by employing **personal assistants (PAs)**. In summary, it is an opportunity to meet the **assessed needs** of the whole person in creative and flexible ways.

³ <http://www.lothiancil.org.uk/about/background.php>; Morris (2005) *Independent Living: The role of evidence and ideology in the development of government policy*. Paper delivered at Cash and Care Conference, Social Policy Research Unit, University of York, 12-13th April 2005.
<http://www.leeds.ac.uk/disabilitystudies/archiveuk/morris/cash%20and%20care%20conference.jennymorris%20paper.pdf>; Land (2005) *Securing the Dignity and Quality of Life of Older Citizens*. Paper delivered at Cash and Care Conference, Social Policy Research Unit, University of York, 12-13th April 2005. Available in Glendinning and Kemp (2006) *Case and Care: Policy challenges in the welfare state*. Bristol: Policy Press.

See also the Equality Act (2006)

<http://www.opsi.gov.uk/acts/acts2006/20060003.htm>

⁴ <http://www.lothiancil.org.uk/about/background.php>

3. This means that **assessment** of need is no longer about which service a person should be referred to, but about individualising the support a person can receive, including offering eligible people self-directed support. Scotland's **Changing Lives**⁵ agenda further reinforces the need for self-directed support as part of new social work strategies that better take account of individual's needs and models are still evolving.

4. What is required is major service redesign so that resources and support can be allocated on a truly individual basis. Whilst this type of provision is developing across the UK, individual budgets are already a reality for some Scottish local authorities. This is because different pots of money are brokered by care managers and can be combined into one bank account.

5. The funding sources consist of local authority budgets that may include Supporting People⁶, funding for equipment and temporary adaptations, and other DWP benefit streams such as the Independent Living Fund (ILF)⁷ and Access to Work⁸. Health money may also be included. Self-directed support does not affect any other state benefits that an individual may be receiving. But like any other care service provided by the council, they will be means tested to see whether they should be expected to make a contribution towards the total cost of their care. Self-directed support does not put an individual at an advantage over other people who have requested services: the same prioritisation and eligibility is applied whether for self-directed support or arranged services.

6. An individual does not have to use self-directed support if they do not want to. It may not be right for everyone. Sometimes even small adjustments to arranged services can make the service more personalised for an individual so that they do not feel they need the full

⁵ The Scottish Executive published the *Changing Lives* report in February 2006 which followed an independent review of Scottish social care. The report states clearly that doing more of the same in social work will not work and there is an expectation that organisations seek innovative approaches to ensure that individuals and communities get the support that is right for them. It also states that people who use services, and their family carers, will have more control over the services they are getting. www.socialworkscotland.org.uk.

⁶ <http://www.scotland.gov.uk/Topics/Housing/Housing/supportpeople/intro>

⁷ <http://www.ilf.org.uk>.

⁸ http://www.direct.gov.uk/en/DisabledPeople/Employmentsupport/WorkSchemesAndProgrammes/DG_4000347

range of self-directed support. Similarly, individuals on self-directed support can revert to arranged services if they choose to.

Kirsty has Huntington's disease which affects her mobility and speech. She also experiences occasional problems with choking.

She now has 6 personal assistants providing cover from 8.00 am till 10.00 pm 7 days a week with her partner covering the overnights.

She has found many advantages with self-directed support as it has allowed her greater flexibility and freedom in how she lives her life. She bakes, and with a new wheelchair, she can now go out in the car for day trips.

*She says: 'Fantastic scheme, makes our life so much easier, can't praise it enough. Help from our **local support organisation** is only a phone call away at all times'.*

Who can get self-directed support?

7. The following groups of people are eligible for self-directed support:

- Disabled⁹ adults assessed as requiring community care services, including housing support services
- Disabled 16 and 17 year olds assessed as requiring community care services, including housing support services
- Disabled people with **parental responsibility** to purchase the children's services their children have been assessed as needing
- Parents and people with parental responsibility for a child in need (under the age of 16) who has been assessed as requiring children's services
- Parents and people with parental responsibility for children whose health or development may be impaired or below a reasonable standard without services from the local authority
- Disabled adults and 16 and 17 year olds to purchase housing support services
- Older people aged 65 years and over who are assessed as needing community care services due to infirmity or age

⁹ All forms of disability are included such as a learning disability or personality disorders.

- **Attorneys** and **guardians** with relevant powers can receive self-directed support on behalf of people who are unable to give **consent** to arranging their own services
- Those community care **service users** aged 65 or over who are accessing **Free Personal and Nursing Care** can arrange for the *personal care* element of the package to be received as self-directed support, see section 14.

8. **Annex B** describes the legal basis of eligibility. It also describes the groups of people who at present cannot receive self-directed support under certain mental health or criminal justice legislation.

How to set up self-directed support

9. The care manager will need to spend time with a person to work in partnership to find out what support they need and what it is possible to provide. They can give a person the information they need about the assessment process, including **self-assessment**. Some **local support services** are also able to spend time with individuals to prepare them for the assessment so that they can get the most from it. They may also be able to get support from a peer group who already have self-directed support and know how things work in practice. At the end of the assessment of their needs the individual and the care manager will agree a personal **care plan** which sets out how those needs will be met.

10. If a person decides to try self-directed support, their care manager can arrange for the allocation of a budget. This is sometimes called an **individual budget (IB)** because it is for the person's sole use and to arrange for their support needs. Their care manager brokers this budget and will make clear what they can spend money on. The individual will also need to show the council that the support they want to buy meets their assessed needs, and must have a separate bank account for their individual budget. The person will need to show how they are spending the money by recording it in various ways and by keeping bank statements and receipts on request. Lots of people get a book keeper to help with this, or use a local pay roll service to help with paying any staff they employ.

11. There are local authority funded local support services in most parts of Scotland that can work through the paperwork with the person and help them manage. They can offer practical support, for example, with buying an individualised service from a service provider. Or if a person is unsure of the idea of recruiting and employing their own staff,

the support services can help with this. Local support services are listed in **Annex C**.

PART 2: GUIDANCE ON LOCAL SCHEMES FOR SELF-DIRECTED SUPPORT

Purpose of part 2

12. This part describes how to set up straightforward and effective schemes for self-directed support, and is principally for local authority staff. It is also hoped that sufficient explanation is supplied to make it useful for other people who may need technical detail, for example, some service users, **carers**, local support services, PAs and service providers.

Section 2: ASSESSMENT, PLANNING AND COSTING SELF-DIRECTED SUPPORT

13. This section goes through the first steps of the journey to maximise a person's independence, and covers stand alone self-directed support as well as where it is part of a **mixed package** of care including traditional arranged services. It also looks at the planning and costing of the package to ensure that there is money available for the user to get a service that the local authority is satisfied will meet assessed need.

Single shared assessment (SSA)

14. The first port of call for anyone seeking any care service is single shared assessment (SSA) which should include some self-assessment work. The emphasis here is on 'single', meaning that one professional carries out the assessment with the individual, often with contributions from other professionals and carers, and that is shared with all those who have an interest to avoid the need for several professionals to undertake separate assessments. The 'shared' refers to the time and skill needed for this holistic approach so that the care manager can work in partnership with the prospective service user and those supporting them. From 2005 it is a requirement that SSA specifically discusses self-directed support as one delivery option.

15. The local authority should inform users of local support services, where available, to support individuals exploring self-directed support and preparing for their assessment. Local support services have a key role in equalising the relationship so that individuals can choose and manage their support. Local authorities should fund those local support organisations who have the capacity to do so to provide this service.

Self-assessment and preparing for being assessed

16. As part of best practice for assessments local authorities should make available information about any eligibility criteria applied in the assessment process that may affect whether support can be offered to individuals. This helps avoid raising expectations about services, which are always subject to assessment.

17. Individuals should be encouraged, as part of a self-assessment process, to consider for themselves what care and support they might need. Doing so will better assist the person in articulating their own needs and so enhance their self-care, which may help prevent

escalation where more extensive service provision becomes necessary. It may also assist someone to regain their previous capability.

18. Self-assessment forms should be designed by user groups to prompt people to think through the tasks with which they need assistance before their needs are assessed by the local authority. **Annex D** has an example of a self-assessment checklist. In addition, some local support services are able to provide courses that can enable users to think of themselves as active citizens making decisions about how to best meet their support needs.

Brokering an individual budget

19. Care managers usually consider multiple funding streams to make up the individual budget (IB) to meet a person's assessed support needs. Systems such as the Indicator of Relative Need (SSA-IoRN)¹⁰ are there to assist local authorities in achieving an equitable use of budgets according to assessed needs. Besides the local authority care budget, funding for equipment and temporary adaptations and Supporting People, there may be Free Personal Care, the Independent Living Fund, Access to Work, Disabled Students Allowance (SAAS)¹¹, Disability Living Allowance (DLA)¹², Carer's Allowance (CA)¹³ and health monies to meet continuing health needs. The funds are combined within one bank account and monitoring done as a whole.

20. The care manager is best placed to perform this brokering function as the process is integral to assessment. Their skills and creativity helps them know about an individual's aspirations and wishes, work with them through times of change and help them attain choice and control. They are professionally trained and publicly accountable, and their cost effective approach is to work in partnership with individuals, their carers and families, and local **advocates** and support services to facilitate good practice.

¹⁰ The SSA IoRN, previously known as the Resource Use Measure (RUM) was developed as a national tool to be applied following the assessment of older people which places individuals into relative need groupings from low (A) to high (1).

<http://www.scotland.gov.uk/Topics/Health/care/JointFuture/SSAIoRN>.

¹¹ http://www.saas.gov.uk/available_support.htm;

<http://www.dwp.gov.uk/lifeevent/benefits/atoz.asp#s>

¹² http://www.dwp.gov.uk/advisers/hb5/dla/dla_1.asp

¹³ http://www.dwp.gov.uk/advisers/hb5/ca/ca_1.asp

21. It is not envisaged that additional organisational arrangements are usually necessary at extra cost involving independent brokers, commissioners or navigators as this may duplicate work already done by care managers and local support organisations and require quality and competence monitoring. Commissioners usually develop new services for more than one individual (block contract) so this is less common for self-directed support. Instead local support services are usually able to work with an individual to spot purchase an individualised service or employ PAs, making independent brokers unnecessary.

Informed consent

22. Almost any disabled or older person should be able to get self-directed support if they choose it. Eligible people must give their consent to do so, or if they evidently lack the capacity to do so, consent can be given by an attorney or guardian. Appropriately trained **advocacy** workers should be made available to support people effectively through the process. Learning disability or cognitive **impairment** of any kind should not be a barrier to a person having more, or more effective, control of their lives. Further detail is given in section 3.

Ability to manage self-directed support

23. The person carrying out the assessment will need to form a judgement of whether the individual is capable of directing and managing a package. For example, some people with dementia or profound and multiple impairments may need help with planning and running a care package. The practitioner should consider and provide the necessary assistance to the user.

24. This could include any of the following:

- advocacy
- communication support
- record keeping
- pay roll service
- good employment practice
- managing self-directed support on an ongoing basis even through periods of fluctuating or deteriorating condition.

25. Where the authority decides, in exceptional circumstances, that a person is unable to manage self-directed support, the reasons for this decision must be communicated competently and sensitively in writing. This allows for any misinformation to be challenged or clarified. The authority should also make the individual aware that they can use the complaints procedure to challenge the local authority's decision not to offer self-directed support.

'...The difference that self-directed support has made to my life has been fantastic... I feel sad that there are people who may be scared of doing this. People should get the support they need and be encouraged...' (Young person in receipt of self-directed support).

Carers' assessments

26. The 2002 Act gives local authorities a duty to inform carers providing 'a substantial amount of care on a regular basis' that they may be entitled to a carer's assessment. Where the carer requests an assessment, this is to establish the level of care they are willing and able to provide and what assistance they need in their caring role. A carer's assessment may be carried out separately, or combined with the assessment of the cared-for person. Further information on this can be found in guidance circular CCD 2/2003 Community Care and Health (Scotland) Act 2002 New Statutory Rights for Carers: Guidance in March 2003¹⁴.

27. A carer's assessment does not at present give the carer an entitlement to self-directed support in their own right. Its purpose is to clarify what they can do, what assistance they may need in order to be able to continue in their caring role, the carer's aspirations, and what assistance they may need planning for life balance beyond the caring role and to be able to keep well.

Personal care plans and self-directed support agreements

28. A personal plan describes how an individual's assessed needs will be met. A self-directed support agreement is a separate contract (see **Annex E**) that spells out the part of these needs which will be met through self-directed support. Both are developed with the user and they should always be given a copy.

¹⁴ http://www.sehd.scot.nhs.uk/publications/CC2003_02full.pdf

Purchasing support

29. By exploring creative options, it may be possible to identify needs-led alternatives rather than service-led solutions. The individual chooses whether to purchase services or become an employer. Users can meet their needs by:

- contracting directly with a service provider e.g. an agency, private provider or voluntary organisation
- employing staff (personal assistants, PAs) to provide the services
- purchasing services from any local authority
- other forms of support, for example, those used on a **recovery** journey after a period of mental ill health, or
- a combination of some or all of the above.

30. The 2003 Regulations prevent people from using direct payments to secure services from some family members. However, this is shortly to be modified by the Adult Support and Protection (Scotland) Act 2007.

Costing a package: an individual's budget

31. The 1968 Act requires local authorities to ensure that the available budget is sufficient to enable the **recipient** to secure support of a standard that will satisfy the local authority that the person's needs are being met. It should meet the cost of providing a service which is of an equivalent standard to that which the local authority would provide. This means that a self-directed support package using service providers needs to take into account the range of hourly rates for day, night, weekend, bank and local holiday and emergency cover. Some local authorities have set maximum rates for standard agency care for particular client groups, and if service users choose a more expensive rate they will be asked to pay the difference.

32. Whilst some individuals using self-directed support prefer to purchase support from service providers, the majority of people take responsibility for employing their own workers directly and costing is done differently.

Costing a personal assistant (PA) employer's package

33. Self-directed support is not about promoting a two-tier workforce of social care with a regulated professional workforce sitting alongside a personal assistant (PA) network. Local authorities will wish to ensure

that rates of pay and conditions allow the smooth running of the arrangements for self-directed support. A critical element will be ensuring that PAs are sufficiently remunerated to wish to continue in that role. Pay rates, other benefits and conditions on offer at local authorities should provide a bench mark for setting equivalent rates of pay for PAs. The importance of being a good and responsible employer cannot be over-stated¹⁵. Good working relationships are essential for recruiting and retaining PAs, and will avoid the financial and emotional costs of high staff turnover.

34. The local authority should take the following items into account when constructing the individual budget:

- start up costs such as advertising and recruitment expenses
- pay rates and maximum working hours legislation for staff
- employers National Insurance
- the minimum statutory holiday and bank holiday pay
- statutory sick pay and cover
- statutory maternity, paternity, adoption or dependents' pay and cover
- **employer's liability insurance**
- training costs
- emergency cover for staff absence
- any required protective clothing for PAs
- any payroll and book-keeping fees.

35. In order to encourage good employment practice the following discretionary elements should also be included where possible. Discretionary elements might include:

- employer's contribution to a pension scheme to match local authority pension contributions
- **employer's indemnity** insurance to insure the employer for claims made against them arising out of their employment of a PA.

36. The local authority should give individuals as much notice as possible of the individual budget, and any contribution the person needs to make towards their support, before the payment begins or the level is changed. It should be clear to the person from the outset that self-

¹⁵ <http://www.acas.org.uk/>

directed support packages may involve their making a contribution, as they would for receiving arranged services.

Assessing a service user contribution

37. Section 87 of the 1968 Act enables the local authority to require the individual to make a financial contribution to the cost of any services they need to meet their assessed needs. In considering if an individual should make a financial contribution, local authorities should treat people on self-directed support as they would treat them if the person was being charged for using the authorities' equivalent services. The individual budget can therefore consist of a combination of an individual's own contribution, a contribution from the local authority, and money from funding streams such as the ILF¹⁶ which are not means tested.

38. Local authorities should refer to the Executive's 2003 circular¹⁷ and CoSLA's guidance to local authorities on charging for non-residential care¹⁸.

39. From June 2003 local authorities have been required to make direct payments either on a gross or a net basis of any contribution required. This guidance changes this position. Local authorities are now required to make direct payments on a gross basis and to recover the individual's contribution later. This ensures that people on self-directed support are on an equal footing with people receiving other local authority services. It also enables there to be clear distinction between the individual budget and the service user's own funds.

40. Local authorities are reminded that since 1 July 2002, people aged 65 and over, have been able to receive personal care services at home free of charge. Local authorities should refer to Executive circular CCD 4/2002: *Free Personal and Nursing Care*¹⁹, particularly *Section 5: Payment Mechanisms*. Where a person aged 65 or over chooses their individual budget to purchase this element of personal care at home the individual should not be asked for a contribution.

¹⁶ <http://www.ilf.org.uk>

¹⁷ Direct Payments: Social Work (Scotland) Act 1968: Sections 12B and C – Policy and Practice Guidance.

<http://www.scotland.gov.uk/Publications/2003/06/17612/23017>

¹⁸ <http://www.cosla.gov.uk/attachments/execgroups/sh/shchargingguidance2006.doc>

¹⁹ <http://www.sehd.scot.nhs.uk/index.asp?name=&org=%25&keyword=ccd&category=-1&number=10&sort=tDate&order=DESC&Submit=Go>

41. Local authorities must ensure that when applying their charging policies to people on self-directed support they do so fairly and equitably with people who receive arranged services²⁰. People in receipt of housing benefit and those receiving housing support services²¹ on a short-term basis (up to 2 years), will not be asked for a contribution, for that element of their self-directed support package relating to housing support, nor will people who receive housing support services previously funded from the Special Needs Allowance package. Details can be found in the Supporting People Charging and Financial Assessment guidance²².

42. Under section 22(4) of the 1995 Act, local authorities have discretionary powers to charge contributions for children's services where the means of the family are sufficient.

Complaints about funding of individual budgets

43. There may be cases where an individual thinks that the total value of the individual budget should be greater than the local authority proposes, or that their contribution should be less than the local authority proposes. In such cases, the local authority is under no obligation to increase the amount offered. Nevertheless the local authority may decide to increase the amount enabling the person to secure the preferred service if it is satisfied that the benefits of doing so outweigh the costs. A consultative approach is encouraged towards reaching a decision about the level of the individual budget. However, where a case cannot be resolved through discussion, the local authority should advise the individual that they might pursue the matter through the local authority's complaints procedure. If this still does not resolve the matter, the complaint can be passed to the Scottish Public Services Ombudsman (see **Annex C**).

²⁰ See circular No: SWSG I/97: Charging for Adult Non-residential Sector Care at <http://www.scotland.gov.uk/library/swsg/index-f/c172.htm> and CoSLA's guidance at <http://www.cosla.gov.uk/attachments/execgroups/sh/shchargingguidance2006.doc>.

²¹ Housing support services are services other than care or housing management services that enable a person to establish or maintain occupancy of a dwelling. These services are provided to help people live as independently as possible in their own homes. Housing support services come within the definition of community care services and therefore the 1968 Act allows disabled people to use direct payments to purchase these services. Housing support services might include services to help with home safety and security or to set up a new tenancy.

²² <http://www.scotland.gov.uk/Topics/Housing/Housing/supportpeople/intro>

44. While any complaint is being considered, the individual may choose to manage on the individual budget being offered, without prejudice to the complaint that it is inadequate. Alternatively the person may choose to refuse to accept the individual budget, in which case the local authority must arrange the relevant services instead.

Section 3: ADDITIONAL SUPPORT: GIVING CONSENT, SUPPORTING DECISION MAKING AND ADVOCACY

Consent by the service user

45. The 1968 Act requires that all eligible adult client groups give consent to receiving direct payments, or if they lack the capacity to do so, consent can be given by an attorney or guardian. Local authorities must not exclude whole client groups of people from being deemed competent to consent to self-directed support. This means that local authorities should start from the premise that each person, aged 16 and over, has the capacity to consent to self-directed support, even if they require help to enable them to do this.

46. The local authority needs to be satisfied that the individual service user or representative has the help and support to enable them to do this, for example, advocacy may be needed. Those with parental responsibility can consent to self-directed support for children under 16 or persons under the age of 18 where that person is incapable of giving consent²³.

47. Local authorities need to be clear about what choices and decisions are involved in consenting to self-directed support for that individual. For example, is the individual consenting to stay in their own home, or to be able to choose a support worker, or to go on a college course one day a week instead of to the day centre?

48. Local authorities and support services (for example, Centres for Independent Living, local support organisations, local authority support services) should make clear that when people consent to self-directed support, whether for themselves or the person they are representing, they take on the responsibility for arranging and purchasing the support to which the payments relate. They also take on additional legal responsibilities, either by contracting with an agency, or as an employer. Where a person purchases support for children, that person has a responsibility to ensure that the child is safe and that their welfare is promoted.

49. Local authorities should only make payments to a person whom they are satisfied accepts the responsibilities involved. Self-directed support may involve a substantial commitment in terms of time and

²³ The Community Care (Direct Payments) (Scotland) Regulations 2003

energy, especially in the set-up phase. During this period the local authority may need to arrange services for the individual rather than leave them without services or rush them into making a decision about self-directed support. Sometimes users find that such interim arranged services suit them and they should not be obliged to take up self-directed support instead of the service they have become accustomed to using.

50. The Adults with Incapacity (Scotland) Act 2000 ('the 2000 Act') sets out a framework for regulating the intervention in the affairs of an adult who has impaired capacity in a wide range of property, financial and welfare matters. Any intervention should be consistent with the principles of the 2000 Act which are that all decisions made on behalf of an adult with impaired capacity must:

- benefit the adult
- take account of the adult's wishes, if these can be ascertained
- take account of the views of relevant others, as far as it is reasonable and practical to do so
- restrict the adult's freedom as little as possible while still achieving the desired benefit, and
- encourage the adult to use existing skills or develop new skills.

Ross is 42, has extra support needs, and lives in a housing association flat. His previous support from the housing association meant contact with many different workers which did not suit him and they came to see him at times that were inconvenient for him.

With advice from his advocate and his social worker, Ross chose to use self-directed support to employ a personal assistant. He is a lot happier with his support now that he is more in control of who helps him and when they help him, and is confident in his new role of employer.

He says: '...The council's doing a good job, and my local support organisation really helped me to get this sorted...'

Supporting decision making and advocacy

51. Besides the support principles enshrined within the 2000 Act, there are other means of supporting decision making across all client groups, for example, **user controlled trusts**, **circles of support**, and advocacy.

This approach emphasises the right of people to whatever assistance they need in order to be confident about making decisions. For example, research has shown that when given appropriate support people with learning disabilities can achieve a better quality of life²⁴. This is equally true for older people, those with autism or those with sensory impairments. Local authorities should satisfy themselves that the support structure is appropriate and that adequate time is allowed for relationships to develop between the individual and the people providing the support.

52. People using self-directed support may also find it helpful to have access to advocacy support²⁵. **Independent advocacy** and **self-advocacy** can help to:

- promote respect for the rights, freedoms and dignity of people, both individually and collectively
- ensure people receive the care or services to which they are entitled, and which they wish to receive
- enhance people's autonomy
- assist people to live as independently as possible and in the least restrictive environment, and
- protect people from harm and exploitation.

'Having just completed our first year on self-directed support to manage the care of my brother-in-law Craig, I would like to say what a positive experience it has been. The scheme has allowed us to tailor Craig's support to suit his needs which seem to change on a daily basis. This has led us to achieve a better quality of life for him. Although the scheme is managed by me, Craig is involved in all aspects and decisions of his support from staffing, to the choices of food he has in his cupboards. This was not always possible with past care providers who seemed to be unable to be as flexible as is required. Hopefully, we can continue learning and improving Craig's care, allowing him to live his life happily and as fulfilled as possible. Lately, when I asked Craig how he felt things were going with him and me as "the boss", he replied "magic". (Brother in law of 47 year old man with learning disabilities).

²⁴ Values Into Action (2001) *Making decisions: best practice and new ideas for supporting people with high support needs to make decisions.*

²⁵ <http://www.siaa.org.uk/documents/DirectoryFundingupdated280207.pdf>

Consent by attorneys and guardians

53. Where a local authority is satisfied that the person who requires the services cannot give consent, even with support to do so, the person's attorney or guardian may consent to receive them on their behalf if they have been granted the relevant powers under the 2000 Act. This should be seen as a last resort. As well as consenting on the adult's behalf, the attorney or guardian with the necessary powers will manage the package directly or indirectly.

54. Under the 2003 regulations, parents caring for a young person aged over 18²⁶ who is unable to give consent (for example, due to severe learning disabilities) will need to apply for guardianship. Attorneys and guardians must act within the general principles of the 2000 Act. The powers for attorneys and guardians to consent to self-directed support will also be of help where an individual's assessed needs change and they are no longer able to give consent to self-directed support in lieu of the new services. Rather than cease the package, the attorney or guardian may give the consent needed for the arrangements to continue. This means that self-directed support can continue when a person's condition fluctuates or deteriorates to the point that they are no longer in control day to day.

55. Self-directed support requires consent in relation to both financial and welfare matters. These powers are strictly interpreted according to what is stated in the court order. Local authorities should request documentary evidence to confirm attorney or guardian status and details of the powers granted. It is possible for one guardian to be given powers over both financial and welfare matters or for there to be a separate welfare guardian and financial guardian. In addition, there may be joint guardians where more than one person applies to hold the same powers jointly.

56. For attorneys, this means that the individual, while capable, usually has to give the attorney financial powers to claim and receive on their behalf all pensions, benefits, allowances, financial contributions, repayments, rebates and the likes to which the person may be entitled. In welfare powers, there is often a form of words indicating that the

²⁶ Those with parental responsibility for a young person under the age of 18 need not apply for guardianship in these circumstances- See Section 3(1) of The Community Care (Direct Payments) (Scotland) Regulations 2003.

attorney ‘may decide what care and accommodation may be appropriate for me.’

57. The Public Guardian²⁷ has a duty to receive and investigate all complaints regarding the exercise of functions relating to the property or financial affairs of an adult made in relation to attorneys or guardians. Local authorities have a responsibility to investigate complaints in relation to welfare, and the Mental Welfare Commission Scotland has a role in protecting the interests of adults with incapacity where the incapacity is as a result of mental disorder.

Parental consent

58. Under the 2003 regulations, a parent or person who has parental responsibility for a child or a young adult (aged under 18) may give consent to receiving direct payments to purchase the support to meet the child or young person’s assessed needs. Social workers also have a duty under the Children (Scotland) Act 1995²⁸ to elicit, listen to and take into account the views of the children concerned in decisions which affect them; increased weight is given to these views from the age of 12.

59. Where a young adult aged 18 or over lacks capacity to give consent to self-directed support, no-one else can consent on his or her behalf without use of the 2000 Act. A parent, for example, is able to act on behalf of his or her child aged 18 and over only if he or she has guardianship.

²⁷ <http://www.publicguardian-scotland.gov.uk/>

²⁸ http://www.opsi.gov.uk/acts/acts1995/Ukpga_19950036_en_1.htm

*Jenny is 18 years old and lives with her mum who is also her legal guardian. She has just left school and started college. Her mum was her full-time carer and the only time she received **respite** was when Jenny's school was running summer camps which were not always suitable for Jenny's needs. Jenny's mum also felt that her daughter was missing out on taking part in activities that other young people were doing as she depended on her mum to support her.*

Jenny has now been using self-directed support for a year. She was awarded 11 hours a week with which she employs a personal assistant for some of the time and contracts an agency for the rest of the time. Her workers assist her with bowling and swimming. This means that Jenny is independent and can mix with people her own age.

Jenny's mum is less worried about her daughter's future and believes that self-directed support has made her re-think what support Jenny has a right to.

Section 4: WHAT YOU CAN BUY

Services or support?

60. Most people begin by buying support from the independent sector and a proportion then move on to employing their own PA. People living in remote and rural locations may find that the PA route is the most likely to be able to meet their needs because other services may not be available. It is important to distinguish between buying services from a self-employed PA and employing salaried PAs, as described in section 5.

61. Thinking in terms of services to meet a person's assessed needs may be limiting compared to thinking of the support they need to achieve independent living. There may be more creative support options available outside mainstream services, for example therapeutic support for those recovering from mental ill health²⁹ (see also section 13).

Support from service providers

62. There is no duty placed on local authorities to sell services. Instead they can choose whether or not to sell services in any particular case. An individual may approach any local authority to secure the services they have been assessed as needing. Where a neighbouring local authority might be the sole provider of the services required, it also opens up the possibility of adjacent local authorities working together to develop shared services. Local authorities may consider it appropriate to include extra cost, such as travel, where provision by another local authority is the only way of meeting the needs of an individual.

63. Service providers should be able to offer flexible tailored packages to suit individual needs. The individual who contracts with the provider can ask for consistency of staff and continuity of support and for the service to be withdrawn if it is of an unsatisfactory standard. It is best practice for local authorities to offer an individual budget of an equivalent monetary value of a council-arranged service to allow individuals to select their chosen option.

²⁹ Direct Payment for Mental Health Users/Survivors *A Guide to Some Key Issues*. NCIL (2001)

64. An individual who wishes to purchase a regulated service can find out about its quality from the Care Commission³⁰ which regulates a wide range of community and support services.

Housing support services

65. Housing support services are services other than care or housing management services that enable a person, aged 16 and over, to establish or maintain occupancy of a dwelling. These services are provided to help people live as independently as possible in their own homes and might include help with home safety and security or to set up a new tenancy. Housing support services are prescribed in the Housing (Scotland) Act 2001 (Housing Support Services) Regulations 2002. From June 2003 local authorities have a duty to offer eligible people self-directed support to purchase these services, including those funded by Supporting People³¹.

66. Disabled 16 and 17 year olds can access housing support services as children under section 22(1) of the 1995 Act.

67. For those aged 18 or over, if no needs other than housing support services are identified a Housing Support Assessment should be carried out looking only at the level and type of housing support service required.

Equipment and temporary adaptations

68. The 1968 Act places a duty on local authorities to offer direct payments so that disabled people may purchase equipment and temporary adaptations³², which would otherwise be provided by local authority social work services.

69. Ownership of the equipment or temporary adaptation bought using the individual budget can lie with the individual and with it the responsibility for service and repair. This needs to be clarified with the individual at the outset. Alternatively, the local authority could continue to maintain the equipment or arrange the maintenance under contract.

³⁰ www.carecommission.com

³¹ <http://www.scotland.gov.uk/Topics/Housing/Housing/supportpeople/intro>

³² Temporary as opposed to permanent adaptations, which are funded according to tenure.

70. When allocating a budget for an individual to purchase equipment or temporary adaptations, the local authority should bear in mind the specialist expertise that may be needed to ensure that what is purchased is safe and appropriate. As well as the payment to cover the initial outlay, local authorities should include a maintenance cost to cover service and repairs where the individual is able to provide confirmation that they have an annual service agreement. Local authorities should also consider whether an element of funding is required to pay for specialist training to use the equipment.

71. People may also have the option to donate equipment (and temporary adaptations) back to the local authority. In these circumstances the local authority will wish to ensure that the equipment being donated has been properly serviced, repaired and maintained and is still fit for purpose.

72. An individual budget cannot be used as a substitute for Housing Improvement and Repair Grants for adaptations for disabled people or for any adaptation that would normally be provided by a landlord. Nor can they be used to purchase equipment that would normally be provided by the NHS, for example wheel chairs.

Health needs and continuing health needs

73. Research has shown there can be distinct advantages for service users when they are able to manage their needs holistically³³. The legal mechanism for joint working is the Community Care (Joint Working etc.) (Scotland) Regulations 2002 (SSI 2002 No. 533) ('the 2002 Regulations') which gives relevant NHS bodies the power to delegate making direct payments to local authorities and the Regulations allow for the pooling of funds for this purpose.

74. While health care remains free at the point of delivery, best practice will still allow health boards to share funds with their local authority partners to provide joint care packages that cover both social and health care needs. Local authorities will need to liaise with NHS bodies to develop protocols around the assessment and monitoring of self-directed support with a health care component. In most instances

³³ Clark, Gough and Macfarlane (2004) *It pays dividends: direct payments and older people*.

this will mean that health care staff will need to monitor the fulfilment of healthcare needs in order to ensure the necessary expertise³⁴.

75. Where a package of support includes jointly commissioned services with health, for example, skincare, the management of pressure sores, the administration of percussive physiotherapy, ongoing management of aspiration and suctioning, specialist cancer, MS, brain or spinal injury care, local authorities are encouraged to work with their NHS partners to provide a jointly funded individual budget wherever possible, covering health and community care. Such health needs must be met by someone who is qualified to do so. Health monies can be used to enhance the hourly rate so that a worker with health skills can be employed, or to increase the number of hours funded so that, for example a second, or other worker can attend to health needs at specific times of the day.

76. Continuing health care needs such as for some aspects of epilepsy and diabetes care, are services that can be delivered by a PA provided that they have been trained by NHS staff, or a suitably qualified agency. Likewise a PA may need to be trained in the use of specialised equipment.

77. Employers remain liable for the health and safety of their staff and the implications of this must be discussed. It is imperative that individuals understand their responsibility in relation to those of local authorities and health boards in the event of an accident or error by staff providing joint packages. Local support organisations can give individuals advice about taking out an insurance policy to cover employer's liability.

³⁴ See Circular CCD 11/2002 at http://www.sehd.scot.nhs.uk/publications/CC2002_11.PDF

Margaret's joint-funded package has enabled her to return from hospital to her flat to enjoy the companionship of a near relative, to return to university (counselling course) and college (upholstery course) and to start undertaking voluntary work. She feels this has been possible due to good support.

She says: 'Problems become challenges, and challenges yield solutions. At 45, and a law graduate, I have enjoyed 3 years of independence and the simple things that many take for granted. I am able to eat the food I want when I want. I've managed to remain in control of my life, to continue driving my adapted vehicle, and have the enjoyment of a new pet.'

Residential accommodation and short breaks

78. A person's individual budget may not be used to purchase long-term stays in residential accommodation for adults or children, but can be used to purchase short breaks subject to the maximum period specified by the 2003 Regulations.

79. An individual budget may be used to pay for short breaks in residential respite provision or towards purchasing more flexible short breaks. For example, self-directed support can be used for a PA to accompany a user on holiday, so providing a complete break for the carer, or children may have a short break with a specialist care worker (see section 12 on children's services).

80. Regulation 6 of the 2003 Regulations specifies that where two periods of respite are less than 4 weeks apart, they should be added together to make a cumulative total. The cumulative total, calculated in this way, cannot be more than 4 weeks in any twelve-month period. However, if the two periods are more than 4 weeks apart they are not added together. For example, someone might have a one-week stay in residential accommodation every 6 weeks. Because each week in residential accommodation is more than 4 weeks apart, they are not added together. The cumulative total is only one week and the 4-week limit is never reached. Another person might have 3 weeks in residential accommodation, 3 weeks at home, and then another week's respite on an independent break with their PA. The 2 periods away from home are less than 4 weeks apart so the person cannot use their direct payments to purchase any more respite within a 12-month period. However if the

local authority considers that further residential accommodation is needed, it can still arrange and fund residential accommodation for the person in the traditional way.

'...Self-directed support has totally transformed our lives. There were absolutely no respite facilities locally which could take our son. We are now in control of obtaining respite care and have been able to send our son on adventure holidays, where he has fun and we get a much needed break!' (Parent of a son with learning disabilities)

Buying services from a self-employed PA

81. Personal assistants (PAs) are usually employed directly by an individual on self-directed support. In exceptional circumstances it is possible for a PA to be self-employed.

82. In the former instance, it is the individual on self-directed support who takes on the employer's responsibilities for the PA's tax, national insurance etc. This is because most individuals will want to decide who the person is that they see, how they work, and when they work. This cannot be guaranteed if a person is self-employed, as they can send a substitute for themselves to do their work. For full details on becoming an employer of PAs, see section 5.

83. There may be instances where a user wishes to have a PA who is already self-employed. A PA cannot be asked to be self-employed to avoid the individual on self-directed support taking on employer's responsibilities such as paying tax and national insurance. It is essential that self-employed PAs provide proof from the Inland Revenue that they are regarded as self-employed for tax purposes. Details of the criteria the Inland Revenue apply to determine if a worker should be classed as self-employed are given at the HM Revenue and Customs website³⁵.

84. If an individual decides to contract with a self-employed worker, the self-employed worker is responsible for:

- providing a service agreement detailing items such as how much the worker is charging and how they will invoice
- providing a written statement to the effect that they will take responsibility for the paying of tax and national insurance

³⁵ <http://www.hmrc.gov.uk/employment-status/index.htm>

- funding their own training, including ensuring that they are trained to carry out the service they are offering
- providing a written statement that they have appropriate insurance indemnity cover, and
- undertaking and meeting the costs of an enhanced disclosure check.

85. Buying services from a self-employed PA means that the user has some additional responsibilities. For example, they should ensure that the PA's self-employed status relates to performing caring functions, and seek evidence of appropriate training undertaken by the self-employed PA. They must also arrange emergency cover for any periods of absence the self-employed worker may have from the contracted work. The self-employed person is not able to arrange this cover unless they are registered with the Care Commission as an agency, otherwise they are effectively sub-contracting. Only registered agencies are able to provide cover as part of their service agreement. If the local authority thinks that someone is acting as an agency and is not registered, they have a duty to report this to the Care Commission. If there is any doubt about whether the terms and conditions under which a worker is carrying out their duties are those of self-employment, then the individual on self-directed support must seek advice from the Inland Revenue.

Section 5: EMPLOYING STAFF: PERSONAL ASSISTANTS AND CLOSE RELATIVES

'...My personal assistant comes to suit me and now I can go to the doctor when it is convenient. I go to the gym and swimming on a Monday, riding with the Riding for the Disabled Association on Tuesday. The difference is like being let out of jail. Now I am free, it has taken a lot of stress and worry away.' (Physically disabled man in his mid 30s).

Personal assistants

86. The option of employing a personal assistant (PA) can be attractive to some people as the best means of meeting their individual needs. Whilst it is empowering, and can increase the choice and flexibility of the package, the role of employer carries important tasks and responsibilities. Those who choose this option need advice and assistance to enable them to meet their obligations as employers as well as to get the most from the relationships they build with their staff.

87. It is important that care is taken when recruiting PAs and that individuals know where to get the type of information, training and practical support that they need. This section outlines some best practice that individuals will need to follow if they are to fulfil their employer's role, and where advice and support can be found.

Safe recruitment

88. Safe and effective recruitment by PA employers requires commitment by the user, the local authority, the support organisation and others to:

- explore what is best for the individual and how this may be achieved
- put in place all the various recommended stages in the recruitment processes, and
- provide appropriate targeted advice and training on roles and responsibilities.

89. The responsibility for ensuring the quality of support rests with the individual. This is because the Care Commission's regulatory system does not cover situations where an individual employs a person directly (i.e. personal assistants), whether paid for through self-directed support

or otherwise, for example using private means. Individuals may contract with or employ people who are not regulated by the Care Commission, provided that those individuals are not certain categories of **close relative**.

90. The prospect of allowing a non local authority support worker into their home may seem daunting for some individuals, even though enhanced disclosure checks will have been carried out. Those thinking of employing a PA can find out a lot from those who have managed to do so successfully.

91. Using safe and effective recruitment and employment processes should also help. This means:

- taking up references, on paper and by telephone
- carrying out police checks (enhanced disclosures, see below)
- staff induction and training
- probationary periods of employment
- **local peer support**
- staff management including meetings
- staff appraisals, including disciplinary procedures
- obtaining employer's liability insurance
- obtaining employer's indemnity cover.

92. The above list does not fully apply where an individual contracts with a self-employed PA, as they will be responsible for their own training and liability insurance.

Enhanced disclosure (ED)

93. Where individuals employ a PA directly, the PA must get an enhanced disclosure (ED) check through Disclosure Scotland which is the clearing house where criminal record checks are carried out under the Police Act 1997. All enhanced disclosure check applications must be countersigned by a registered person or a person nominated by them. All local authorities in Scotland are registered with Disclosure Scotland as are a number of direct payments support organisations³⁶ and so they can countersign applications. But because individuals cannot countersign applications, they will not receive a copy of the ED. This will

³⁶Currently, registered bodies for this purpose are SPAEN, the Princess Royal Carers Trust in Dundee, Dumfries and Galloway Direct Payments Support Service Partnership and the Scottish Disclosure Advisory Service (see **Annex C**).

be sent to both the applicant and the registered person who countersigned the application. If the registered person asks for a fee for this service, then any additional cost should be met by the local authority. The registered body cannot normally give advice on the applicant's suitability for employment.

94. The sharing of information contained on the ED is governed by the 1997 Act and a Code of Practice issued by Scottish Ministers. Also relevant is the Data Protection Act 1998, the Human Rights Act 1998 and the common law duty of confidentiality. Under the 1997 Act it is possible for the registered person to pass the ED to the individual service user. The prospective PA may also show the certificate to anyone. Only in exceptional circumstances can information be shared further.

The enhanced disclosure process

Pre-interview screening

95. Section 3 described the agreement that the local authority has with an individual. This agreement should include the following:

- (i) the individual assumes the responsibilities of an employer if they choose to employ PAs, and that they adhere to good employment practice;
- (ii) the individual should ask prospective PAs to initiate an ED application via the relevant local authority or through using another registered body, after interviewing and taking up references etc but prior to appointment being confirmed;
- (iii) the individual secures the written consent of the prospective PA to share information derived from the disclosure process with the local authority. Unless this is given, the local authority, even where it has countersigned the application on behalf of the individual, cannot make use of the information contained on the ED for its own purposes, and that includes considerations about the safety of making, or continuing to make, payments for self-directed support.

96. As part of safe recruitment and good employment practice, the PA employer must see full proof of a prospective PA's identity including present and recent addresses, and share this information with the local authority.

97. A self-declaration will be required from a prospective PA that any past criminal history, ongoing criminal investigations, or other information as to their conduct or behaviour, does not make them unsuitable to undertake such work. For those employing PAs to support children under 18, a PA commits an offence if they apply for such work whilst on the Disqualified from Working with Children List (DWCL).

Enhanced disclosure (ED)

98. If a PA is successful at interview, the post should be offered subject to completion of both a satisfactory enhanced disclosure (ED) as well as a suitable probationary period. The PA cannot be employed until consideration of an ED is completed.

Decision to employ a PA

99. The ED certificate may or may not contain information. Some possible outcomes from the ED are:

- No information is returned on the ED. The PA employer is able to go ahead and employ the prospective PA, subject to safe recruitment processes including checkable references and the probationary period recommended by good employment practice.
- DWCL or information from equivalent lists held elsewhere in the UK is disclosed on an application in relation to a child care post. The employer cannot employ the prospective PA. Note that access to the DWCL is only available for those applications to Disclosure Scotland that are requested to enable the consideration of a person's suitability for a purpose set out in section 113C(2) of the Police Act 1997.
- Some information is returned on the ED. This might be unspent criminal convictions (current), spent criminal convictions (old) or if they have incurred any reprimand warning or caution. It may also reveal that the PA is placed on the list of individuals barred from working with adults which operates in England and Wales, the Protection of Vulnerable Adults list. As part of good recruitment practice, no prospective employer should unfairly discriminate against the applicant solely on the basis of the information on the disclosure. For example, an item declared may have no relevance to the ability of the person to carry out the PA duties required, and/or not be of a serious nature, and/or not part of a pattern of

offending behaviour and/or have taken place a long time ago and/or the prospective PA has demonstrated in some way that his or her circumstances have changed since the offending behaviour.

100. Unless the prospective PA is applying for a child care post from which they are disqualified from working, the PA employer has a right to decide that the information is relevant to the post and to decide the person is unsuitable for this work. For adult care posts, the ED may reveal that a person is on the Protection of Vulnerable Adults List held in England and Wales (and consequently disqualified from such work in that jurisdiction), and that would be a factor that should be taken into account when assessing suitability. Only in the case of child care posts is it an offence to employ a PA who is disqualified from working. Where an applicant may be deemed unsuccessful, this information should be provided to the applicant in writing. For example, a PA employer may have decided that they wish to apply the same recruitment standards to employing PAs as the local authority. A local authority will need to inform service users about those standards.

101. The prospective PA should give their agreement to the information on the Disclosure Certificate being shared with the local authority for its purposes. In this situation, if there is a disagreement between the PA employer and local authority about the relevance of information on an ED to the prospective PA's suitability for the post, and the PA employer wishes to employ the PA, the local authority will wish to assess the level of risk to the individual on self-directed support, and may discuss the circumstances separately with the PA. Where, following an assessment of risk and discussion with the PA, the local authority remains concerned as to the welfare of the individual the local authority will consider whether to make payments for self-directed support.

102. In rare circumstances police intelligence may be provided by a chief officer only to the person who countersigned the application. For example, it may be related to investigative police work in progress. Only the counter signatory would have sight of this and it will not be shared further without the written consent of the chief officer who provided the information.

103. Local authorities also need to take account of exceptional circumstances on a case by case basis of a prospective PA's suitability to provide the necessary support. Exceptional circumstances for employment of PAs will shortly be applied under the Adult Support and Protection (Scotland) Act 2007 for the employment of close relatives.

Under certain of such exceptional circumstances (for example, perhaps in the final stages of an individual's illness) the local authority may decide that a close relative may be employed before the ED is issued and assessed. Once received their continued employment would be subject to the normal consideration of information within an ED. A probationary period would also be necessary.

104. For further advice on the ED process contact the local authority care manager, Disclosure Scotland, SPAEN (Scottish Personal Assistant Employers Network), the Princess Royal Carers Trust in Dundee, Dumfries and Galloway Direct Payments Support Service Partnership or the Scottish Disclosure Advisory Service (see **Annex C**). Local authorities are reminded to seek legal advice from Council Solicitors on any matter of doubt.

Chris lives with his family who used to provide all his personal care and assist him to go out. He has been using self-directed support for four years which has allowed him to employ 5 PAs who help him with all aspects of personal care during the day. They also enable him to go out during the day when he wants, instead of waiting for times when a member of his family is free.

Chris has more control over his life. He can decide what kind of support he needs and when he wants it. His full time PA, Richard, has been working with him for the last four years and says that Chris has become much more outgoing and self-confident since he started working with him.

Self-directed support also enables his family to get on with their lives without worrying about him or planning their day around him. They are much happier that Chris can now do what he wants with people that he trusts.

Short stays in hospital

105. Local authorities should fund PA employer packages during short stays in hospital, where appropriate. This will enable individuals to continue paying employees (not service providers) for the initial four weeks of any hospital stay. Where the hospital stay is planned and sufficient notice can be given, a period of annual leave could be included. Local authorities should encourage PA employers to include arrangements for hospital admission within the employment contract and

terms and conditions. In all circumstances the statutory requirements governed by employment legislation must be applied.

106. The continuance of this funding beyond the initial four week period will be subject to local agreement. Assessment of the needs of an individual, whilst in hospital, may mean that the local authority agrees that a PA is required beyond four weeks, with regular review of the arrangement.

107. In some circumstances it may be part of the assessed need that the PA continues to provide support to the employer while they are in hospital, for example, when there is no-one to bring personal care items to hospital. Contingency funds could be used to fund the admission period.

108. In circumstances where the PA is not required to provide a service during the hospital stay, local arrangements can be made to pay a retainer fee (e.g. 50%) to enable the continued employment of the PA, with a resumption of the contracted hours on discharge from hospital. This will ensure continuity of care for the employer and avoid delayed discharge.

109. Where the period in hospital is likely to be prolonged or the discharge plan is likely to require considerably more support at home, self-directed support might resume after a transition period of arranged services. This could support the discharge plan and facilitate further assessment in the home environment to ensure that the person's needs are met, taking account of any preference towards becoming, or resuming the role of, a PA employer.

Employing close relatives

110. The rules on employing close relatives are to be changed following amendment of direct payments primary legislation within the Adult Support and Protection (Scotland) Act 2007. Local authorities will be able to offer increased flexibility in tailoring individualised packages, including allowing, in exceptional circumstances, the employment of certain categories of close relatives.

111. Meanwhile, regulations about employing close relatives (currently the 2003 Regulations) make it a condition of the payment of direct payments that the person to whom the payment is made does not use the payment to secure services from certain people. These are:

- the spouse or civil partner of the person to whom the services are to be given (the beneficiary) wherever the spouse or civil partner lives
- the beneficiary's partner (i.e. the other member of an unmarried couple), where the couple live together as though they were married. This also includes same sex couples who are not civil partners, but who live together as if they were.
- a close relative of the beneficiary if the close relative lives in the same household as the beneficiary
- the spouse or civil partner of a close relative if the close relative and the close relative's spouse or civil partner both live in the same household as the beneficiary, and
- the partner (i.e. the other member of an unmarried couple, including a same sex couple, who live together) of a close relative if the close relative lives in the same household as the beneficiary *and* the partner and close relative live together as though they were married. This also includes same sex couples who are not civil partners, but who live together as if they were.

112. A close relative in this context is a parent, parent-in-law, aunt, uncle, grandparent, son, daughter, son-in-law, daughter-in-law, stepson or stepdaughter, brother or sister. It also applies to the equivalent relationships arising through civil partnership and through a relationship where the same sex couple are not civil partners but live together as if they were. Until new regulations are made, a local authority is unable to apply an exception to the rule about employing these people, even if it is satisfied that such employment would be the most appropriate way of securing the relevant services.

113. The condition against using direct payments to secure services from the people mentioned in the sub-sections in paragraph 111 does not extend to securing services from:

- a close relative of the beneficiary who does not live in the same household as the beneficiary
- the spouse or civil partner of a close relative of the beneficiary if either the close relative or the spouse or civil partner of the close relative does not live in the same household as the beneficiary
- the partner of a close relative if the close relative does not live in the same household as the beneficiary

- someone living in the same household as the beneficiary who does not fall within the sub-sections in paragraph 111, or
- any other person, wherever they live, who does not fall within the sub-sections in paragraph 111.

114. Under section 12B(5) of the 1968 Act, if a local authority is not satisfied that a condition imposed by the 2003 Regulations has been met in relation to a direct payment (or part of a direct payment) made by them, the local authority may require the payment (or part payment) to be repaid to them (see section 8).

Section 6: INFORMATION, SUPPORT AND TRAINING

115. Local support services have a crucial role to play in delivery of self-directed support. These organisations can provide training, peer support, advocacy, awareness-raising and confidence-building as part of the first hand knowledge they can pass on to new and current users.

Users' input into local procedures for self-directed support

116. Under the Local Government (Scotland) Act 2003, local authorities have a duty to involve service users in the development and planning of any services they provide, including when preparing their Community Care and Children's Services Plans. Service users need to be involved in the design, development and review of self-directed care policies and procedures locally as this assists in their design to suit individual needs. Care should be taken to include the views of people with different needs-people from minority ethnic backgrounds and people of different ages including older people aged 65 or over, people with learning disabilities or sensory impairments or people who are mental health services users. The views of carers, local support organisations and of potential service providers will also be important. Local support organisations should be involved on a local authority steering group overseeing the local implementation and operation of self-directed support, and may assist in providing training for staff. In addition, local authorities are required to carry out equal opportunity requirements under current law. This includes promoting equality of opportunity between disabled people and other people and promoting positive attitudes towards disabled people under the Disability Equality Duty of the Disability Discrimination Act (2005)³⁷.

117. Whatever form the consultation takes, it is important that people who have been consulted receive proper feedback about what has happened, and how their views have been taken into account. It is also important that the lines of communication remain open, so that the local authority remains responsive to users' views over time.

³⁷ www.drc-gb.org/disabilityequalityduty/. Under the specific duties of the Act, many public bodies should have produced and published a Disability Equality Scheme by 4 December 2006.

Information

118. Information about self-directed support must be included in information about the full range of services that local authorities provide, including self-assessment and assessment stages. More detailed information should be made available separately in formats that are accessible to people with different forms of disability and to people whose first language is not English. Working in partnership with a local support organisation will help ensure that information is presented in accessible formats.

119. Self-directed support can be difficult to explain neatly in a couple of sentences, and prior knowledge cannot be assumed of either direct payments or the arranged services that they replace or complement. All local information must give details of the self-directed support available to people locally and nationally, and in addition to self-directed support, some people may have little real knowledge about their current council services, how they operate, who pays for the services or who controls the spending. For this reason, it is cost effective for local authorities to provide funding for individuals to access self-assessment and other support to help them prepare for the assessment with a local user-led support organisation.

120. Information about self-directed support should be included in local authority Community Care Plans, Children's Plans and **Partnership in Practice** agreements (PiPs)³⁸. Local area co-ordinators will get to know people with learning disabilities and their families in their local communities and help identify their needs and ensure they are met, including using self-directed support.

121. Various booklets, fact sheets and other information about self-directed support are available from UPDATE and other national and local organisations listed in **Annex C**.

³⁸ PiP agreements set out plans for implementing *The same as you?*, including plans to put in place local area co-ordinators to promote self-directed support for people with learning disabilities.

'Self-directed support has had a positive impact on our lives! I would not have been able to achieve this without the help and support I received and continue to receive from my local Centre for Inclusive Living (CIL). They have supported me through the whole process and assisted me in all aspects of employing a PA from drawing up the job description to the contract of employment. Thankfully my local CIL takes care of the payroll side of things so I do not have to worry about the financial side. I know that if I have any questions or problems they are happy to help and if I am unable to phone I can e-mail them and I get a speedy reply.'
(Disabled parent, Edinburgh)

Support

122. Research shows that having local support is essential to success and is cost effective³⁹. A well-run local support organisation also reduces the work of the local authority. Independently operated support organisations work in partnership with users, local authorities, voluntary organisations, service providers and advocacy services to offer information and practical services for individuals, such as payrolling systems for PA employers.

123. Local support organisations have experience of flexible and creative responses to individuals' support needs which is invaluable for supporting other under-represented groups. But to enable them to do this, local organisations need reliable local authority funding to increase their capacity and develop their services for all users. With appropriate funding user-led support organisations may be able to help build expertise into new and developing support organisations for specific user groups, such as older people aged 65 and over, or for minority ethnic groups.

³⁹ Hurtsfield, Parashar and Schofield (2007) *The costs and benefits of independent living*; Heywood and Turner (2007) *Better outcomes, lower costs. Implications for health and social care budgets of investment in housing adaptations, improvements and equipment: a review of the evidence. Executive summary*. Both Hurtsfield et al (2007) and Heywood et al (2007) available at <http://www.officefordisability.gov.uk/publications/>

Pearson, C (2006) *Direct Payments and the personalisation of care*; Riddell et al (2006) *The Implementation of Direct Payments For People Who Use Care Services*; Witcher et al (2000) *Direct Payments: the impact on choice and control for disabled people*; Barnes et al, (2000) *Creating Independent Futures: An Evaluation of Services Led by Disabled People*

124. Local authorities should also consider whether it would be helpful for other people to have access to the local support service. For example, carers may need advice about how self-directed support works, particularly if they are assisting someone with managing the arrangements. People who are self-funding their services may also welcome the advice of a support service.

Why independent and user-led support?

125. Advice and support should be accessible, impartial, independent and wherever possible, provided by people with experience of using self-directed support. Such peer support is about sharing experiences, exchanging practical information and ideas, and sometimes troubleshooting over a longer period to ensure things work for an individual⁴⁰.

126. It is important that authorities do not allow the lack of a user-led support organisation to prevent the increase in uptake of self-directed support. Active networks can help build up steering committees to sit within non user-led support organisations or to form management committees that will form new support services. Some national as well as local support services offer training in managing committees and using organisational improvement frameworks such as 'Big Picture Facilitators'. For further information see the UPDATE website⁴¹ for *Five Steps – A Guide to Providing Direct Payments Support Services* (2002) and the fact sheet *The Role of the Support Organisation*. If local authorities set up in-house support, then in issues relating to employment, they can refer the individual to Citizen's Advice, ACAS, and SPAEN (see **Annex C**).

What kind of support and when?

127. Support organisations may be able to offer users support and training at four key stages in the journey to self-directed care which are:

- self-assessment and preparing for the assessment
- care planning

⁴⁰ Riddell et al (2006) *The Implementation of Direct Payments for People Who Use Care Services*; Clark, Gough and Macfarlane (2004) *It pays dividends: direct payments and older people*.

⁴¹ http://www.update.org.uk/new_web/locked/features/Features_DP_2.htm

- setting up the care package
- managing care.

Training

128. Local authorities will need to devise a training strategy that addresses the individual needs of service users, their care managers, PAs, and health partners. This may involve joint training of key participants led by local support organisations.

129. At present there is no recognised qualification for being a PA which is something that needs to be advanced in the longer term. This means that induction in-service and on-going training become critical components in delivering tailored services to meet individual need. All of which needs to be underpinned by training on employment law and health and safety for PAs, PA employers and local authority staff. It is important that those involved in delivery of support understand that this is all about independent living. This means that once a PA is trained in first aid, moving and assisting, and training for any continuing health care needs such as certain aspects of diabetes and epilepsy, it is the individual who will provide training and induction according to their personal needs. This is part of establishing expectations for employer and employee of working arrangements and building the working relationship.

130. Local support services may be able to lead training for individual users that includes the following elements, where applicable:

- for users - what it means to be in charge of your own support.
- for agency users - how to shop around service providers, better control of agency care provision, how to set up effective contracts, use of agencies in respite and emergency cover situations, and supervision of agency staff.
- for PA employers - training on safe recruitment, employment, management, development and retention of PAs. Other useful training might be undertaken in the first and subsequent years, such as: disability equality training, assertiveness skills, building self-esteem, managing conflict and self-advocacy.

- for care managers - training for those who carry out local authority care assessments, care management and monitoring of self-directed support. Training should include elements such as the importance of income maximisation, Independent Living Fund, Supporting People grant and other funding sources which may be available to purchase care and support in the home, in the community, in education or in the workplace.

National support for self-directed support

131. Regional and national bodies may have an important role to play in supporting users. Some of the larger independent living support organisations such as Lothian Centre for Integrated Living, Glasgow Centre for Inclusive Living and the Scottish Personal Assistant Employer's Network (SPAEN) have well established training programmes which can be purchased throughout Scotland for users, PAs and local authority staff. Such organisations are crucial in capacity building the network of local support organisations so that they can deliver quality and consistency in the training available locally. They are also there to provide information and services. Independent living options are about choice, and there should be a choice of sources and types of information available for users to take account of individuals' as well as different user groups' needs (see **Annex C**).

132. For example, the centres for integrated living may be able to provide a range of services that include an independent, impartial advice and information service, independent living advocacy, peer support and counselling, training, help recruiting PAs, and payrolling services⁴².

133. SPAEN is a national support organisation offering advice, support, advocacy and training on the practicalities of PA employment procedures including all aspects of safe recruitment, the drafting and issuing of terms and conditions of employment, and the day to day personnel management of employees⁴³. Underpinning SPAEN's services is an employers' indemnity scheme and access to a comprehensive system of personnel and employment law advice. SPAEN is also a registered body for vetting enhanced disclosure checks.

⁴² In addition to self-directed support services these centres may be able to provide disability equality training, housing information, employment and training support services, accessible meeting and conference facilities, assessment of community care services, outreach skills, campaign, policy and local development work.

⁴³ www.spaen.co.uk.

134. Other organisations and projects offer targeted help for different user groups. For example, at present approximately one third of individuals on self-directed support are aged 65 and over. To reach even greater numbers of older people, the Scottish Helpline for Older People (SHOP⁴⁴) is a consortium of key organisations working to improve information on self-directed support for older people. The Scottish Consortium for Learning Disability (SCLD⁴⁵) has produced a guide on receiving direct payments for people with learning disabilities (see **Annex F**).

⁴⁴ SHOP telephone helpline 0845 833 0200, Monday to Friday 10 am to 4 pm

⁴⁵ <http://www.sclld.org.uk/>

Section 7 MANAGING AND MONITORING SELF-DIRECTED SUPPORT

Making payments

135. It is good practice to make payments in advance so that recipients are in a position to pay for the support they are purchasing. It is, however, up to local authorities to decide how frequently payments should be made. It is important that where self-directed support is financed from more than one local authority budget or other funding stream the individual receives one single payment to cover all the services he or she has been assessed as needing.

136. Local authorities will need to set up proportionate mechanisms that enable them to monitor payments which are made. Whatever the arrangements for payment, they will need to be reliable, as late or incorrect payments may put at risk the person's ability to secure the support they need. The local authority may also need to set up procedures for making additional payments in emergencies, for example, if needs change. Where payments are made directly to a bank account a written statement of the payment details should be sent to the individual for information.

Managing payments

137. People may receive as much assistance as they require to manage the money, but they remain accountable for the way it is spent. People may ask carers, family members, user controlled trusts, circles of support, peer support or other third parties such as support services to help them. Such support can be invaluable, whatever its source, and users may also choose to buy in assistance, for example using a payroll service from a local support service. There is no restriction on who may help a person in this way, although the restrictions on paying relatives already described will apply.

138. Where significant support is being provided, the local authority will need to ensure that any monitoring and review procedures involve direct contact with the individual for whom the payments are made, if necessary in the absence of the person who is helping them. This is to ensure that the individual is content with the way in which the money is being used. Both local authorities and individuals on self-directed support should also be aware of the potential conflict of interest if the individual secures services from the same person who is helping them to

manage the payments. The same applies where an attorney or guardian intends to provide services for the individual.

139. Some people who initially need help to manage their self-directed support may in time be able to manage on their own. There is no restriction on the length of time that a person may receive help to manage their package.

Payments to a third party

140. With the individual's consent, the payments may be made to a third party but the person who gives consent to the payments must retain control over how they are spent. Self-directed support facilitates independent living, not a switch from dependence on the local authority to dependence on a third party. This means that people may express a preference about how a service is to be provided, and delegate the details to a third party so that they will not have to authorise every transaction. However, it must be open to the individual to overrule any decisions made by the third party. Local authorities should satisfy themselves that the relationship between the individual and the third party has been discussed and agreed before the package begins. They must also be satisfied that the individual is aware that they can receive the payments direct.

Management during periods of fluctuating health

141. Some people with fluctuating needs may only require help to manage their support at certain times. It is important that local authorities satisfy themselves that individuals have support in place when they need it. In these circumstances there is a need to plan ahead and make arrangements whereby a designated person or group of people - circle of support, trustees - can be given permission by the user to take over during a period when unable to manage. Having some form of **advance directive** should be considered an essential component. This would ensure that if they become ill they retain as much control and choice as possible of the arrangements and are able to regain full control if they become well again. This may help prevent a recipient reverting to local authority provision unless they wish this to happen. Advance directives make it possible for people with mental health support needs to state in writing what needs they have if they become particularly distressed or unable to manage. For example a person could write down what a support worker should do if they have a crisis, or write guidelines for how to assess risk, or provide a list of useful telephone

numbers that the support worker could phone for advice or information if necessary⁴⁶.

142. If the person's condition is likely to deteriorate to the point where they are unable to manage even with assistance, the local authority might consider ways of enabling the person to plan in advance how this is managed, for example, a power of attorney. A back-up service controlled by the local authority could be set up and triggered during periods when the person is unable to manage. Equally, local authorities might decide to offer self-directed support to people whose condition means that they are likely, at some point in the future, to lose the ability to manage permanently. In those circumstances they will still need to satisfy themselves that safeguards are in place to alert them in such circumstances. People whose condition is likely to fluctuate or deteriorate permanently should be given an opportunity to explore any issues they may have about their ongoing ability to manage their package. In such cases the local authority should make it clear to the individual that they can decide to stop self-directed support at any time and receive arranged services instead.

Emergency assistance

143. Providing self-directed support, rather than arranging actual services, does not affect a local authority's function of providing emergency assistance under Section 12 of the 1968 Act or Section 22 of the Children (Scotland) Act 1995 ('the 1995 Act'). If the authority considers the circumstances to be so exceptional as to require such assistance, they may provide it in respect of the services to which the direct payments relate (see Section 12C (3) of the 1968 Act).

144. Local authorities should discuss with each person what arrangements they will make for emergencies. Local authorities should ensure that the person receives the support they need if the usual arrangements break down, for example, through sickness of one of the person's PAs. It is reasonable for a local authority to expect the person to have contingency plans and these should be clarified at the outset. However, if a local authority becomes aware that someone is unable to secure support to meet their needs, then their responsibility to arrange services for that person is the same as if the individual was not on self-

⁴⁶ For more information on advance directives see *Direct payments for mental health users/survivors: A guide to some key issues* published by the National Centre for Independent Living.

directed support. The local authority may decide to step in, albeit temporarily, and arrange the necessary services, but it should first consider providing assistance to enable the person to continue to manage their own support.

145. Examples of contingency plans which people on self-directed support 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, it will be helpful if the individual knows they can contact a named individual in the local authority or a local support service whom they can ask for help. Such contingencies should form part of the contract agreement.

Local monitoring of individuals' packages

146. There are two forms of monitoring that local authorities undertake for packages of self-directed support: monitoring of service and monitoring of finances.

147. Consenting to self-directed support for some aspects of meeting assessed need means the local authority no longer arranges services for that part of the package. It follows that the local authority will need to set up monitoring arrangements so as to satisfy itself that arrangements are meeting needs. Local authorities should discuss with recipients the information they will be expected to provide and the way in which monitoring will be carried out. Self-directed support should not begin until the recipient has agreed to any conditions which are necessary for monitoring purposes.

148. Care managers should not rely on individuals asking for help, particularly when someone begins on self-directed support for the first time. Regular reviews should be arranged to discuss how the package is working. A local independent support organisation or independent advocacy service may help some people raise any issues which are giving concern.

149. Packages which include health services will require to be monitored by personnel with the necessary expertise to judge whether these particular assessed needs are being met. In most instances this

will mean that health care staff will need to be involved in the monitoring process.

150. Each local authority should also set up financial monitoring arrangements for audit purposes, to fulfil its responsibility to ensure that public funds are spent on the intended support. CIPFA have produced guidance for local authorities on this point and local authorities should ensure that up to date advice is being used⁴⁷. However it is important that monitoring is proportionate and focused on outcomes, with as light a touch as possible.

151. For packages to work, it is essential that these two forms of monitoring are co-ordinated. The financial monitoring should be carried out by a finance officer and monitoring of the services by the care manager. It is essential that that monitoring information is exchanged internally and that all those involved understand the purpose of self-directed support, and the role that the local authority's monitoring plays in the successful operation of the policy. In particular, information from both forms of monitoring should be considered in any decision to change the level of, or stop, self-directed support.

152. Honest mistakes should not be penalised. A message of continuity and security is crucial, because the payments often provide the support an individual cannot live without. For example, stop payment warnings should not be automatically issued when an administrative matter goes wrong.

153. As well as monitoring how well self-directed support is meeting the needs of individuals, local authorities will wish to monitor how local self-directed support schemes are working overall. As part of this, authorities should actively seek the comments and suggestions of people who receive self-directed support or who have considered doing so.

Reviews and reassessments

154. It is essential that local authorities carry out regular reviews of the arrangements. The first review date should be set when self-directed support begins. People should be made aware that they can request a review sooner if their circumstances change. The purpose of the review is to establish whether the objectives set in the original plan are being

⁴⁷ <http://www.cipfa.org.uk/>

met. The local authority will also wish to be satisfied that the individual is protected from harm and exploitation.

155. The local authority will wish to speak to the individual on their own during the review. If the individual needs support the local authority should ensure that the person is given the option of having support from an independent supporter or advocate. Local authorities may also wish to speak to family members and informal carers to satisfy themselves that the person is not experiencing any difficulties with arrangements. Where an attorney, guardian or parent is consenting to the self-directed support the local authority will also wish to discuss arrangements with them.

Section 8 **WHEN THINGS DON'T GO ACCORDING TO PLAN**

156. If an individual contacts the authority to seek emergency assistance, or if the local authority's monitoring or review process shows that the person's needs are not being met, the care manager will need to consider what action should be taken. 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.

157. The care manager should consider the following questions and potential responses:

- Have the person's needs changed? → Reassessment.
- Is the amount of money sufficient to enable the person to secure the relevant services? → Review the individual budget.
- Is the person still able to manage self-directed support? → Review the support they may need to help them overcome issues and manage longer term.
- Does the person wish to continue on self-directed support? → First explore whether they require more support → Arrange services as necessary.
- Has all the money been spent on the support for which it was intended? → If the money has clearly been diverted to other purposes consider seeking repayment. → A surplus is permissible within a given timescale for contingency purposes or to pay a PA's quarterly PAYE, sick leave and outstanding bills from service providers.
- Is the support being purchased safeguarding the person's welfare? → If there is any doubt, local authorities should speak to the individual receiving the services on their own (whenever possible) and review the services being purchased with them. Where an attorney, guardian or parent is consenting to the self-directed support the local authority will also wish to discuss arrangements with them.

Seeking repayment

158. It is up to the local authority to decide when it is appropriate to seek recovery. The 1968 Act enables local authorities to require some or all of the money they have paid out to be repaid if they are not satisfied that it has been used to secure the support to which it relates. They may also require repayment if the person has not met any condition, which the authority has properly imposed, and those imposed by the regulations. Local authorities should take into account hardship considerations in deciding whether to seek repayments.

Discontinuing self-directed support

159. Self-directed support may be discontinued because:

- the individual prefers receiving arranged services
- the individual is no longer able to manage self-directed support with the available support
- the local authority is not satisfied that the individual's needs are being met, and
- the local authority has concerns over misspent funds.

160. Local authorities should not automatically assume when problems arise that the solution is to discontinue self-directed support. If the local authority does decide to withdraw payments then it will first need to arrange the relevant services instead, unless the withdrawal was following a reassessment after which it concluded that the services were no longer needed.

161. Local authorities should continue self-directed support where a person enters hospital for a short period in order to allow PA contracts to remain in place. This is to ensure invaluable continuity of care once the person is able to return home, avoid repeating the costly and time consuming PA recruitment process and the need for interim care arrangements. Where local policy arrangements allow, this can also ensure that personal care can continue to be delivered in the temporary hospital setting.

162. There may be circumstances in which the local authority wishes to discontinue self-directed support temporarily. For example when a person enters hospital for a longer period, or because his or her condition improves. Similarly when a person is temporarily unable to manage self-directed support even with support, perhaps again due to

fluctuation in his or her condition or the support available. In these cases, the local authority will need to discuss with the person how best to manage. The aim should be to enable the person to resume responsibility for their own services after the interruption, if that remains their wish.

163. Clearly, wherever possible, any decision to discontinue should follow discussion with the individual and informal carer, and the local authority should, in any case, keep the individual informed throughout the process. The local authority may also need to keep in touch with the Independent Living Fund (ILF)⁴⁸ and share information where appropriate in cases where the individual is also receiving ILF funding.

164. The local authority should inform people as soon as possible if it is considering discontinuing self-directed support, and if appropriate give them an opportunity to demonstrate that they can continue to manage self-directed support. Local authorities should set a minimum period of notice, which will normally be given before self-directed support are discontinued, and include it in the information to be provided to people who are considering self-directed support, which could also usefully form part of the contract agreement.

165. It may be necessary in exceptional circumstances to discontinue self-directed support without giving notice. In considering this course of action, local authorities will first need to take account of the individual's contractual responsibilities with a service provider or an employee. They will also have to take into consideration any outstanding financial liabilities the individual may have. Local authorities should explain to people, before they begin on self-directed support, the circumstances in which it might be discontinued with no notice and discuss with them the implications this has for the arrangements that people might make.

166. The local authority might decide to take over the management of the person's arrangements in the interim. In considering whether it is practical, desirable and cost-effective to maintain the person's arrangements, the local authority should bear in mind any contracts into which the person has entered. An example is that the local authority will not be able to take over a contract with a service provider which is not registered with the Care Commission. Likewise it may not be practical for the local authority to take over the employment of a PA.

⁴⁸ <http://www.ilf.org.uk>

167. Where self-directed support is discontinued, some people may find themselves with ongoing contractual responsibilities or having to terminate contracts for services, including possibly making employees redundant. The local authority will wish to discuss this with people before they begin on self-directed support and agree how this would be handled.

168. Local authorities should also consider how to recover unspent individual budget if the recipient dies. For example, if someone wishes to pay an agency in advance for its services, the local authority should bear in mind that it may be difficult to recover money paid for services which were not in fact delivered. Local authorities should also consider that before their death the individual might have incurred liabilities, which should legitimately be paid for using the individual budget, for example, if they had received services for which payment had not been made at the time of death. There may also be occasions where additional funding is required to settle liabilities in full.

Local authority complaints procedures

169. Individuals on self-directed support who experience difficulties with the service their local authority is providing should in the first instance try to resolve matters with their care manager or **direct payments lead officer**. Local support organisations may have a role to play supporting users in clarifying the position and offering advocacy where this is possible.

170. In the event of informal discussions not resolving an issue, users can make use of their local authority's complaints procedure. People may make complaints about any action, decision or apparent failing of the local authority and individuals will have recourse through the Scottish Public Services Ombudsman (see **Annex C**) once all other avenues have been exhausted. They will not be able to use this route for complaints about services which they have secured from independent providers (including people they employ directly) using the individual budget. However, people should address any complaints that they may have about the services they purchase to the service providers themselves and take up complaints about their PAs with these employees. Alternatively, a complaint can be made to the Care Commission about any registered service or about the actions of the Care Commission itself. Support organisations such as the Independent Living Centres and SPAEN can provide information and advice about how to conduct any complaints (see **Annex C**).

Section 9: FINANCING SELF-DIRECTED SUPPORT

171. Financing self-directed support should be part of mainstream funding activity at local authority level. The key message is that over time the resources need to follow the policy of enabling more people to manage their own support.

172. Local authorities will require to establish specific plans and take-up targets to significantly increase the number of people on self-directed support year on year to meet projected demand. Local resource allocation models need to be developed to fund self-directed support using existing budgets, transferring funding to self-directed support from equivalent care services. The strategy for carrying this out should also be explicitly established and discussed with service providers and local support services to ensure transparency and enable them to plan future services.

173. Experience has shown that financial management of self-directed support is potentially easier where there are more flexible and user-focused approaches in all services through:

- budgets devolved to a local level
- higher levels of external **spot purchasing**/contracting
- a user focus to care planning and individualised service delivery, and
- established individual budgets.

Recommendations for longer term financial planning

174. Most of the funding for self-directed support will require to be found from existing budgets, and the ways to do this successfully will include:

(i) Incremental resource virement

175. On a year on year basis local authorities should organise their budgets so that a percentage of their existing budgets for traditional services can be moved to fund self-directed support. Systems need to be set up to change staffing establishments or reduce purchasing budget levels incrementally to enable **virement** of funding into the cost centres which finance self-directed support. The release of resources from home care, purchasing budgets and spot contracts needs to take account of the present and projected demand for self-directed support.

The strategy for achieving this should be explicitly established and discussed with service providers and local support services.

(ii) Broader service strategies for change

176. It is more difficult to release funding from buildings-based services, and services which are the subject of **block contracts**. Individual self-directed support packages may be difficult to fund from any one fixed service, so what is needed to finance self-directed support schemes is a planned change in the balance of funding, shifting a proportion of budgets from fixed services to more flexible purchasing budgets.

177. Buildings-based services and block contracted resources may require an overall re-provisioning strategy that might include targeting specific numbers or groups of service users. It will take account of the effect on care standards and unit costs. The potential to release finance incrementally from building-based resources will require finance managers to draw on the experience they have gained over the last 20 years in shifting the balance of care from institutional resources across wide areas of service. For example, partial leaseback from building-based services may provide an option for release of funds in some cases. There may be opportunity to use long-term care budgets where self-directed support is seen as a cost effective way to support people in their home environment and so keep some people who wish to avoid it, out of care home provision.

178. Block contracts give service providers valuable security in developing and managing resources, but this approach can also run contrary to an individualised approach to support. Whilst block contracts will remain an important feature of the care market, local authorities and providers need to review their block contracts and make adjustments within the spirit of the direct payments legislation. This includes block contracts for housing support under Supporting People funding.

Extra resources for self-directed support

179. Self-directed support is a means to individually purchase the support that would otherwise be arranged by the local authority, so it must be met from existing overall resources. However, in recognition of additional costs incurred whilst self-directed support schemes are developed in tandem to arranged services, the Scottish Executive allocated an additional £1.8 million expenditure during 2006 to Scottish

local authorities and £2 million annually thereafter to bring self-directed support fully into mainstream provision. This is to be used to fund:

- local support that where possible is independent and user-led
- self-assessment and care management training for individuals on self-directed support and their PAs, and
- a designated local authority lead officer to take forward local roll out of self-directed support, including training of local authority colleagues: care managers, area managers, finance managers, and directors of service.

Mainstreaming local authority funding of support organisations

180. Funding of local support should be part of mainstream financing activity at local authority level and is one indicator for assessing local authority performance under the Joint Performance Information and Assessment Framework (JPIAF)⁴⁹. The level of investment in a support system will partly depend on the type of service provided. It also needs to be proportionate to the expected number of people on self-directed support.

181. Local authorities are expected to fund essential training for users and PAs. To strongly encourage take-up of these training opportunities, local authorities should fund user training separately from the hourly rate for support, whether by ring-fencing funds per individual, or funding provided via the local support organisation. Individuals on self-directed support should understand and fulfil the training obligations placed on them. Such training should be accompanied by a voluntary code of practice established for individuals through partnership working with peer-led support organisations.

Long term best value and quality of life

182. Local authorities are required to operate within the principles of cost effectiveness and long-term best value. Both cost and effectiveness need to be assessed, and effectiveness needs to take account of the quality of life of the user in the short and longer term.

183. Research suggests that on average self-directed support packages are cost effective when compared to other forms of home or residential care if the full cost of each is taken into account, including administrative

⁴⁹ <http://www.scotland.gov.uk/Publications/2003/03/16630/19312>

and other general overheads that may require careful attention to provide a true cost⁵⁰. There may be start up costs for setting up a self-directed support package, especially if the person decides to employ their own staff, which may decrease once arrangements are in place. But even if this necessitates a slightly higher initial investment, there may be savings achieved in the longer term, such as diminishing the need to enter a care home.

184. Long-term benefits are not just about money. Financial prioritisation and local community care planning should recognise and place true value upon the independence and empowerment of service users, with care managers and support staff working in partnership with the individual so that they are able to take control of their support arrangements to the extent that they feel best suits them. This is in line with Social Work ethics, SSSC Codes of Practice and the International Federation of Social Work⁵¹. Those on self-directed support, their care managers, carers and other support staff, attest to the value it can add in terms of flexibility, choice, control and social inclusion. It delivers the means to live life in a more spontaneous manner. Equity and budget control may require some cost ceilings but judgements of long term best value should take account of individuals' quality of life and allowance be made for exceptional circumstances.

⁵⁰ Zarb and Nadash (1994) *Cashing in on Independence: Counting the costs and benefits of cash and services*. London: BCOOP; Hurtsfield, Parashar and Schofield (2007) *The costs and benefits of independent living*; Heywood and Turner (2007) *Better outcomes, lower costs. Implications for health and social care budgets of investment in housing adaptations, improvements and equipment: a review of the evidence. Executive summary*. Both Hurtsfield et al (2007) and Heywood et al (2007) available at <http://www.officefordisability.gov.uk/publications/>.

⁵¹ The International Federation of Social Work (IFSW) "recognises that social work...has universal application to meet human needs...and to develop human potential. Professional social workers are dedicated to service for the welfare and self-fulfilment of human beings...to the enhancement and improvement of the quality of life of people; and to the achievement of social justice". <http://www.ifsw.org/en/p38000002.html>

Section 10 MONITORING OF LOCAL AUTHORITY PERFORMANCE

185. There are two means by which the Executive monitors whether local authorities are carrying out their duty to offer self-directed support to eligible people, and provide the support and training that they need.

186. Firstly, local authorities are required to fill in the quarterly statistical return DP1 of key monitoring information. National statistics which use this return are published annually in September on the Scottish Executive website⁵². The survey asks for the value of packages and the number of clients on self-directed support, split by age, gender and client group. For the first time in 2005-06 it also asked about ethnicity, the contributors to the total care package, the weekly hours in the package, what the care is used for, and who delivers it for example whether by a service provider or a personal assistant (PA)⁵³.

187. Qualitative indicators are also needed to assess local authority performance and their ability to provide the information and support to individuals that they need. This monitoring takes place through the Local Improvement Targets (LITs) of the Joint Performance Information and Assessment Framework (JPIAF). In particular it is an expectation that local authorities provide local support and training, both for direct payments recipients and PAs, and local authority staff involved in financing and delivering care locally. Further information on LITs and associated national outcomes for community care can be found on the Scottish Executive Joint Future website⁵⁴.

⁵² <http://www.scotland.gov.uk/Publications/2006/09/25160444/1>

⁵³ <http://www.scotland.gov.uk/Topics/Statistics/17672/9462>

⁵⁴ <http://www.scotland.gov.uk/Topics/Health/care/JointFuture/LITS>

PART 3: GUIDANCE FOR SPECIFIC CLIENT GROUPS

Purpose of part 3

188. Part 3 of this guidance sets out good practice for equalising access to self-directed support for people from specific client groups. It is intended to support the efforts that all local authorities, Health Boards, and local support organisations will wish to make to ensure that self-directed support becomes routinely available to those from minority ethnic communities (section 11); those using children's services (section 12), people using mental health services (section 13), and older people aged 65 and over (section 14), and that statutory duties are met.

189. Local support services should also aim to expand their service to better meet the needs of various client groups. This may require dialogue and partnership work with representative groups, for example minority ethnic representatives, children's or older people's organisations, disability groups, and carer's representatives. They should expand their outreach so that the places where potential users routinely meet (for example, GPs, social networks) have the targeted information individuals might need.

Section 11: DIRECT PAYMENTS FOR MINORITY ETHNIC COMMUNITIES

190. This section should be read in conjunction with the general sections.

191. Because of its innovative potential, self-directed support could be one way of ensuring minority ethnic individuals and families have better access to community care services. Users' assessed needs, including language and specific cultural needs, could be appropriately met through individually tailored support.

Meeting local needs

192. Availability of appropriate services such as translators, trained care managers and service providers, targeted local support, and PAs will all be necessary for the shift to self-directed support to become a reality and for people to be meaningfully integrated into Scottish society. Like others, minority ethnic individuals may have needs that are not obvious. Translators can equalise access to support for minority ethnic elders and disabled people to overcome communication support needs.

193. Some local authorities are able to get external support organisations to access their in-house translator services. Where this is not feasible, local authorities are required to provide sufficient funds to external support organisations so that they can buy in this service.

194. Local support organisations have some success in targeting minority ethnic trainees for PA training courses. For example, older people may wish to spend their final years in the company of people with whom they most identify: their own faith communities, those who eat their traditional food and those who watch their own language television.

Mrs Khan has dementia and as her physical well-being was deteriorating rapidly, she required support for her personal care, and to help her be less disorientated and anxious. Whilst she is able to speak the language of her birth place, she does not speak or understand English. Her family felt that conventional social services were not appropriate for her as she would not be able to communicate her needs and wishes. So her daughter provided all of her support.

Through self-directed support Mrs Khan now pays a personal assistant who can speak her language for 25 hours a week of support and her daughter continues to provide additional support. This arrangement means that Mrs Khan has been able to build up a relationship with her PA and there is consistency in her daily life. Her PA knows her needs and can help her to go for walks with her new baby granddaughter, go swimming at her local pool and to go shopping for the food that she prefers to eat.

How to mainstream self-directed support for local minority ethnic users

195. Ensuring that there is adequate funding of targeted local support services is one of the key ways for local authorities to ensure that self-directed support is routinely available for minority ethnic individuals. This support will help local authorities to:

- promote self-directed support for minority ethnic users, as many people may only hear of self-directed support through word of mouth, may not be sure if they are eligible, or may not be aware of it at all. Awareness of locally funded support needs to reach the whole community and this can be achieved through, for example, outreach programmes
- provide targeted information, appropriate training and specialist support to meet minority ethnic users' needs, and
- train local authority care managers on race equality issues, and encourage a culture of open dialogue to enable more minority ethnic people to take up self-directed support.

Further information

196. The Department of Health in England has produced 'Breaking Barriers', a video or DVD on direct payments aimed at people from minority ethnic communities ⁵⁵.

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<http://www.dh.gov.uk/PolicyAndGuidance/OrganisationPolicy/FinanceAndPlanning/DirectPayments/fs/en>.

Section 12: SELF-DIRECTED SUPPORT FOR USERS OF CHILDREN'S SERVICES

197. This section should be read in conjunction with the general sections.

198. Existing guidance accompanying the 1995 Act on the integrated planning of children's services and recent publications such as *For Scotland's Children*⁵⁶ emphasise the importance of:

- promoting the upbringing of children and young people within their families so far as this is consistent with safeguarding and promoting their welfare
- giving children and young people the opportunity to become more independent in the future
- local authorities working in partnership with families
- recognising that children and young people are individuals with their own wishes and feelings
- listening to children and young people and taking into account their views
- actively involving children, young people and parents in assessments and decision-making, and
- having regard to issues of race, language, religion and culture.

199. Self-directed support should be available to parents of children and young people in need as, with appropriate support, it can offer the innovative practical solutions often sought amidst the logistical complexities of families' daily lives. It may be particularly valuable for those whose needs have been recognised as being less well served by available local authority services. Parents should be encouraged and supported to use self-directed support with a view to enabling their children and young people to access the same kinds of opportunities and activities as their non-disabled peers.

⁵⁶ <http://www.scotland.gov.uk/library3/education/fcsr-00.asp>

'Our family may only have the two of us but between us we have multiple physical disabilities and a moderate learning disability. A year ago we successfully applied to join the self-directed support scheme and now have a team of 3 support workers. Between them they provide a whole range of support as needed and when we need it. This can be everything from personal care, to companionship, fetching shopping, housework and even coming on holiday with us. It may be a couple of hours to take my son swimming or an overnight stay when I am in hospital. In fact we get double the value because every hour one of them spends helping my son is an hour's respite for me too. We also have a freelance care worker on standby for the odd time when the team can't help.

It's not always plain sailing. The whole process has been made much easier by the support of the local self-directed support agency. They keep us up to date, lend a listening ear, give advice and have been the ones to find the training opportunities for us. In fact I wouldn't recommend doing this without them.

It is worth it though. This family is now much healthier, happier and fulfilled than this time last year. I'm no longer the disabled person, the user or the carer – I'm just me and it's great.'

Eligibility, assessment and support

200. Local councils are required to provide families with information about the full range of services available to them, including the option of self-directed support. They should also have access to self-assessment support to enable them to work through what their needs are and how best to meet them.

201. An integrated assessment is undertaken under section 23 of the Children (Scotland) Act 1995 ('the 1995 Act') and is designed to establish the needs of the child in a holistic manner. To avoid any duplication, local authorities should ensure the assessment process is fully co-ordinated between adult and children's services and other relevant departments such as education.

202. Direct payments are available for children's services provided under section 22(1) of the 1995 Act (see **Annex B**). For this part of the 1995 Act, children are defined as aged under 16. Direct payments are

not for services under any other sections of that Act nor services provided by local authorities under the Education (Scotland) Act 1980. Young people aged 16 and 17 can use self-directed support to meet their assessed needs if they have the capacity to manage it with the necessary support, but if they do not have this capacity, their parents can access it on their behalf until they are aged 18, under the terms of the 2003 regulations.

203. Whatever decisions are made when the child reaches age 16 or 17, people with parental responsibility for a child may not continue using self-directed support to purchase services that meet the needs of that child once the child reaches the age of 18. As part of their preparation for transition to adult services at 18, young people will need to be made aware of how to use the 2000 Act to ensure legal continuity for parents/guardians to act on their behalf where they lack the capacity to make certain named welfare or financial decisions about their lives (see section 3).

204. Section 22(1) does not define the type of services and support which local authorities can deliver, but refers to providing a range and level of services to safeguard and promote the welfare of children in need. The definition of a child in need is very broad. It includes children under the age of 16 who have a disability themselves, those who are affected adversely by the disability of any other person in the family, or those children whose health or development may be impaired or below a reasonable standard without services from the local authority. While the focus of service provided under section 22 is to support the child, services may be provided to the wider family if those services help to safeguard or promote the welfare of the child. Families and children are likely to have a wide range of support needs and therefore the services required will need to include flexibility and choice to support each individual case.

205. Each local authority will need to assess individual cases and identify through consultation with parent/guardians and the young person what would be the most beneficial service, and whether this would be met through local authority services or through self-directed support. Self-directed support will not be suitable for all children in need. It is for care managers to decide whether such assignments would help or potentially add another stress at a particular time, for example when family dynamics may not be working well in basic areas.

206. The support purchased does not have to be the same as the service that would have been delivered by the local authority, so long as it meets the assessed needs. For example, a disabled child who might have attended local authority facilities may now choose to employ a personal assistant (PA).

207. Parents may choose to use self-directed support to employ a person or contract with a service provider or a combination of both. Local authorities should aim to identify and emphasise the potential for flexibility in any literature regarding self-directed support. If going the PA employer route, more than one PA is generally needed, for example to provide cover for holidays and sickness. Service providers may be used to provide emergency cover or to provide cover for a PA's holidays and sickness. They might also provide a local agency service, a residential short breaks unit, a sitter service, a placement at a day nursery or after school club or a local authority service (in their own or neighbouring authority). Self-directed support can also be used to purchase equipment needed by their child.

Disabled parent

208. Disabled people who are parents can use self-directed support for services available under section 22(1) of the 1995 Act to help with their parenting role. Their children are defined as children in need due to the disabilities of his or her parent(s). In addition, disabled parents can receive services to meet their own assessed needs under section 12 of the 1968 Act. This means that self-directed support can be used to meet the assessed needs of their family arising from the parent's disability. Although two pieces of legislation are involved it is important that the needs of the disabled person and their family are looked at in a joined up way. In the interest of the family and to avoid duplication, local authorities should ensure that the assessment process is streamlined and co-ordinated between adult and children's services and other equally relevant departments such as education.

209. Local authorities should work in partnership with families to provide services that will best meet the needs of the children within the context of the family situation. The provision of services that assist disabled parents who need practical help in bringing up their children is often the most effective means of promoting the welfare of their children. This applies equally in terms of self-directed support.

'Self-directed support has meant increased freedom and choices for both me and my eight year old daughter. Our social work home help service was unable to adapt to our needs and the times we needed support when I attended college. Self-directed support has enabled me to employ a person that we are both happy with, this person comes at a time that meets my needs and the needs of my family. The flexibility this provides means I am able to change the times my P.A. comes to our home so I no longer have to worry about my other commitments fitting in with someone else's timetable. This means both of us have a better quality of life and are able to be more spontaneous.' (Disabled parent, Edinburgh).

Involving children

210. It is essential that the views of children are part of the choices involved in self-directed support. *A Parent's Guide to Direct Payments*⁵⁷ emphasises the importance of children's views being taken into account when service options are being considered and choices made by parents. Depending on their ability, age and understanding, children should either accompany parents when they visit all the options for services or visit the top choices of service options that the parents make. Children's opinions need to be actively sought and their behaviour observed with the adults who will be supporting them. A few trial or observation visits may be needed to get their views.

211. Children should be given appropriate help to express their views and wishes and should have access to independent advocacy when appropriate. Local authorities will need to handle such issues sensitively in terms of the family situation where there may be parental conflict with the views of the child.

212. Parents may use self-directed support to purchase personal care services to meet the assessed needs of their disabled child. 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 their child's wishes when they have a cognitive impairment.

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<http://www.everychildmatters.gov.uk/socialcare/disabledchildren/directpaymentfaqs>

Parental consent

213. A parent or person who has parental responsibility for a child (aged under 16 years) may give consent to self-directed support to purchase the services the child or young person has been assessed as needing. Local authorities must be satisfied that the parent giving the consent will make arrangements that will best meet the child's needs. Social workers also have a duty under the 1995 Act to elicit, listen to and take into account the views of the children; increased weight is given to these views from the age of 12.

214. In the case of a 16 or 17 year old who requires services, the local authority must first seek consent from the young person, ensuring that he or she has the support required to help him or her make that decision. Where the young person is over the age of 16 but under the age of 18 and unable to give his or her consent, the persons having parental responsibility must consent on the young person's behalf before self-directed support can be used. Where the young person is over the age of 18 and unable to give his or her consent, a parent can only consent on the child's behalf if they are the appointed guardian or attorney.

People with parental responsibility for disabled children

215. Disabled children and their families may find it more arduous to access mainstream services, for example childcare, after school clubs and leisure activities. Sometimes by working with local authorities these difficulties may be overcome and children can access mainstream services. However, some families with disabled children may not consider the existing services provided or commissioned by their local authority appropriate for their child and think that they can make arrangements themselves which will be more beneficial. Self-directed support can be used for such arrangements.

216. Local authorities should work in partnership with parents in accordance with the Guidance accompanying the 1995 Act (see **Annex B**). In doing so they should carefully consider whether it would be appropriate for self-directed support where a child is subject to a Home Supervision Order or has been compulsorily removed from the home under child protection procedures. So long as the local authority is satisfied that the assessed needs of the disabled child and family will be met through the arrangements the parent is making using the self-directed support, the local authority does not arrange services.

However, local authorities retain their responsibilities under the 1995 Act to assess and, where appropriate, review the needs of disabled children and their families in the normal way.

Disabled 16 and 17 year olds in transition services

217. Parents often face challenges in supporting and preparing young people 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 young person's move towards independence. For any young person (with or without a disability) the process of growing up involves the gradual taking on of more and more responsibility for themselves.

218. The flexibility of self-directed support enables disabled 16 and 17 year olds to be more independent and have greater control over their lives. Parents may need support and sometimes encouragement to let their disabled child take risks in their everyday life. This may include allowing their 16 or 17 year old to manage their own support. The young person should be made aware that independent advocacy may be of help to them.

219. There may be situations where disabled young people will express their wish to manage self-directed support themselves but the local authority considers that they will not be able to do so in a way that will promote their welfare. This may be for a number of reasons, and may not be as straightforward as dealing with issues such as employment and accounts. The young person should receive the practical support that they need to enable them to manage the package, including assistance from parents, carers and local support services, for example with payrolling. They can also receive assistance from user controlled trusts or circles of support. Ultimately the local authority has a duty to ensure that the arrangements put in place with self-directed support (as with any service) will ensure the young person's safety and promote their welfare. Where this is not the case, the local authority should explain, in writing, to the person why self-directed support would be inappropriate.

220. A young person's ability to manage will depend on the size of the support package, and will also change as they mature. For example, a young person may be able to manage part of their support package using self-directed support but would not be able to manage the full

package. The ability to manage may change as the young person gains more experience. The local authority may want to make transitional arrangements whereby initially the young person manages only a small proportion of their support. This proportion could increase as the young person matures with the objective of full management of the support package at age 18. The client's needs may change greatly at this stage of their lives so packages require constant reviewing.

221. Young disabled people may receive assistance with managing self-directed support, just as any other individual 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. 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 age 16.

Childminders

222. There are two main restrictions on whom parents can employ to care for their child. Generally they cannot employ a close relative who lives in the same household as the child. If the child is being cared for by a person in that person's own home, then that person needs to be a registered childminder. This does not apply if the child is being looked after in their own home. Local authorities will be able to provide information about childminders in the area.

223. For non-residential short breaks away from home, (except in response to an overnight emergency) the childminder must apply for a condition to be added to their registration that states that the arrangements to provide overnight care are adequate. The registration certificate will also stipulate how many children may be cared for which is also important for insurance purposes⁵⁸.

Looked after status

224. Self-directed support can be used to purchase flexible short break options if the local authority is satisfied that the respite care bought will safeguard and promote the welfare of the child. The child does not become 'looked after' under the terms of section 25 of the 1995 Act if the

⁵⁸ <http://www.childminding.org/>

parent is in complete control of the respite arrangements⁵⁹. Paragraphs 78 to 80 give details of how much respite a person can receive in a 12 month period and examples of more flexible respite options such as a PA accompanying a disabled child on a family break.

Employing PAs

225. Local authorities must 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 person⁶⁰.

226. *A Parent's Guide to Direct Payments*⁶¹ emphasises the importance of the employee having a positive attitude towards disability in general and more specifically towards assisting the child to reach their full potential.

227. The parent's guide emphasises the importance of using references and checks and recommends that parents do not advertise and interview people on their own, but with help from local support services or friends, to ensure an objective approach.

228. Local authorities should ensure that: an enhanced disclosure check has been carried out where the intention is to employ a PA, even where the parents know the person well. It is of paramount importance that parents take up references for prospective employees.

229. If a local authority assesses a parent/guardian/young person as being able to manage their own employees, the choice of who that individual employs should be theirs. However, where local authorities are concerned about the suitability of a PA based on enhanced disclosure checks, and the person decides to go ahead and employ that PA, the appropriateness of the self-directed support may have to be reviewed.

⁵⁹ Children on self-directed support do not fall into the 'looked after' category under section 25 of the Children (Scotland) Act 1995.

⁶⁰ *Working Together to Safeguard Children: A Guide to inter-agency working to safeguard and promote the welfare of children* (Department of Health et al, 2006), paragraph 11.27 <http://www.everychildmatters.gov.uk/resources-and-practice/IG00060/>

⁶¹ <http://www.everychildmatters.gov.uk/socialcare/disabledchildren/directpaymentfaqs>

230. Prior to the PA starting work, parents need to make arrangements to train them to do the job. This is an essential part of the package that local authorities fund, and should include formal training that may be required such as tube feeding or lifting. As the employer, parents are responsible for a PA's health and safety and they may request a specific risk assessment be carried out in their home with their child.

'We have 3 children, Rachel aged 10 who attends the local primary school, Peter aged 8 and profoundly autistic (requires 2:1 care and is non verbal) attending specialist school on a Monday-Friday residential placement during school terms and David aged 6 who is severely autistic and attends a local primary school with full time 1:1 support. Peter and David have to be kept apart at all times as their autism does not allow them to share the same spaces.

We attended a PECS (Picture Exchange Communication System) course to help Peter communicate his needs as he was becoming increasingly frustrated being unable to do so. This difficulty was also frustrating for us as parents. After the course it took a couple of hours to teach the picture exchange concept to Peter and through self-directed support we have been able to keep this method of communication.

Self-directed support gives us control and flexibility to use the hours when we need them most. We have handpicked our PAs who are all highly trained in autism. They are very reliable, non judgemental and have very good relationships with all three of our children. They are excellent role models. In conclusion, self-directed support is a wonderful tool' (Parent of two sons on the autism spectrum).

How to mainstream self-directed support for children and their parents

231. Ensuring that there is adequate funding of local support services is the key for local authorities to ensure that self-directed support is routinely available for children and young people through their families. This support will help local authorities:

- promote self-directed support for children and young people
- ensure the families of disabled children and young people have access to self-directed support information targeted to their needs
- provide specialist support targeted to children's and young people's needs, for example an advocate or support worker may be needed with specialist skills, and

- train local authority care managers, and encourage a culture of positive risk taking to enable more children and young people to benefit from self-directed support if it meets their needs.

Further information

232. A Parent's Guide to Direct Payments published by the Department of Health ⁶².

⁶² This guide is very useful for its general approach, but references to legislation and regulations all relate to the laws of England and Wales. Self-directed support in Scotland operates under legislation specific to Scotland which is covered in detail in **Annex B**.

Section 13: SELF-DIRECTED SUPPORT FOR USERS OF MENTAL HEALTH SERVICES

233. This section should be read in conjunction with the general sections.

234. Self-directed support accords well with the new duties under sections 25-31 of the Mental Health (Care and Treatment) (Scotland) Act 2003 and its ethos of promoting social inclusion. Self-directed support used imaginatively can lead to a positive impact on mental health and reduce the need for crisis services or emergency admissions to hospital. It can also help reduce the amount of time spent in hospital if there is the support in place at home to enable the individual to return sooner. And it can help increase confidence, self-esteem, assertiveness, independence, participation in mainstream activities, as well as increasing an individual's sense of purpose and optimism. Self-directed support can help equalise access to the local community so that individuals can be integrated into Scottish society.

235. As a general principle, local councils should aim to encourage choice by enabling people to address their own needs as they consider best, whilst satisfying themselves that the agreed care plan outcomes are being achieved. This may be a particularly significant change of emphasis for mental health service users who may now be able to access a mixture of health and social care activities in the community.

236. Current thinking encourages people to live as full a life as they are able and to pursue a journey of recovery. This whole system recovery approach is about looking both within and beyond mental health service provision at the whole range of opportunities and support that a person with mental health needs might utilise to enable them to live their life as they wish. It is an approach that is vital to the effective development of mental health services, and one that is promoted by the use of self-directed support. It is about practitioners making the shift from assessing whether someone requires an arranged service, to assessing what their needs are to aid their recovery, perhaps assisting them to participate in a community activity.

'...If I am having a bad day I can alter days or times – that takes away the pressure of a set commitment. In return I am also flexible with her (employee) where necessary, so it works very well. Looking back over the last 18 months of being on this scheme, I feel I have come a long way from the isolation and depression. But the most important part of it all is that direct payments staff are always just a phone call away. I feel this is a vital part of the success of the scheme.'

Eligibility, assessment and support

237. Local authorities, community health partnerships⁶³ and non-statutory providers of mental health services and support must ensure that self-directed support becomes routinely available to those eligible people who use mental health services. Self-directed support may also be particularly valuable for those whose needs have been recognised as being less well served by collective provision or are less likely to access arranged services. **Annex B** lists those currently unable to receive direct payments under the Mental Health (Care and Treatment) (Scotland) Act 2003.

238. Self-directed support may include support for the person's mental health problems, such as support with a relapse prevention plan. It might be used for support at such times as evenings or weekends when mental health services can be more difficult to access. It can also be used to provide support for those with fluctuating conditions when the individual's support needs may vary and they may sometimes need more assistance than at other times.

239. Self-directed support will usually be used to provide an alternative to attending day centres or day hospitals. Subject to local circumstances, self-directed support might be there to enable an individual to go to mainstream computer, art or music lessons, join a fishing club or be supported to become a volunteer helping others. The service user might be assessed as needing a support worker to help them attend exercise classes at a local gym, or go swimming, instead of attending relaxation classes at a day centre.

240. Local circumstances will affect what is available to service users according to their assessed needs. Individuals might be assessed as needing day or night support workers, respite breaks, talking and

⁶³ <http://www.sehd.scot.nhs.uk/chp/>

complementary therapies, or training and career guidance if they are assessed as needing this to go to work. PAs may provide the support that enables someone to go back to work. All of these are uses of self-directed support which fall outside of the description of services in most peoples' understanding, but which have proved to be effective in meeting assessed needs. It may be there to provide social aspects of recovery, such as helping an individual do more with friends, family and the local community if this is what they are assessed as needing, and this is what they want to do. It is important to emphasise that although some individuals may require PAs to support their access to occasional leisure activities as part of their recovery, the user must fund the actual activities themselves, for example going to the cinema.

241. Mental health partnerships need to share an understanding of and commitment to the goals of recovery and independent living. Many already apply a whole systems approach to funding, enabling more flexible contracting arrangements, and training and other support to be provided by all partners. Increased expenditure by local authorities on self-directed support can be accommodated by changes in the balance of funding from health partners. There needs to be agreement over joint eligibility criteria to receive both health and social care services.

242. There also needs to be a local joint strategy for the implementation of self-directed support within mental health services that has fully involved users in its design. The strategy should include: joint training; shared language and straight forward systems; recognition that some needs can be met through either health or social care or a combination; provision of targeted support for individuals; guidance to mental health staff; and information to service users. For example, community psychiatric nurses (CPNs) should feel confident that they are able to assess someone for self-directed support.

Meeting local needs

243. Local support services should be funded by joint mental health services (joint health and local authority teams), to work in partnership with mental health support organisations so that they may better accommodate these service users. This may be particularly challenging if local users are not accessing traditional community care services in the first place, or in contact with their council for other services, but instead are used to receiving services from the NHS.

244. Local support needs to be funded so that mental health service users are able to access the direct payment services offered to other eligible people. In addition to these however, there is a need to recognise and respond to the specific needs of mental health service users. For example, individuals may not have experience of user-led assessments. Where there are fluctuating needs, care will be needed to estimate how long a PA should be available to offer emotional support during periods of increased stress. Support in managing the package may be needed if someone is becoming suspicious or paranoid or is becoming very withdrawn, or if they need admission to hospital for non-psychiatric illness. People with mental health support needs may be stigmatised or thought of as dangerous so extra support may be needed during recruitment.

Lucy is a young woman with an enduring mental health condition who needs constant supervision as she hears voices and needs support to focus on activities and keep herself safe. For example, she needs assistance in using kitchen equipment, remembering to lock the house and crossing the road.

Lucy decided to become a PA employer with the support of her parents, and the local support service which provides her with a payroll service and help with recruitment. She employs a team of six carers who are close in age to herself. She uses her 64 hours per week of support at a local kennels where she works, and to attend her fitness classes, shopping, going to the cinema, and other interests she pursues. Although her hours are mainly fixed Monday to Friday, Lucy uses an allowance of floating hours to go to specific events such as concerts, or have days away occasionally.

How to mainstream self-directed support for mental health service users.

245. Ensuring that there is adequate funding of local support services is the key for local authorities and health boards to ensure that self-directed support is routinely available for users of mental health services. This support will help local authorities:

- promote self-directed support for mental health service users
- provide targeted information, for example, where readers are not able to concentrate for long periods or take in much in one go

- provide general advice on self-directed support as well as specialist mental health advice. For example, a specialist advocate or support worker may be needed for self-assessment and to prepare for the assessment process, care planning and care management
- provide training for council and health staff and users, include self-assessment training, **advance statements** and the use of crisis plans with particular attention to the use of third party support at times of crisis as a means of managing risk⁶⁴
- encourage imaginative use of self-directed support for individual users, perhaps introducing it as a small part of an overall package so that individuals and the professionals supporting them have a chance to try it out. Where individuals choose to do so, to develop partnerships between users, such that together they might be able to purchase training or education to assist their development (e.g. IT, graphic design, and drama)
- encourage self-directed support as part of a culture of positive risk taking, enabling people to take first steps where previously they had encountered wariness or alarm associated with potential relapse. Health and social care professionals need a can-do attitude for promoting self-directed support that is about recognising individuals' potential and wanting them to succeed, and about managing rather than eliminating risk, and
- provide flexible funding to meet anticipated variable demand for self-directed support as part of a recovery plan.

Further information

246. Direct Payments for People with Mental Health Problems, A Guide to Action (Department of Health February 2006)⁶⁵.

⁶⁴ *Direct Payment for Mental Health Users/Survivors a Guide to Some Key Issues.* NCIL (2001)

⁶⁵ *A Guide to Action* is very useful for its general approach, but references to legislation and regulations all relate to England and Wales. Self directed support in Scotland operates under legislation specific to Scotland which are covered in detail in **Annex B**.

Section 14: SELF-DIRECTED SUPPORT FOR OLDER PEOPLE

247. This section should be read in conjunction with the general sections.

248. All older people aged 65 and over are eligible for self-directed support to meet their assessed personal care needs if they are living at home. This is their entitlement as part of the free personal and nursing care (FPNC) available to people aged over 65 years in Scotland⁶⁶.

249. Older people may choose to have some services delivered by their local authority, and others via self-directed support. Some may wish to introduce self-directed support to their package gradually to enable them to gain confidence in their ability to manage them. Currently, very few people accessing FPNC do so via self-directed support, but as local experience and support builds, numbers are expected to significantly increase. Self-directed support can help equalise access to the local community so that individuals can be more meaningfully integrated into Scottish society. Local authorities need to ensure that self-directed support options are routinely available for older people, as with any other eligible client group. Information and training is an essential part of this process, see section 6, and older people can expect to be given details of local people who can support them to consider and use self-directed support. Local authorities should also fund self-assessment work so that people can work out what their needs are and how best to meet them.

‘...I am so very grateful for self-directed support. I don’t know what I would do without it now, it’s such a great help’.... (Older person with physical disabilities, also caring for husband with dementia)

Eligibility, assessment and care

250. The services older people may be assessed as needing are anything from podiatry to equipment, to home support services or community psychiatric nursing. For example, older people or those with disabilities may experience mental health problems such as depression. The causes may range from declining health, mobility and general activity to financial problems or feelings of social isolation. Lack of friendships and support or mourning the death of partners is not uncommon, nor is the uncertainty about the future created by periods of hospital care and even delayed discharge from hospital. Older people

⁶⁶ <http://www.scotland.gov.uk/Topics/Health/care/17655>

with learning disabilities or dementia may have more complex needs but should not be seen as different from older people generally, and they should have the same access to mainstream health and social care support.

251. Flexibility, choice and control over how their assessed care needs are met is a right of older people as much as any other eligible care groups. Older people can expect to be given the maximum possible informed choice and control over how their assessed needs are met including using self-directed support to meet some or all of their needs. Self-directed support is one option to enable people to maintain their independence and individual quality of life and should be offered to older people who are eligible at every assessment and review.

252. Once self-directed support packages are being properly managed with the necessary support, they may also bring increased security for some individuals wishing to avoid going into a care home.

253. The nursing care element of Free Personal and Nursing Care is not available as part of a self-directed support package unless it is for continuing health care needs. This means those primary care tasks carried out at the person's home that do not require to be carried out by a qualified health professional, for example routine aspects of diabetes and epilepsy care (see section 4). Arrangements need to be put in place across Scotland to encourage self-directed health care at home as part of a wider package to support independent living. Integrating care and health through joint management and funding should lead to more responsive relationships between users and service providers.

'When I became ill, at first I needed care and companionship for most of the day. The self-directed support system allowed me to choose a personal assistant from my own village community. This gave me a lot of confidence. As a result, my husband was able to continue work for two years, until his recent retirement.' (Older lady with physical disabilities).

Employing PAs

254. Whilst use of service providers may best suit many older people, others may prefer to employ their own staff. This may be because some people already pay people for support on a casual basis by using their own money. If they decide to accept FPNC funding using self-directed

support, they will have to adopt transparent book-keeping systems and take on the responsibilities of being a PA employer.

Mr Scott lives in a rural area and went onto self-directed support 2 years ago because this better met his assessed needs. He has a care package of 30 hours per week, 17 hours of which is free personal care. He has contracts with five self employed personal assistants and is delighted with the care he receives, emphasising the importance of relationship building between himself and his PAs in order to achieve this. Mr Scott's PAs also offer additional basic health care support.

Meeting local needs

255. Local support organisations will need to work collaboratively with older people's organisations to better accommodate older people's support needs. For example, older people take pride in retaining their independence and may be reluctant to accept help. Services will need to train staff to respond sensitively to individual's concerns.

Consent and capacity issues

256. Older people, as with other eligible groups, need to consent to self-directed support if the local authority assesses them capable of managing them with the necessary support. Section 3 offers guidance on consent and capacity issues. For those lacking capacity, consent may be given by guardians and attorneys authorised to do so under the Adults with Incapacity (Scotland) Act 2000 ('The 2000 Act').

Cost ceilings

257. Whilst it is clear that local authorities must operate within budget, the total amount of funding received within the support package needs to be sufficient to meet the older person's assessed needs. The aim is to tailor a package that allows users flexibility, choice and control over how their assessed needs are met.

How to mainstream self-directed support for older people

258. Local authorities need to ensure that funding of local support services is sufficient to deliver the level and type of support that older people need to self-directed support. This support will help local authorities to:

- promote self-directed support for older service users aged 65 and over
- ensure older users and potential users have access to information targeted to their needs
- offer older users self-assessment and other support to help prepare for the assessment process
- provide specialist support targeted to older people's needs, for example an advocate or support worker may be needed with specialist skills, and
- train local authority care managers, and encourage a culture of positive risk taking to enable older people to benefit from self-directed support if it meets their needs.

Further information

259. For further information contact the Scottish Helpline for Older People (SHOP), see **Annex C**.

ANNEX A

GLOSSARY

active citizens

People accessing support for social care, education, employment and other aspects of their lives should not be thought of as dependent and vulnerable. Instead they should have choice and control over the support that helps to increase their independence, and enables them to engage and participate in their communities as active citizens.

advance directives

A plan that people can make for the times when they may/will experience mental health difficulties. The plan may set out what they wish their personal assistants (and others involved in their care) to do to best support them or even to manage their affairs.

advance statement

Unlike an advance directive, this term has a specific legal meaning under the Mental Health (Care and Treatment) (Scotland) Act 2003 and so is rarely used in a self-directed support context. It is a statement made by someone, when well, about the care and treatment that they would like to receive when severely unwell and subject to compulsory powers under the Act. It requires to be witnessed and if overruled this action must be notified to the Mental Welfare Commission and will be reviewed by them.

advocate/advocacy

(see also 'independent advocacy' and 'self-advocacy').

Advocacy is when a person or a group of people speak up for themselves or others. It is about supporting and sometimes representing people's needs, opinions and choices. It is also about offering support for another person or a group of people, who are unable to represent their own interests, in a variety of situations. Advocacy can help people become more aware of their own rights. It can help people to exercise those rights and be involved in, and influence decisions that are being made about their future.

assessed needs

(see also 'assessment' and 'care plan').

These are agreed during the assessment process and the ways they are to be addressed are noted in the care plan. These are the needs a local authority identifies a person as having, and which they have a duty to

meet with the provision of support and/or services. This may mean providing support so that a person can be supported to live independently and safely at home if that is their wish.

assessment

This is a partnership process by which the health and social care department of a local authority and/or health authority works with an individual to identify their support needs to meet their personal and social care requirements. The individual may also be supported by a family member, carer, representative from a local direct payments support organisation (if required), and/or an advocate, and relevant professionals.

attorney

(see also 'guardian').

A legal term for someone authorised under the Adults with Incapacity (Scotland) Act 2000 to act on a person's behalf where they have lost the ability to make certain decisions in their life without this support. The attorney is authorised by the person to undertake certain financial or welfare matters in advance of this loss, perhaps as a result of reduced capacity due to dementia.

block contracts

Block contracts are where a service is bought for many individuals.

care plan

A document detailing how an individual's assessed care and support needs are to be met. This is drawn up following the assessment process by the local/health authority working in partnership with the individual.

carer

An informal carer is a person of any age who provides, or intends to provide, care on a regular and substantial basis, as defined in section 12AA of the Social Work Scotland Act 1968 and section 24 of the Children (Scotland) Act 1995. That is, carers of any age caring (or intending to care for) adults or children.

Changing Lives

Scotland's Changing Lives⁶⁷ agenda reinforces the need for direct payments as a tool to achieve independent living by means of self-directing their own support. This is part of new social work strategies that recognise that personalised and individualised support services should be arranged around the person.

circle of support

A group of people who meet at intervals to help an individual accomplish their personal goals in life. Its members are people who have a strong commitment to that individual.

close relative

Someone related to the direct payments 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, sister or the spouse or partner of any of the foregoing.

consent

The legal agreement to a choice or action freely made by an individual without coercion, as well as acceptance of the responsibilities associated with that choice or action. Legally, the individual must be 'mentally capable' of giving consent before it is valid.

control

To have autonomy and power over your own life and what happens to you, regardless of how much support is needed to put your choices into action.

direct payments

A term used interchangeably with self-directed support and appearing in legislation (see **Annex B**). The definition is historical and focused on a system of delivery rather than the flexible independence outcomes that individuals can achieve when they choose and control their lives. Self-directed support is for people who have been assessed as needing help from health and social care services, and who would like to arrange for

⁶⁷ The Scottish Executive published the Changing Lives report in February 2006 which followed an independent review of Scottish social care. There is an expectation that organisations seek innovative approaches to ensure that individuals and communities get the personalised support that is right for them. It also states that people who use services and their family carers, will have more control over the services they are getting. Publications and information on the implementation of Changing Lives can be found at www.socialworkscotland.org.uk.

their own care and support instead of receiving them directly from the local authority. A person must be able to give their consent to be on self-directed support and be able to manage it even if they need help to do this on a day-to-day basis.

disability

The loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical, attitudinal and social barriers that exist in society.

employer's indemnity

Protection or security against damage or loss. This will indemnify the employer in respect of any claims by an employee, relating to the contract/terms and conditions of employment. Indemnity insurance of the type offered by organisations such as SPAEN supports employers to deal with personnel issues and is optional. For example, it can provide the legal costs incurred in the case of defending employment tribunal proceedings, as well as any compensation awarded at employment tribunals in cases of unfair dismissal.

employer's liability insurance

Employer's liability insurance is mandatory. It is cover for bodily harm/disease sustained by employees in the course of employment. It does not cover personnel issues. Note that this differs from Public Liability Insurance (which is cover for any damages that a member of the public may be awarded as a result of injury or damage to them or their property caused by a business).

Free Personal and Nursing Care (FPNC)

This is the support available without charge for everyone in Scotland aged 65 and over who needs it, whether at home, in hospital or in a care home.

guardian

(see 'attorney').

For an adult aged 16+, this is a legal term for someone authorised under the Adults with Incapacity (Scotland) Act 2000 to act on a person's behalf where they are unable to make certain specified decisions in their life about financial or welfare matters. Guardians are appointed by Sheriffs.

For a child aged under 16, a guardian is someone appointed by a parent, or where necessary the sheriff, to take over parents'

responsibilities and rights after a parent dies or when a parent is unable to care for the child⁶⁸. The guardian's role applies until the child is 18.

impairment

The loss or limitation of physical, mental or sensory function on a long-term or permanent basis.

independent advocacy

(see 'advocate/advocacy' and 'self-advocate').

Independent advocacy is carried out by individuals and organisations who are completely separate from those organisations providing services to the person. Independent advocates act only according to the wishes of the person being advocated for.

independent living

The Independent Living Movement has formed a philosophy, which emphasises disabled people's rights as citizens rather than recipients of care. The meaning of independence has been redefined in terms of being able to achieve personal goals, by exerting choice (over where to live, how to live and who provides assistance), and control (over who assists, how, when and what they do). The term of personal assistance was chosen to reflect these aspirations and counteract dominant understandings of care. Self-directed support is a crucial means for Independent Living.

Independent Living is to "...ensure that disabled people of all ages have the same freedom, choice, dignity and control as other citizens at home, at work and in the community. It does not mean living by yourself or fending for yourself. It means rights to practical assistance and support to participate in society and live an ordinary life." (Disability Rights Commission – Independent Living Bill, June 2006)

Independent Living Trust

(see 'user-controlled trust').

An Independent Living Trust or user-controlled trust is an obligation binding a trustee to deal with property or money in a particular way, for the benefit of one or more beneficiaries. The Trust is witnessed, and registered with the Inland Revenue. The trust ensures the individual remains the focal point of any decision making regarding their care.

⁶⁸ See section 7 of the Children (Scotland) Act 1995.

individual budget (IB)

If a person decides to try self-directed support, their care manager can arrange for the allocation of a budget which is sometimes called an individual budget (IB) because it is for the person's sole use to arrange for their support needs. Their care manager brokers this budget and will make clear what they can spend money on. The individual will also need to show the council that the support they want to buy meets their assessed needs, and must have a separate bank account for their individual budget.

lead officer/ local authority self-directed support lead officer

Usually positioned within the social work department of a local authority, these people are responsible for the delivery of self-directed support. One of the new expectations of this guidance is that each local authority will fund a dedicated 'direct payments lead officer' whose role will be to:

- increase uptake of self-directed support
- develop local support organisations
- develop training for the employers of personal assistants, and
- develop training for people who are interested in becoming personal assistants.

local support organisations

(see 'local support services').

local support services

Local support services offer direct payments support, advice and training to service users, their family and carers, local authority staff, service providers and PAs. They are ideally independent support organisations by and for disabled people located within the voluntary sector. These organisations are underpinned by the belief that disabled people are best placed to offer support and advice to other disabled people, based on a shared experience and commonality of living life as a disabled person. This is recognised as peer support. In some local authorities this has not yet proved possible and an in-house support service is provided to help people with self directed care.

mixed package

Self-directed support plus an arranged social care service from the council.

parental responsibility

To safeguard and promote the child's health, development and welfare, provide direction and guidance and act as the child's legal representative as defined in the Children (Scotland) Act 1995.

peer support

(see 'local support services').

personal assistant (PA)

A support worker employed by an individual using direct payments.

Pips Partnership in Practice (PiP) agreements

These are a recommendation from the *Same as you?* initiative to improve support and services for people with learning disabilities so that they can live more independent lives. They are local partnership agreements between local authorities, the local NHS and other partners describing how they plan to implement the *Same as you?* guidelines. They are written for every area of Scotland.

<http://www.scotland.gov.uk/Topics/Health/care/VAUnit/PIPAgreements>

recipient

A person who receives direct payments (as used in this guidance).

recovery

A term used in this guidance in a mental health context. This is where a person is getting over a period of experiencing mental health difficulties, or learning to live with an enduring mental illness, so that they can have as meaningful and satisfying life as they are able, as defined by each person, in the presence or absence of symptoms. It is important to be clear that there is no right or wrong way to recover, and the result may or may not be a complete cure. It is about the person having control over and input into their own life instead of simply receiving medical or other treatment. Each individual's recovery, like his or her experience of mental health difficulties, is a unique and deeply personal process.

respite

Short break which is to act as a positive experience for the person with support needs and the carer, where there is one. The term includes a wide range of different services of limited duration. The common factor is not what service is provided, but its purpose. Respite can be offered in a wide variety of settings, including breaks in residential homes, respite-only units (e.g. specialist guest houses), breaks in the home of

another individual or family who have been specially recruited, breaks at home through a support worker or sitting service, or holiday type breaks.

self-advocacy

(see 'advocate / advocacy' and 'independent advocacy').

Where people are supported to be able to promote their needs and wishes for themselves.

self-directed support

This is when an individual wishes to have the choice and control over the way in which their care/personal needs are met, with whatever support they need to do this. Direct Payments are a form of self-directed support and are part of the personalisation agenda within the Changing Lives policy agenda (see Changing Lives) which encourages service users to gain more control of the services available to support them. As part of Changing Lives, the 'In Control' approach and/or Individual Budgets (IBs) are being introduced in some parts of Scotland. Their aim is to allow people who require 'support to manage' their own care package and enable them to utilise such tools as a Direct Payment.

service user

A person who uses a service (as used in this guidance).

Single Shared Assessment (SSA)

This is where a person is assessed by one or more professionals for all their care, support and continuing health needs that they may have and which may entitle them to support from their local or health authority, but it is brought together in a single comprehensive document.

social model of disability

People with impairments are disabled by the fact that they are excluded from participation within the mainstream of society as a result of physical, environmental and attitudinal barriers which prevent them from gaining equal access to education, employment, information, housing, public transport, leisure opportunities, and so on.

It encourages the view that people accessing support for aspects of their lives are not to be perceived as dependent and vulnerable. Instead they should be offered choice and control over support that helps to increase their independence, and enables them to engage and participate in their communities as active citizens.

Using the social model, disability is no longer seen as an individual problem but it becomes a social issue. Disability emerges within a society which is organised to meet the needs of the majority of people who do not have significant impairments and which treats differently the needs of people who do.

spot purchasing

Spot purchasing is where an individualised service is bought for one individual.

support organisation

(see 'local support services').

user

A person who uses services (as used in this guidance).

user-controlled trust

(see 'Independent Living Trust').

A user-controlled trust or Independent Living Trust is an obligation binding a trustee to deal with property or money in a particular way, for the benefit of one or more beneficiaries. The Trust is witnessed, and registered with the Inland Revenue. The trust ensures the individual remains the focal point of any decision making regarding their care.

virement

A technical term used by finance managers that means a regulated transfer or re-allocation of money from one account to another, especially with regard to public funds.

LEGISLATIVE CONTEXT

Note that self-directed support is termed **direct payments** in statute. The definition is historical and focused on a system of delivery rather than the flexible independence outcomes that individuals can achieve when they choose and control support to meet their assessed needs.

1. Introduction

The legislation that enables self-directed support is contained within:

- **The Social Work (Scotland) Act 1968**
guidance on the sections relating to direct payments can be found at:
<http://www.scotland.gov.uk/Publications/2003/03/16777/20192>
- **The Community Care (Direct Payments) Act 1996**
<http://www.opsi.gov.uk/acts/acts1996/1996030.htm>
- **Regulation of Care (Scotland) Act 2001**
<http://www.opsi.gov.uk/legislation/scotland/acts2001/20010008.htm>
- **Community Care and Health (Scotland) Act 2002**
<http://www.opsi.gov.uk/legislation/scotland/acts2002/20020005.htm>
- **The Community Care (Direct Payments) (Scotland) Regulations 2003 (SSI 2003 No. 243)**
<http://www.opsi.gov.uk/legislation/scotland/ssi2003/20030243.htm>
- **The Community Care (Direct Payments) (Scotland) Amendment Regulations 2005 (SSI 2005 No. 114)**
<http://www.opsi.gov.uk/legislation/scotland/ssi2005/20050114.htm>

- **The Mental Health (Care and Treatment) (Scotland) Act 2003 (Modification of Subordinate Legislation) Order 2005 (SSI 2005 No. 445)**
http://www.opsi.gov.uk/legislation/scotland/ssi2005/ssi_20050445_en.pdf
- **The Disability Equality Duty (DED)**
www.drc-gb.org/disabilityequalityduty/
- **National Health Service Reform (Scotland) Act 2004 (asp 7)**
<http://www.opsi.gov.uk/legislation/scotland/acts2004/20040007.htm>

The Community Care (Direct Payments) Act 1996 ('the 1996 Act') inserts sections 12B and 12C into the Social Work (Scotland) Act 1968 ('the 1968 Act'). These sections are further amended by section 70 of the Regulation of Care (Scotland) Act 2001 ('the 2001 Act') and section 7 of the Community Care and Health (Scotland) Act 2002 ('the 2002 Act'). They now place a duty on local authorities, to offer direct payments to people other than those not eligible as specified in regulations made under section 12B, enabling them to arrange and purchase the community care or children's services they have been assessed as needing.

2. The Social Work (Scotland) Act 1968

Sections 12B and 12C of the 1968 Act place a duty on local authorities to make direct payments available to certain adults and children who wish to receive them. This includes disabled people.

Direct payments are an alternative to local authority arranged community care and children's services and therefore need only be offered at the point where the local authority would normally have agreed to provide the services. They must not put people who choose to receive local authority services at a disadvantage.

3. Which services direct payments can be used for

Direct payments may only be offered to eligible adults who under section 12A of the 1968 Act, have been assessed as needing community care services. They can be used to purchase all community care services and support except long term residential accommodation. For

the purposes of the direct payments legislation 'community care' services are defined by section 5A of the 1968 Act as '...services, which a local authority are under a duty or have a power to provide, or to secure the provision of, under Part II of the Act or section 25 (provision of care and support services for persons who have or have had a mental disorder), 26 (provision of services designed to promote well-being and social development of such persons) or 27 (assistance with travel in connection with such services) of the Mental Health Care and Treatment (Scotland) Act 2003. This definition includes housing support services and equipment and temporary adaptations. Since December 2001 direct payments have also been available for services for children in need provided under section 22(1) of the Children (Scotland) Act 1995 ('the 1995 Act')⁶⁹. Part 2 of the 2002 Act allows delivery of health services and some continuing health needs by direct payments if the local authority and NHS Board have arrangements to allow this to happen. The choice of support people can use to meet their assessed needs is covered at sections 4 and 5.

4. Who can receive direct payments?

Those eligible to receive direct payments are certain persons, including older people aged 65 and over who are assessed as in need of services, who are capable of managing direct payments, with or without assistance. However, before receiving direct payments the person requiring the service must give his or her consent. Where a person is over 18 and clearly unable to give consent, or is under the age of 18, Regulation 3 of The Community Care (Direct Payments) (Scotland) Regulations 2003 ('the 2003 Regulations') specifies certain categories of people who are able to give consent on behalf of the service user, namely those with parental responsibility, attorneys and guardians who have powers to manage direct payments on the user's behalf.

The 2003 Regulations define a 'person in need' by referring to the definition in Section 94(1) (b) of the 1968 Act. This might include people (adults or children) with any kind of disability (see below). The following groups of people are eligible to receive direct payments:

- Disabled adults to purchase community care services
- Disabled people aged 16 and 17 to purchase children's services

⁶⁹ http://www.opsi.gov.uk/acts/acts1995/Ukpga_19950036_en_1.htm

- Disabled people with parental responsibility to purchase the children's services their children have been assessed as needing
- Parents and people with parental responsibility for a disabled child to purchase the services the disabled child has been assessed as needing
- Children in need
- Disabled adults and 16 and 17 year olds to purchase housing support services
- Older people aged 65 years and over who are assessed as needing community care services due to infirmity or age, and
- Attorneys and guardians, with the relevant powers can receive direct payments on behalf of people who are unable to give consent to arranging their own services.

Those community care service users aged 65 or over who are accessing Free Personal and Nursing Care can arrange for the personal care element of the package to be made as a direct payment. (More information is available in section 14).

5. Who cannot receive direct payments?

Not everyone who is eligible for community care or children's services will be eligible for direct payments. The 2003 Regulations, (made under Section 12B (1) (b) of the 1968 Act) specify that direct payments may not be offered to certain people who are restricted by certain mental health or criminal justice legislation. People in these groups are required to receive specific community care services. Offering them direct payments in lieu of those services would not give a sufficient guarantee that the person would receive the services required. Further details of restrictions are given in Regulation 45(13) of the Mental Health (Care and Treatment) (Scotland) Act 2003 (Modification of Subordinate Legislation) Order 2005 (SSI 2005 no. 445) which amends regulation 2 of the 2003 Regulations.

The categories are:

- Persons subject to a compulsory treatment order under the Mental Health (Care and Treatment) (Scotland) Act 2003 where a certificate has been granted suspending the measure authorising detention

- Persons subject to a compulsion order under the Criminal Procedure (Scotland) Act 1995 where a certificate has been granted suspending the measure authorising detention
- Persons subject to an emergency detention certificate granted under the Mental Health (Care and Treatment) (Scotland) Act 2003 where a certificate has been granted suspending the measure authorising detention
- Persons subject to a short term detention certificate granted under the Mental Health (Care and Treatment) (Scotland) Act 2003 where a certificate has been granted suspending the measure authorising detention, and
- Persons subject to a compulsion order under the Criminal Procedure (Scotland) Act 1995 and a restriction order under the same Act who have been conditionally discharged.

6. The Community Care and Health (Scotland) Act 2002

Section 7 of the Community Care and Health (Scotland) Act 2002 introduced a number of provisions, which amend section 12B of the 1968 Act. These provisions have helped make direct payments more widely available and increased take up amongst disabled people and older people who require community care and children's services.

In addition to being able to recruit staff and purchase support from private agencies or voluntary sector providers, the 2002 Act made it possible for direct payments to be used to purchase services from any local authority. Where direct payments are made on a 'gross' basis local authorities have been given a legal mechanism for recovering any amount an individual was assessed as being able to contribute.

7. The Community Care (Direct Payments) (Scotland) Regulations 2003

From 1 June 2003 local authorities have been under a statutory duty, in terms of The Community Care (Direct Payments) (Scotland) Regulations 2003 ('the 2003 Regulations'), to offer direct payments to all who are potentially eligible, as defined by these Regulations.

8. The Community Care (Direct Payments) (Scotland) Amendment Regulations 2005

From 1 April 2005, under these Regulations the duty to offer direct payments was extended to all persons aged 65 or over assessed as

needing community care services because of infirmity or old age (see regulation 2).

9. The Mental Health (Care and Treatment) (Scotland) Act 2003 (Modification of Subordinate Legislation) Order 2005

In terms of this Order, from 5 October 2005 references in the 2003 Regulations to the Mental Health Act 1984 are replaced by references to the Mental Health (Care and Treatment) (Scotland) Act (2003). The exclusions listed under this Order are noted in this annex under 'Who cannot receive direct payments'.

10. The Disability Equality Duty (DED)

The Disability Equality Duty⁷⁰ (DED) came into force on 4 December 2006. This legal duty requires all public bodies to actively look at ways of ensuring that disabled people are treated equally. All of those covered by the specific duties must also have produced a Disability Equality Scheme.

11. National Health Service Reform (Scotland) Act 2004 (asp 7)

Under this Local Government act, Community Health Partnerships (CHPs)⁷¹ were established as committees or sub-committees of a Health Board.

12. Adult Support and Protection (Scotland) Act 2007

This Act, which was passed by the Scottish Parliament on 15 February, includes an amendment to direct payment legislation. The Act empowers local authorities to offer increased flexibility in tailoring individualised packages, including allowing, in exceptional circumstances, the employment of certain categories of close relatives. It received Royal Assent on 21 March 2007, and the associated regulations will be enacted shortly. Meanwhile, the 2003 Regulations specify the persons from whom services may not be obtained by means of a direct payment who are essentially close relatives (see section 5). An update to this guidance will be issued when this Bill has been passed and an implementation schedule for the direct payment amendment has been set.

⁷⁰ www.drc-gb.org/disabilityequalityduty/

⁷¹ <http://www.sehd.scot.nhs.uk/chp/>

13. Health Committee Care Inquiry August 2005 to May 2006

The Health Committee held an inquiry into the success of direct payments delivery since enactment of the Community Care and Health (Scotland) Act 2002. The Committee strongly supported what direct payments are able to achieve in terms of increasing the autonomy of those who receive them, and enabling care packages to be tailored more closely to people's needs. The Report of 13 June 2006 emphasised the benefits of: increasing take-up across Scotland so that more people can benefit from direct payments; the importance of local support services; and the necessary commitment that needs to be made at senior level within local authorities to ensure that direct payments are properly integrated into the range of care solutions available locally. **Annex H** provides a summary of current direct payments research.

SUPPORT SERVICES

Local authorities can give service users details of local support services and organisations that can offer advice, information and services. Alternatively the Scottish Consortium of Direct Payments Support Organisations (SCDPSO) or the Scottish Personal Assistant Employers Network (SPAEN) can direct you to your nearest local support, or you can choose the appropriate organisation from the following list (for SCDPSO and SPAEN's contact details see the list of 'Other Statutory Bodies and Support Organisations for disabled and older people and children').

Local Support Services

If there is currently no support service within the area the self-directed support adviser from the local authority has been noted down.

Local Authority Area	Local Support Service
Aberdeen	Aberdeen City Council Kirkgate House St Nicholas Street Aberdeen AB10 1HW Direct Payment Co-ordinator: Elaine Berry Telephone: 01224 264 090 Email: eberry@aberdeencity.gov.uk
Aberdeenshire	Direct Payments Caledonia Crichton Bank Business Centre Mill Road Port Elphinstone Inverurie AB51 5NQ Telephone: 01467 628837 Email: info@dpcaledonia.org.uk Website: www.dpcaledonia.org.uk

Angus	<p>Direct Payments Support Service Thomas Herd House 10-12 Ward Road Dundee DD1 1LX Contact: Barbara Maguire Telephone: 01382 226440 Email: directpayments@dundecarerscentre.org.uk barbara.maguire@dundecarerscentre.org.uk Website: www.dundecarerscentre.org.uk</p>
Argyll and Bute	<p>Argyll and Bute Council Sensory Impairment Dolphin Hall Annexe Manse Avenue Dunoon PA23 8DQ Direct Payments Advisor: Dinah Macdonald Mobile: 07795 052656 Email: dinah.macdonald@argyll-bute.gov.uk</p>
Borders	<p>Borders Direct Payments Agency Anderson's Chambers Market Street Galashiels TD1 3AF Telephone: 01896 759700 Email: borders.directpayment@virgin.net Website: http://www.bordersdpa.org.uk</p>
Clackmannanshire	<p>Forth Valley Direct Payments Support Service Dundas Resource Centre Oxgang Road Grangemouth FK3 9EF Telephone: 01324 508794 Email: directpayments@fsmail.net</p>

<p>Dumfries and Galloway</p>	<p>Dumfries and Galloway Direct Payments Support Service Partnership 166 St Michael Street Dumfries DG1 2PR Telephone: 01387 240000 Mobile: 07834 667545 Email: dgdpsupportservice@btconnect.com</p>
<p>Dundee</p>	<p>Dundee Direct Payments Support Service Thomas Herd House 10-12 Ward Road Dundee DD1 1LX Contact: Vanessa Dallas-Ross Telephone: 01382 226440 Email: directpayments@dundecarerscentre.org.uk vanessa.dallas-ross@dundecarerscentre.org.uk Website: www.dundecarerscentre.org.uk</p>
<p>East Ayrshire</p>	<p>Ayrshire Independent Living Network (AILN) Eglinton Disability Resource Centre Pavilion 9 Ayrshire Central Hospital Kilwinning Road Irvine KA12 8SS Telephone: 01294 272260 Email: mail@ailn.org Website: www.ailn.org</p>

East Dunbartonshire	East Dunbartonshire Direct Payments Support Service Suite 1 Enterprise House Southbank Business Park Kirkintilloch G66 1XQ Telephone: 0141 776 2219/6342 Fax: 0141 776 2219 Email: direct.payments@eddpss.co.uk Web site: www.eddpss.co.uk
East Lothian	Lothian Centre for Integrated Living (LCIL) Norton Park Centre 57 Albion Road Edinburgh EH7 5QY Telephone: 0131 475 2350 Email: lcil@lothiancil.org.uk
East Renfrewshire	East Renfrewshire Council Independent Living Services Lygates House 224 Ayr Road Newton Mearns East Renfrewshire G77 6FR Contact: Innes Turner Telephone: 0141 577 3367 Email: innes.turner@eastrenfrewshire.gov.uk
Edinburgh	See East Lothian
Falkirk	See Clackmannanshire

Fife	<p>Fife Council Fife Direct Payments Support Service Talbot Cottage Station Road Leven KY8 4QU Contact: Rhona McCallum Telephone: 01333 592656 Email: rhona.mccallum@fife.gov.uk Website: http://www.fife.gov.uk/atoz/index.cfm?fuseaction=service.display&objectid=E7303EE0-651C-4410-B4B26419B670B708</p>
Glasgow	<p>Glasgow Centre for Inclusive Living 117-127 Brook Street Bridgeton Glasgow G40 3AP Telephone: 0141 550 4455 Email: gcil@gcil.org.uk Website: http://www.gcil.org.uk</p>
Highland	<p>Highland Council Kinmylies Building Leachkin Road Inverness IV3 8NN Direct Payment Support Officer: Claire Sutherland Telephone: 01463 703425 Email: claire.sutherland@highland.gov.uk</p>

Inverclyde	<p>Inverclyde Council 10/16 Gibshill Road Greenock PA15 2UP PA Advisor: Kathleen McGhee Telephone: 01475 714 350 Email: kathleen.mcghee@inverclyde.gov.uk</p> <p>Strone Office 1 Aberfoyle Road Greenock PA15 3DE Contact: Iseabail Howat Telephone: 01475 714 600 Email: iseabail.howat@inverclyde.gov.uk</p>
Midlothian	See East Lothian
Moray	<p>Direct Payments Caledonia c/o Moray Resource Centre Maisondieu Road Elgin IV30 1RX Telephone : 01343 552307 Email : dp.caledonia@moray.gov.uk Website : www.dpcaledonia.org.uk</p>
North Ayrshire	See East Ayrshire
North Lanarkshire	<p>North Lanarkshire Council Social Work Dept Scott House 73 – 77 Merry Street Motherwell ML1 1JE Contact: Morag Dendy Telephone: 01698 332 075 Email: dendym@northlan.gsx.gov.uk</p>

<p>Orkney</p>	<p>Independent Living Project Orkney Carers Centre Anchor Buildings 6 Bridge St Kirkwall Orkney KW15 1HR Contact: Olivia Tait Telephone: 01856 870 777 Email: ilproject@tiscali.co.uk</p>
<p>Perth and Kinross</p>	<p>Perth and Kinross Direct Payments Support Agency Perth and Kinross Association of Voluntary Services The Gateway North Methven Street Perth PH1 5PP Contact: Annette Summersgill Telephone: 01738 567 076 Email: annette.summersgill@pkavs.org.uk Website: www.pkavs.org.uk</p>
<p>Renfrewshire</p>	<p>Renfrewshire Council Social Work Department Independent Living Team Social Work Headquarters, North Building Cotton Street Paisley PA1 1ZT Contact: Janice Toner Telephone: 0141 842 5123 (Advice Line Tuesday, Wednesday and Thursday 1.30 pm to 4.00 pm) Email: Janice.toner@renfrewshire.gov.uk</p>

Shetland Islands	Direct Payments Support Service Citizens Advice Bureau Market House 14 Market Street Lerwick Shetland ZE1 0JP Contact: Angus Davidson Telephone: 01595 694 696 Email: angus.davidson@shetland.org sicab@zetnet.co.uk
South Ayrshire	See East Ayrshire
South Lanarkshire	South Lanarkshire Council Direct Payments Development Officer Floor 9, Council Offices Almada Street Hamilton ML3 0AA Contact : Karen Frame Telephone: 01698 453 716 Email: Karen.frame@southlanarkshire.gov.uk
Stirling	See Clackmannanshire
West Dunbartonshire	West Dunbartonshire Council Beardmore Business Centre 9 Beardmore Street Dalmuir G81 4HA Disability Development Worker: Victoria McKenzie Telephone: 0141 562 2327 Email: victoria.mckenzie@west-dunbarton.gov.uk
West Lothian	See East Lothian

Western Isles**Cobhair Bharraigh**

Kentangaval

Castlebay

Isle of Barra

HS9 5XL

Telephone: 01871 810 906

Email: cobhairbharraigh@waitrose.com**Crossroads Harris**

Harris Voluntary Service

Room 2, Old Hostel

Tarbet

Harris HS3 3BG

Telephone: 01859 502 171

Email: hcvvs@scvo.org.uk**Tagsa Uibhist**

East Camp

Balivawich

Benbecula

HS7 5LA

Telephone: 01870 602 111

Email: tagsa.uibhist@care4free.net

Other Statutory Bodies and Support Organisations for disabled and older people and children

Age Concern Scotland

Causewayside House

160 Causewayside

Edinburgh

EH9 1PR

Telephone: 0845 833 0200

Textphone: 0845 226 5851

E-mail: enquiries@acscot.org.uk

Website: <http://www.ageconcernscotland.org.uk/>

Free phone Helpline: 0800 00 99 66 (7.00am-7.00pm, 7 days a week)

Barnardos Scotland

235 Corstorphine Road

Edinburgh

EH12 7AR

Telephone: 0131 334 9893

Website: <http://www.barnardos.org.uk/scotland>

Capability Scotland

Advice Service Capability Scotland (ASCS)

11 Ellersly Road

Edinburgh

EH12 6HY

Telephone: 0131 313 5510

Email: ascs@capability-scotland.org.uk

Website: <http://www.capability-scotland.org.uk>

Care Commission

Compass House

11 Riverside Drive

Dundee

DD1 4NY

Telephone: 01382 207100

Telephone: 0845 603 0890 (Local rate applies)

The Care Commission can be contacted at its Headquarters, as above, or at regional offices listed on the website:

<http://www.carecommission.com/>

Children 1st

83 Whitehouse Loan
Edinburgh
EH9 1AT
Telephone: 0131 446 2300
Website: <http://www.children1st.org.uk/>

Children in Scotland

Princes House
5 Shandwick Place
Edinburgh
EH2 4RG
Telephone: 0131 228 8484
Email: info@childreninscotland.org.uk
Website: <http://www.childreninscotland.org.uk>

Contact a Family Scotland

Norton Park
57 Albion Road
Edinburgh
EH7 5QY
Telephone: 0131 475 2608
Email: scotland.office@cafamily.org.uk
Website: <http://www.cafamily.org.uk>

Helpline 0808 808 3555 (Free phone for parents and families: 10.00am - 4.00pm Monday to Friday, 5.30pm to 7.30pm Mondays only)
Text phone: 0808 808 3556
Website: <http://www.cafamily.org.uk/helpline.html>

Down's Syndrome Scotland

158/160 Balgreen Road
Edinburgh
EH11 3AU
Telephone: 0131 313 4225
Email: info@dsscotland.org.uk
Website: <http://www.dsscotland.org.uk>

Enable Scotland

6th Floor
7 Buchanan Street
Glasgow
G1 3HL
Telephone: 0141 226 4541
Email: enable@enable.org.uk
Website: <http://www.enable.org.uk>

In Control Scotland

Room 16
Adelphi Centre
12 Commercial Road
Glasgow
G5 0PQ
Telephone: 0141 518 5433
Email: incontrolscot@scl.d.co.uk

Mental Welfare Commission for Scotland

K Floor, Argyle House,
3 Lady Lawson Street,
Edinburgh
EH3 9SH
Telephone: 0131 222 6111
Email: enquiries@mwscot.org.uk
Website: <http://www.mwscot.org.uk>

National Centre for Independent Living (NCIL)

4th Floor
Hampton House
20 Albert Embankment
London
SE1 7TJ
Telephone: 0207 587 1663
Fax: 0207 582 2469
E-mail: info@ncil.org.uk
Website: www.ncil.org.uk

New Employer Helpline

Helpline: 0845 6070 143

Monday-Friday 8.00am-8.00pm

Saturday-Sunday 8.00am-5.00pm

Text phone: 0845 602 1380 (for employers who are deaf or hard of hearing)

Website: <http://www.hmrc.gov.uk/employers/new-emp-telephone.htm>

Office of the Public Guardian

Hadrian House

Callendar Business Park

Callendar Road

Falkirk

FK1 1XR

Telephone: 01324 678300

Email: opg@scotcourts.gov.uk

Website: <http://www.publicguardian-scotland.gov.uk/>

PAMIS

Springfield House

15/16 Springfield

University of Dundee

Dundee

DD1 4JE

Telephone: 01382 385 154

Email: pamis@dundee.ac.uk

Website: <http://www.dundee.ac.uk/pamis>

People First (Scotland)

77-79 Easter Road

Edinburgh

EH7 5PW

Telephone: 0131 478 7707

Fax: 0131 478 7404

E-mail: peoplefirst1@btconnect.com

Scotland's Commissioner for Children and Young People

85 Holyrood Road

Edinburgh

EH8 8AU

Telephone : 0131 558 3733

Email: info@sccyp.org.uk

Website: <http://www.sccyp.org.uk/>

Scottish Consortium for Learning Disability (SCLD)

Room 16
Adelphi Centre
12 Commercial Road
Glasgow
G5 0DQ
Telephone: 0141 418 5420
Fax: 0141 429 1142
E-mail: administrator@sclد.co.uk
Website: <http://www.sclد.org.uk/>

Scottish Consortium of Direct Payments Support Organisations (SCDPSO)

PO Box 7561
Glasgow
G42 2DG
Telephone: 0870 850 7795
Email: scdpso@btinternet.com
Website: www.scdpso.org.uk

Scottish Disclosure Advisory Service

52 Murdoch Terrace
Dunblane
FK15 9JF
Telephone: 01786 825313
Email: Michael@mchale90.fsnet.co.uk

Scottish Helpline for Older People (SHOP)

Scottish Helpline for Older People
Age Concern Scotland
Causewayside House
160 Causewayside
Edinburgh
EH9 1PR
Helpline: 0845 125 9732 (Monday to Friday, 10.00am - 4.00pm)

Scottish Independent Advocacy Alliance

Melrose House
69a George Street
Edinburgh
EH2 2JG
Telephone: 0131 260 5380
Email: enquiry@siaa.org.uk
Website: www.siaa.org.uk

Scottish Personal Assistant Employers Network (SPAEN)

Unit 9
Motherwell Business Centre
130 Coursington Road
Motherwell
ML1 1PR
Telephone: 01698 250280
Email: info@spaen.co.uk
Website: www.spaen.co.uk

Scottish Public Services Ombudsman (SPSO)

Freepost EH641
Edinburgh
EH3 0BR
Telephone: 0800 377 7330
Email: ask@spsso.org.uk
Website: <http://www.spsso.org.uk>

UPDATE

27 Beaverhall Road
Edinburgh
EH7 4JE
Telephone: 0131 558 5200
Fax: 0131 558 5202
E-mail: info@update.org.uk
Website: www.update.org.uk
Or for a direct link to their information on direct payments
see http://www.update.org.uk/staff/web_faq_public_list_directpays.php

Values into Action (VIA)

Oxford House

Derbyshire Street

London

E2 6HG

Telephone: 0207 729 5436

Fax: 0207 729 7797

E-mail: general@viauk.org

Website: <http://www.viauk.org>

Voices of eXperience (VOX)

c/o The Mental Health Foundation (Scotland)

5th Floor Merchants House

30 George Square

Glasgow G2 1EG

Telephone: 0141 572 1663

Email: voxscotland@yahoo.co.uk

Website: <http://www.voxscotland.org.uk>

SELF-ASSESSMENT QUESTIONS

How long does it take you to get up, go to the toilet, bathed, get dried, dressed and get ready?

How long does it take to have breakfast and clear up afterwards?

How much time does it take to prepare and cook other meals and clear up afterwards? You should include other snacks or drinks you have either during the day or night.

Do you need assistance to use the toilet at other times of the day or night? If so, how often?

Do you need a rest period during the day? How much assistance do you need with this?

Do you go to college, work (voluntary or otherwise) or any other regular activity for which you need assistance?

How many hours per week does it take to clean your house – vacuuming, dusting, changing your bed, washing and ironing, laundry etc?

How often do you go to the bank, post office and how long does it take you to deal with correspondence, pay bills etc?

How often do you go shopping and how long does it take?

How often do you go to a social or recreational activity and how much time does that take?

How long does it take to get ready for and to get to bed at night?

Do you need assistance during the night for anything such as turning, going to the toilet or taking medication?

Do you need support to plan your:

- day
- budget
- meal
- support circle
- future

There may well be other activities you want to include on this list, but it should help you be clear about the total number of hours of assistance per week you will need.

CONTRACT WITH LOCAL AUTHORITY

When your needs are assessed and self-directed support is about to be put in place, you should receive a letter or contract from the local authority. This will describe how the following questions have been resolved:

How much money (giving a breakdown) does the local authority consider necessary to secure the appropriate services?

How much of this total will the local authority contribute to the individual budget, and how much is the person expected to contribute?

How often and in what form will payments be made?

What arrangements does the local authority propose for monitoring? How often? What information should the person provide? What access will be required to the person's home or financial records?

What information does the local authority require for audit purposes, and when?

When will the next review take place?

What should the person do if they want to stop self-directed support?

In what circumstances will the local authority consider discontinuing (permanently or temporarily)?

How will the local authority and individual handle any temporary gap in service?

How much notice will be given if the local authority discontinues?

How will any outstanding commitments be handled if payments are discontinued?

In what circumstances would payments be withdrawn with no notice?

In what circumstances would the local authority seek repayment?

Has the individual been made aware of the local authority's complaints procedure?

Is there a retainer fee for staff if the person on self-directed support is admitted to hospital for a short period? The person would have a contract of employment with their staff and if they were unable to retain staff, depending on the circumstances of the admission, it could disrupt their longer term support and could delay discharge from hospital.

Can an individual on self-directed support nominate someone to be involved in the monitoring process with them?

OTHER SOURCES OF INFORMATION (publications and websites)

Publications

Community Care Providers Scotland (written by the voluntary sector) (2002) *Direct payments: Issues for service providers*.

Department of Health. *Breaking Barriers*.

<http://www.dh.gov.uk/PolicyAndGuidance/OrganisationPolicy/FinanceAndPlanning/DirectPayments/fs/en>.

Department of Health. *A parent's guide to direct payments*.

<http://www.everychildmatters.gov.uk/socialcare/disabledchildren/directpaymentfaqs>

Lothian Centre for Integrated Living (2005) *It's your life*.

Lothian Centre for Integrated Living (latest edition April 2006) *Your guide to payroll*.

National Centre for Independent Living (2000) *A rough guide to managing personal assistants*.⁷²

National Centre for Independent Living. *Direct payments for mental health users/survivors: A guide to some key issues*⁷³.

National Social Inclusion Programme, the Care Services Improvement Partnership and the National Institute for Mental Health in England (2006) *An introduction to direct payments in mental health services: Information for people eligible to use mental health services and carers*.

Scottish Executive (2000) *The same as you? A review of services for people with learning disabilities*.

<http://www.scotland.gov.uk/ldsr/docs/tsay-00.asp>

⁷² This is very useful for its general approach, but references to legislation and regulations all relate to the laws of England and Wales. Direct Payments in Scotland operate under legislation specific to Scotland (see **Annex B**).

⁷³ This is very useful for its general approach, but references to legislation and regulations all relate to the laws of England and Wales. Direct Payments in Scotland operate under legislation specific to Scotland (see **Annex B**).

Scottish Executive (2003) *A guide to receiving direct payments in Scotland*. <http://www.scotland.gov.uk/Publications/2002/04/14662/4093>

Scottish Executive (2003) *Equipped for Inclusion. Report of the Strategy Forum: equipment and adaptations*.

<http://www.scotland.gov.uk/consultations/social/efir-00.asp>

SHS Trust. *Ways to work: Converting day services*.

Values into Action (2001) *Making decisions: Best practice and new ideas for supporting people with high support needs to make decisions*.

Values into Action (2001) *Trusting independence: A practical guide to independent living trusts*.

Websites

Abuse – children at risk of:

<http://www.everychildmatters.gov.uk/resources-and-practice/IG00060/>

Advocacy organisations:

<http://www.siaa.org.uk/documents/DirectoryFundingupdated280207.pdf>

Care management in community care guidance:

http://www.show.scot.nhs.uk/sehd/publications/CC2004_08.pdf

Changing Lives:

<http://www.socialworkscotland.org.uk>

Charging and financial assessment guidance:

<http://www.scotland.gov.uk/Topics/Housing/Housing/supportpeople/CFA>

Charging for adult non-residential sector care:

<http://www.cosla.gov.uk/attachments/execgroups/sh/shchargingguidance2006.doc>

<http://www.scotland.gov.uk/library/swsg/index-f/c172.htm>

Childminding:

<http://www.childminding.org>

Disclosures:

<http://www.disclosurescotland.co.uk>

Employment status:

<http://www.hmrc.gov.uk/employment-status/index.htm>

Equipment and temporary adaptations:

<http://www.scotland.gov.uk/Topics/Health/care/JointFuture/equipmentandadaptations>

Equipped for Inclusion:

<http://www.scotland.gov.uk/consultations/social/efir-00.asp>

Financial monitoring arrangements guidance:

<http://www.cipfa.org.uk>

Free Personal and Nursing Care:

<http://www.show.scot.nhs.uk/sehd/ccd.asp>

<http://www.scotland.gov.uk/Topics/Health/care/17655>

HM Revenue and Customs:

<http://www.hmrc.gov.uk/employment-status/index.htm>

Housing support services:

<http://www.scotland.gov.uk/Publications/2003/06/17612/23017>

Independent Living Fund:

<http://www.ilf.org.uk/about.htm>

Joint Future Agenda:

<http://www.scotland.gov.uk/Topics/Health/care/JointFuture>

Joint Performance Information and Assessment Framework (JPIAF):

<http://www.scotland.gov.uk/Publications/2003/03/16630/19312>

Joint working guidance:

http://www.sehd.scot.nhs.uk/publications/CC2002_11.PDF

Local Improvement Targets:

<http://www.scotland.gov.uk/Topics/Health/care/JointFuture/LITS>

National training framework for care management:

[http://www.spkweb.org.uk/Subjects/Training/
National training framework overview](http://www.spkweb.org.uk/Subjects/Training/National_training_framework_overview)

Partnership for a better Scotland: Partnership Agreement:

<http://www.scotland.gov.uk/Publications/2003/05/17150/21952>

Scottish Executive return DP1:

<http://www.scotland.gov.uk/Publications/2006/09/25160444/1>
<http://www.scotland.gov.uk/Topics/Statistics/17672/9462>

Single Shared Assessment of community care needs guidance:

[http://www.show.scot.nhs.uk/sehd/publications/
DC20011129CCD8single.pdf](http://www.show.scot.nhs.uk/sehd/publications/DC20011129CCD8single.pdf)

Social model of disability:

<http://www.lothiancil.org.uk/about/background.php>

Statutory rights for carers:

http://www.sehd.scot.nhs.uk/publications/CC2003_02full.pdf

Support organisations:

<http://www.scdpso.org.uk>
[http://www.update.org.uk/new_web/locked/dir1/directpaymentorgs/
Info Local Advice Dir.htm](http://www.update.org.uk/new_web/locked/dir1/directpaymentorgs/Info_Local_Advice_Dir.htm)

Supporting People:

[http://www.scotland.gov.uk/Topics/Housing/Housing/
supportpeople/intro](http://www.scotland.gov.uk/Topics/Housing/Housing/supportpeople/intro)

Fact sheets

A variety of fact sheets are available from the following sources:

Age Concern

<http://www.ageconcernscotland.org.uk/>

- Finding Help at Home
- Direct Payments from Social Work
- Disability & Ageing, Your Rights to Social Services
- Local Authorities Assessment for Community Care Services
- Paying for Care and Support at Home

Contact a Family

<http://www.cafamily.org.uk>

- Finding and Paying for Childcare
- Employing a Paid Carer

Counsel and Care

<http://www.counselandcare.org.uk/>

- Guide to Direct Payments (brief): for people over 65 years old (forthcoming September 2007)
- Guide to Direct Payments (complete): for people over 65 years old (forthcoming September 2007)

Glasgow Centre for Inclusive Living

<http://www.gcil.org.uk/>

- Funding Independent Living

Scottish Consortium for Learning Disability

<http://www.sclld.org.uk/>

- An Easy Guide to Direct Payments in Scotland
- Journey to Independence: How to run your life with Direct Payments
- Moving On to Adult Life

SPAEN

<http://www.spaen.co.uk>

A number of leaflets are available from SPAEN.

UPDATE

<http://www.update.org.uk/>

- Fact sheets previously available from Direct Payments Scotland are now at http://www.update.org.uk/new_web/locked/features/Features_DP_2.htm
- Five Steps: A guide to providing direct payments support services.

EMPLOYING STAFF

PA employers have a range of important responsibilities, all of which they can receive training on and other practical support from their local support service and SPAEN (see **Annex C**). This list is not exhaustive:

- Staff recruitment
- Induction training
- Managing staff and relationship building
- Staff appraisal
- Equal opportunities
- Fair and unfair dismissal
- Handling employee grievances
- Health and safety
- Insurance and indemnity (for you as an employer and for your employee)
- National Insurance contributions
- Pay negotiations and awards
- Period of notice
- Redundancy
- Salary
- Statutory sick pay, maternity and paternity pay, adoption pay and leave
- Tax
- Unions
- Written statement of employment particulars

SPAEN's Coaching and development programme offers various modules designed to assist people employing PAs to deal effectively and confidently with employment and personnel issues. More information can be found at <http://www.spaen.co.uk/services/training.htm>

Glasgow Centre for Inclusive Living provide a range of training modules on inclusive living for disabled people and training for people who want to gain employment as personal assistants. More information can be found at <http://www.gcil.org.uk/services.html>

For more information about employment see the following websites:

Advisory, Conciliation and Arbitration Service (ACAS)

<http://www.acas.org.uk/>

Citizens Advice Bureau

http://www.adviceguide.org.uk/scotland/life/employment_scotland.htm

Direct Gov

<http://www.direct.gov.uk/Employment/Employees/fs/en>

Trade Union Congress (TUC)

http://www.tuc.org.uk/tuc/rights_main.cfm

SUMMARY OF RECENT RESEARCH ON SELF-DIRECTED SUPPORT

Recent research has focused on the following themes:

1. Independent living brings improvements in quality of life and emotional, physical and social health

Work by Sally Witcher (2000), Frances Hasler (2006), Riddell, Ahlgren, Pearson, Williams, Watson, and MacFarlane (2006) and Pearson, (2006) have all demonstrated the positive benefits to disabled users of the independent living that self-directed support can deliver. Other work has focussed on the benefits to older people e.g. Clark, Gough and Macfarlane (2004) and that of the Joseph Rowntree Foundation (2004 onwards).

2. Self-directed support is cost effective

Hurtsfield, Parashar and Schofield (2007) and Heywood and Turner (2007)⁷⁴ are the most recent research studies demonstrating the cost effectiveness of self-directed support. Other studies include Zarb and Nadash (1994).

3. There are recognised obstacles to overcome in local implementation

The recent Scottish Executive working group on Direct Payments for Older People (DPOP) identified a number of contributing factors towards low uptake in many parts of Scotland, including:

- The need for awareness-raising, advice, information and training for service users through local support services
- The need for a dedicated lead officer in each local authority, staff training, and the winning of 'hearts and minds' at all service and management levels on the benefits of self-directed support

⁷⁴ Hurtsfield, Parashar and Schofield (2007) *The costs and benefits of independent living*; Heywood and Turner (2007) *Better outcomes, lower costs. Implications for health and social care budgets of investment in housing adaptations, improvements and equipment: a review of the evidence. Executive summary*. Both Hurtsfield et al (2007) and Heywood et al (2007) available at <http://www.officefordisability.gov.uk/publications/>

- Many local authorities have yet to fund local self-directed support schemes sufficiently, and
- Local authorities' concerns about the ability of users to cope with self-directed support, and the quality of care they may receive.

The above points are supported and further emphasised by findings presented by Riddell et al. (2006)⁷⁵ at the Scottish Parliament's Health Committee Care Inquiry⁷⁶ that looked at the effectiveness of implementation of self-directed support since enactment of the Health and Social Care (Scotland) Act 2002. This research currently provides the most up to date research picture for Scotland.

Riddell et al (2006) cite funding, training and confidence issues among users and social workers alike as current obstacles in Scotland. However they report that users' believe that self-directed support is manageable with support. Glasby and Littlechild (2001) identified availability and access to appropriate information and support and the attitudes of social work professionals who are concerned about self-directed support as factors. Pearson (2006) stresses that whilst resource constraints impact on delivery of self-directed support, there is a need for a cultural change, incorporating a shift in values and attitudes if self-directed support specifically, and user choice and control more generally, are to become a reality for recipients.

4. Best practice solutions are developing, for example, the need for local authorities to fund local support

Whilst such research raises legitimate concerns, they are largely issues concerning the **processes** of self-directed support which Rummery (2005) suggests 'could be fairly simply (if not necessarily cheaply) addressed'. Witcher, Stalker, Roadburg and Jones' (2000) findings suggest with the 'right approach and support, infrastructure barriers can be dismantled or, better still, prevented from arising altogether'. Riddell et al (2006) are similarly positive.

Clark, Gough and Macfarlane's (2004) best-practice solution focus recognises the pivotal role that both local authority care managers and support services have in delivery of self-directed support. They

⁷⁵ <http://www.scottish.parliament.uk/business/committees/health/reports-06/her06-report.htm>

⁷⁶ <http://www.scottish.parliament.uk/business/committees/health/index.htm>

conclude that 'funding of support services should reflect their value both to users and to the local authority'.

The need to fund local support services was also a key conclusion of Riddell et al (2006) who further emphasised its importance in the spoken evidence they gave at the Care Inquiry.

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www.scdpso.org.uk, tel 0870 850 7795

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