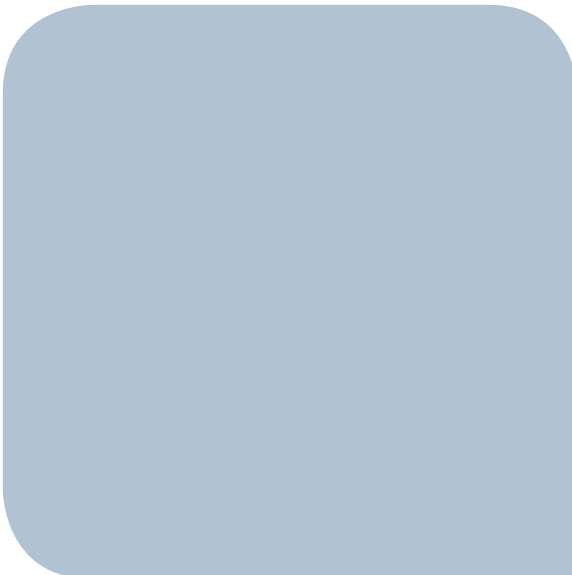
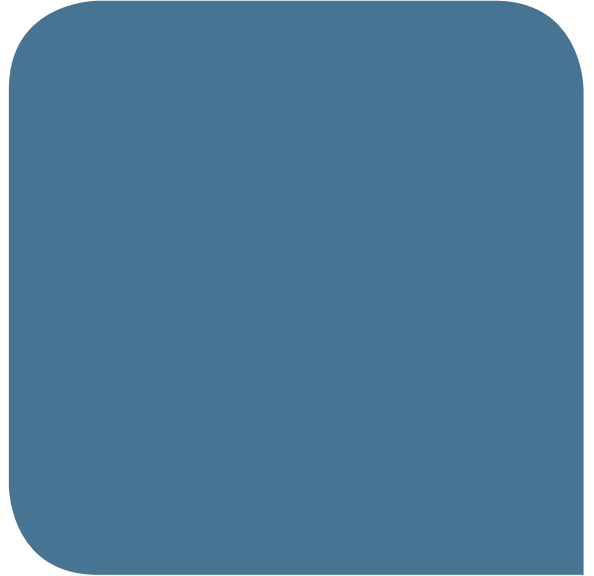


Direct payments: answering frequently asked questions



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Sara Lewis

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Written by Sara Lewis

Produced by The Policy Press
Fourth Floor, Beacon House
Queen's Road
Bristol BS8 1QU
tel 0117 331 4054
fax 0117 331 4093
tpp-info@bristol.ac.uk
www.policypress.org.uk

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www.scie.org.uk

Social Care Institute for Excellence
Goldings House
2 Hay's Lane
London SE1 2HB
tel 020 7089 6840
fax 020 7089 6841
textphone 020 7089 6893
www.scie.org.uk

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John Evans, a national expert on direct payments
Jennie McGhie Hambidge, chair of Disability Wales

Researchers

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Introduction

This guide has been written with support from the National Centre for Independent Living. It aims to offer creative and innovative examples of how the legislation on direct payments can successfully be applied to achieve positive outcomes for those who use them.

It is hoped that the guide will inspire health and social care staff to embrace the principles of independent living and think more freely in applying direct payments to a wider audience. It answers a range of questions through a series of examples, which have been captured by a practice survey undertaken by the Centre for Social Action at De Montfort University.¹ This has been supplemented by information and material from several other sources to provide a comprehensive document for health and social care staff. The guide is designed to answer specific questions easily, as well as provide access to numerous useful websites.

The text contained within the boxes are examples of practice provided by service users, social care staff and staff from Direct Payment Support Services. This information is taken from the De Montfort practice survey. Any examples from other sources are accredited accordingly.

The guide is produced as part of the SCIE work plan under the theme of adults. Consequently, direct payments for children and young people are not explicitly reported on. However, for helpful information and advice in this area there are numerous resources available:

- The Council for Disabled Children has produced a guide for local councils on the implementation of direct payments in children's services, called *Direct experience*.² This can be accessed through the National Children's Bureau website <www.ncb.org.uk>.
- The Joseph Rowntree Foundation has published a report³ to highlight the main issues facing young disabled people who would like to access direct payments, and how to promote take-up. It can be accessed via the Joseph Rowntree Foundation website <<http://www.jrf.org.uk/knowledge/findings/socialcare/553.asp>>.
- Guidance for parents and young people can also be found on the Department of Health website <www.dh.gov.uk>.

As a whole, this guide should offer interesting reading for people using or considering direct payments, as well as other stakeholders.

Foreword

For much of my life I have fought alongside other disabled service users for the right to independent living. Independent living is not about living alone, putting your own socks on and making a cup of tea. Independent living is about having the support to access life opportunities and choices in everyday life that we all take for granted, like going to the neighbourhood school, getting a job and caring for our families.

Direct payments are an essential feature of independent living. Without the means to purchase the support I need to go to work, support my family and actively engage in community life, I would be economically dependent and socially disengaged. Direct payments are vital to my sense of well-being and self-determination.

There has been a low take up of direct payments in England, particularly amongst black and ethnic minority groups; this despite the Direct Payment Regulations introduced in 2003, which require local authorities to offer direct payments to all people using community care services. (Corresponding regulations were introduced in Wales in 2004.)

Yet, amongst the group of people who receive them, there is evidence to show that direct payments can be transformational and can work across all service user groups. Expanding the use of direct payments requires imagination, creativity and innovation from health and social care staff. It also requires commitment, time and resources from senior managers, and – not least of all – staff need permission to take risks and experiment.

This guide demonstrates that there are numerous methods for promoting and successfully implementing direct payments. The examples provided illustrate the impact they can and have had. Now is the time to employ these methods so that all people who would benefit from direct payments are given the opportunity to live independently and to manage their own support.

Jane Campbell
Chair
Social Care Institute for Excellence

1 What is a direct payment?

- A direct payment (DP) is money given to individuals by social services departments to buy the support they have been assessed as needing. This is in lieu of services, and there is no set financial limit.
- Guidance on direct payments, including 'easy read' versions, can be found on the Department of Health website <www.dh.gov.uk/directpayments>.
- The Welsh Assembly also provides information and guidance for authorities in Wales <www.wales.gov.uk>, with the corresponding regulations that came into effect in August 2004.
- You can also access information on direct payments from the National Centre for Independent Living (NCIL) <www.ncil.org.uk>.
- In April 2003, regulations came into force that required councils in England to offer direct payments to all people using community care services.
- Direct payments have also become a key performance indicator for local authorities (LAs): Performance Assessment Framework Indicator AO/C51, Department of Health.

Direct payments have been framed in terms of support (not illness or incapacity); in terms of ensuring that people can have the kind and amount of support they need to live their lives as fully, as freely and with as many choices and opportunities as they can. They can have more choice, they can have more control because they can, with help and independent guidance, get the kind of support and assistance they need to live their lives.

*Professor Peter Beresford, Centre for Citizen Participation,
Brunel University in the Joseph Rowntree Foundation publication:
'Implementing direct payments in mental health'⁴*

2 Why direct payments?

- Direct payments are a comparatively new approach to supporting disabled people to lead more independent lives and exercise choice and control over the services they receive.
- These are the key principles of independent living, and are underpinned by the social model of disability that redefines disability as the disadvantages caused by society that exclude disabled people from mainstream services.
- 'Independent living' is a philosophy and a movement of disabled people who work for equal rights and equal opportunities, self-respect and self-determination. Direct payments contribute to enabling that philosophy to become a reality <www.ncil.org.uk>.

Independent living means support that is flexible and tailor-made for the individual, in contrast with identifying people's needs through professional assessments and other forms of community care support.⁵

- Following persistent campaigning by disabled people, who had highlighted the limited nature of the support they were receiving from social services departments, the 1996 Community Care (Direct Payments) Act⁶ came into effect in April 1997. This gave local authorities in England, Wales and Northern Ireland the power (but not the duty) to make direct payments.
- The 2005 Strategy Unit report *Improving the life chances of disabled people*⁷ proposes that the government should set an ambitious vision for improving the life chances of disabled people: 'By 2025, disabled people in Britain should have full opportunities and choices to improve their quality of life and will be respected and included as equal members of society.'
- It goes on to state that independent living should be achieved by moving progressively to individual budgets for disabled people, drawing together the services to which they are entitled and giving them greater choice over the mix of support they receive in the form of cash and/or direct provision of services. In the shorter term, measures should also be taken to improve the advice services available to disabled people and address existing problems with suitable housing and transport.

For individuals, a direct payment can mean the difference between having to live in an institutional setting and having the assistance you want to be able to live in your own home.⁶

Of course, not everyone will want to use a direct payment. But the qualities that people value from using them – choice, control and increased flexibility – need to find their way into mainstream service provision. And direct payments should be genuinely available to all eligible people. Direct payments can and do change people's lives. We want them to change many more people's lives. And to achieve this it is crucial that the voices of the people who are at the very centre of this debate – the many thousands of people who use social care services every day – are heard.⁹

A disabled person employs a personal assistant to support their own verbal communication. The personal assistant will repeat what the disabled person says for the benefit of listeners unfamiliar with the disabled person's speech

pattern. The disabled person works in developing transport planning and strategy. Communication is a central part of their work and they develop visual communication techniques to support their assisted verbal communication skills in developing this work.

Example supplied by NCIL

3 Who can get them? What can they be used for?

- Initially, people aged 18-65 who were assessed as needing community care services were eligible. Direct payments were then extended to older disabled people in 2000.
- Since April 2001, direct payments have been available to carers, parents of disabled children and disabled young people aged 16 or 17 years old.
- Everyone who is eligible has to consent to direct payment and be able to manage it, with support if required (see Chapter 13 on assessment and Chapter 14 on consent).
- There are many examples of how direct payments have transformed users' lives, giving them more independence, flexibility and choice.

I now work full-time and my PA [personal assistant] complements, supports and enables me to live a full life. In the past, using an agency, I had no control who came to my house, when, what they did or anything. Now I have control, choice and the right to live my life the way I choose.

Direct payment service user

- Payments can be made for day-to-day things such as dressing, cooking, driving, bathing children, support to facilitate discharge from hospital. They can also be used for social activities – visiting friends, evening classes and college courses, gardening – as well as for assistance to access training and employment.

One of the most exciting aspects of direct payments is their adaptability. Service users can use them to organise their care in a whole range of new and more effective ways. Indeed, local authorities are encouraged to explore innovative and creative options for meeting people's needs ... the possibilities seem almost endless.¹⁰

- Flexibility is an essential part of direct payments, and they can also be used as part of a combined package. For example, part of a care package can be provided through direct services, such as a day centre, while other parts can be through direct payments, enabling someone to live independently and choose their own support.
- For the most part, direct payments are used to employ personal assistants, although this is slowly beginning to change.

A 56-year-old man with early-onset dementia has a very short concentration span requiring almost constant stimulation, which he seeks out from his wife, the main carer. The situation is likely to breakdown if the wife does not receive regular breaks and the husband does not receive regular stimulation. He also requires support to maintain links and regular contact with his family, but he is finding it difficult to remember how to use the train to reach them. Traditionally he would have been provided with three hours of domiciliary home care each week, plus two days a week at a day centre. The approximate cost of this service would have been £600 per month. He now receives a direct payment of £200 per month, and his wife receives a carer's direct payment of £55 a month. This is how they meet their eligible assessed needs: He now has a Sky satellite TV subscription that costs £40 per month. He can watch sport and football, which holds his concentration and which he enjoys immensely. This facility is available seven days a week. He

now has a sports club membership and goes to the gym with a personal assistant every week. He also goes swimming when he can. The cost of the PA is £100 a month and the sports club membership costs £28 a month. His wife receives a carer's direct payment to fund her membership as they enjoy swimming together. He uses £150 a year to fund transport obtained through the community volunteer transport service, to travel with his wife to Center Parcs to stay with his family for holidays. He also pays the community volunteer transport service, so he can travel with his wife to stay with their family in London whenever possible. He uses part of the money to pay for a taxi every month to attend, with his wife, a club for people with early-onset dementia and their carers. His wife pays for half the cost of the taxi from a carer's direct payment she receives in her own right.

Example supplied by Essex Direct Payments development manager

A man with a diagnosis of severe and enduring mental illness and alcohol dependency had recently been through rehab. He was engaging very well with services but wished to move to another area. He had been paying off rent arrears, accrued during the time when he was not managing particularly well, but the area he wished to move to would not accommodate him until the debt was cleared. It was the opinion of the care team that an early move would be beneficial to him and his long-term prognosis. Direct Payments agreed to clear the remaining debt.

Example provided by Essex Direct Payments development manager

- One of the key areas for concern since the inception of direct payments has been about who can be paid for providing care and support.
- It is clear and understandable that many people would be more comfortable employing family members and friends, and the legislation supports this to a degree. However, it is only in exceptional circumstances that service users can pay relatives who live with them:

Some councils say they are confused over the rules governing how individuals can use their direct payments to pay close relatives. We're reminding councils that there is no legal restriction on individuals using their direct payment to pay close relatives who don't live with them.

Due to us changing the law last April, in exceptional circumstances, people can also use their direct payment to pay a relative who lives with them, if they and their local council decide this is the only satisfactory way of meeting their care needs.

*Dr Stephen Ladyman, former Minister for Community,
Department of Health, 26 January 2004*

- To date, the majority of direct payments have been made to people who have a physical impairment. However, with the right support, people with mental health issues and/or learning disabilities and older people can also manage them.
- The following are examples of developments and innovations across England and Wales that have enabled direct payments to be made:

We have money from the Direct Payments Development Fund to run a 'support network' project aimed at building on the 'circles of support' model and applying it to DP users.

Independent Living, Norfolk

Our advocacy service is involved on many occasions, and we have a worker identified within the support service to provide the extra support that may be needed by people with learning difficulties. Referrals can be made to us and some care managers involve us at an early stage for this group.

Independent Choices, Northamptonshire

Older people receiving direct payments reported feeling happier, more motivated and having an improved quality of life than before. There was a positive impact upon their social, emotional and physical health.¹¹

We tend to involve family members and friends more with this group. They like to feel that they are supported by someone they know. Social workers assume that older people do not want the hassle. I know that older people like direct payments as it gives them so much dignity, choice, respect and control. They like joint visits. Some use DPs for overnight stays, short-term care and many other ways in which they need part-time support without losing their pride! The 'older person's forum' meets monthly to discuss any concerns, issues they may have.

Gateshead LA

We were struggling with older people and direct payments, so we brought in what we call an 'inclusion broker' [who speaks on behalf of older people]. They were also responsible for all paper work that deals with direct payments and recruitment of personal assistants. If you have someone to work in partnership with the person, it seems to work much better. After we brought in the 'inclusion broker', referrals trebled within four months.

Tameside LA

We have advance directives for when people have crises and are not able to manage their schemes themselves – they will nominate someone to take over at such times. We use advocates – fewer problems around getting consent. Many of the issues are about being prepared for when people's situations change – e.g. so that there are instructions for workers on what to do when the user has a crisis. Preparation and planning is the key – having people with power of attorney lined up to take over when the user is unable to be in control themselves. The problems for mental health are around risk assessment: practitioners are concerned that care will be provided by people who are not trained and supervised to both recognise and respond appropriately to crisis situations. We're tackling that with training, training and more training. Having mental health service users take part in training has been very effective and gives the most powerful message.

Essex LA

Sarah was bright and organised, although she lived with serious mental health problems. She had had services from the staff at one independent home care agency for eight years, but a change in the boundary meant she no longer came

within their contracted remit. Direct payments were an alternative way for her to purchase care, originally with the intention of preventing a change in provider. In fact, that provider could not continue anyway, so she used the money to buy care, designed to her personal specification, from another provider. But the really impressive thing was the therapeutic impact of using direct payments for Sarah. She felt more in control and it increased her self-esteem. Because she felt too vulnerable to interview and employ someone directly, she used an agency. The direct payments support team at Mount Pleasant were excellent, superb in fact. They met Sarah and answered all her questions.

Contributed by Hertfordshire Mental Health Trust

A person with learning difficulties employs a personal assistant to help them plan and organise their weekly diary and read, understand and reply to official communications, and another one to assist with managing their finances. The first supporter worker assists them in supervising the second worker, giving some independence in this work. The disabled person works as a trainer to introduce independent living skills to other disabled people and professionals. The personal assistance supports them in doing this work.

Example supplied by NCIL

- Direct payments can also be used for some equipment. For up-to-date information and advice, check the website of ICES – Integrating Community Equipment Services: <www.icesdoh.org>.
- ICES states that 'If certain conditions are satisfied, a local authority must make a direct payment up to the reasonable cost of securing the provision of the service or equipment.'¹⁰

Joe wanted a new sit-down shower with additional features. In order to get the model of his choice, he was given a direct payment to cover up to the amount the local authority deemed reasonable. He then paid the remainder himself.

Contributed by NCIL

- Certain groups are not eligible under the legislation:
 - > offenders subject to court orders
 - > those detained under mental health legislation on leave of absence from hospital
 - conditionally discharged detained patients subject to Home Office restrictions
 - > people subject to guardianship or supervised discharge.

For more information, check Department of Health direct payments guidance, which can be accessed at: <http://www.dh.gov.uk/assetRoot/04/06/92/62/04069262.pdf>.

- There are also restrictions about using direct payments for health rather than social care needs. According to the Department of Health:

Whilst the Department of Health is unable to comment on individual cases, direct payments made under the Health and Social Care Act 2001 relate only to certain local authority social services. This means that, where an individual has an identified health need which falls to the NHS, that part of any 'care' package cannot be delivered as a direct payment within the meaning of the legislation, including

where a local authority is acting under a partnership arrangement pursuant to section 31 of the Health Act 1999. This statement is not, nor is it intended to be, a comprehensive description of the legal position concerning direct payments, and councils are advised to take their own legal advice on this issue.¹³

4 How will direct payments improve things?

- It is clear that direct payments require a change in culture for staff in local authorities. It requires a shift in power and more emphasis on applying resources to need rather than need to existing services.
- It is a move from being the gatekeepers of services to providing the type of support that people actually want and from which they can benefit.
- This can lead to a dramatic increase in job satisfaction and the knowledge that, as a care manager, you have been able to work in collaboration with service users to make a difference to how they lead their lives.
- Of course, not all service users will want to take up direct payments. Some will be content with the services they receive and not want anything to change.
- However, one of the main reasons for the change is that it has been recognised that existing services are not suitable to fulfil everyone's needs, and there is clearly mileage in giving people choice and flexibility.

Direct payments offer greater independence and flexibility in support arrangements, and for people from black and minority ethnic communities, this can mean improved access to culturally sensitive support. For people experiencing mental health problems, direct payments can facilitate social inclusion, through providing support to access mainstream activities that are not stigmatising or mental health focused.⁴

I wanted people who looked at me and talked to me, treated me like a human being. The agency that provided my services before direct payments kept sending me people and I kept rejecting them, so when I heard about direct payments and being able to choose my workers, it seemed like a positive choice to move from any old crap that they wanted to send me to having somebody I felt comfortable with.

Direct payments service user

What's being asked of you is not easy, I know that. It means a change in approach. It means going much further in treating the people you work with as individuals and tailoring support around them. It means letting them be in charge. And it means really signing up to the principles of independent living, and helping people move away from being dependent on you for help to being dependent only on themselves. That's no small task!

*Speech by Dr Stephen Ladyman, former Minister for Community,
Department of Health, 18 May 2004*

Nobody promotes direct payments (DPs) better than the people using them. This became clear to me when I was working in a physical disabilities social work team and was meeting disabled people every day who were describing what a difference DPs had made to their lives and how it had given them more control. I now do training with social workers and my co-trainer is disabled and a DP user with a PA, and this also promotes DPs in a very positive way. We hope to use this approach in promoting DPs to older people by encouraging a DP user in this field to share their experience with people their own age. We have a new worker we hope can follow up on this.

Coventry LA

Two-and-a-half years ago when we relaunched the direct payments scheme, I visited all the care managers in all the teams and did a presentation on direct payments, what the concept was all about and the long-term benefits for the service users. As a result, there were a few social workers who became very keen to introduce this into their work, they understood the potential benefits, were very supportive and believed DPs were a good way forward for all. When they had set up some schemes, there was discussion of the cases within the local team and they were able to pass on their positive thoughts and beliefs to other team members and colleagues. They also worked closely with the DP champions. Peer support, word of mouth was a very good way of educating other team members.

Hounslow LA

5 How do we know direct payments actually work?

- There is much evidence from service users of the incredible difference direct payments have made to their lives and lifestyles.
- Additionally, there is testimony from staff within local authorities who have seen the impact of working in an environment that offers choice and the opportunity for service users to have more control over their own lives.
- Original examples of creativity and innovation in the application of direct payments appear every day – the possibilities are endless. The following are just a few of the success stories:

Three people who were living close to each other in a shared almshouse were each awarded direct payments for a number of hours. The hours allocated were not by themselves enough to make recruiting individual personal assistants (PAs) a very viable prospect, but by combining them, three people were able to create a joint package that was sufficiently attractive to recruit one PA to work with all three people. All three had separate work contracts with the PA so there were three employers, but through negotiation with each other, they were able to make the process work for about two years, before they each moved on to employing their own PAs. Their close physical proximity in the home was clearly helpful in enabling the PA to make maximum use of the time available and for the disabled people to plan their activities.

Nottingham and Nottinghamshire Direct Payments Support Service

Direct payments have supported individuals who have been able to employ support workers who speak the same language as they do. They have had greater flexibility on the hour they choose to be supported – more choice of activities and overall consistency.

Southwark Choice Support

Direct payments allowed a disabled gentleman to employ a friend, to be able to go fishing on holiday, visit his children's school, have a life.

Isle of Wight DIAL

One woman who had multiple sclerosis – worked full-time and needed assistance with household chores so could conserve energy for work and maintain income and independence.

Gateshead LA

A disabled adult who does voluntary work for a national charity uses her direct payments to employ a PA to accompany her on visits to the HQ in London when she needs to work there.

Milton Keynes LA

Direct payments were given to a single parent of a two-year-old. The mother has a particular condition requiring periods of rest and six-weekly hospital visits. Her DP has enabled her to pay for a live-in nanny.

Isle of Wight LA

Direct payment has been used to purchase a trip on a sailing ship manned by disabled people. Package offered full-care support during a two-week trip.

Buckinghamshire People's Voices

Service user with specific cultural dietary needs was able to employ someone to prepare a meal once a day.

Brighton Direct Payment Advice Service

An older person employs a personal assistant to work with the physical tasks required and another support worker to assist with payroll support work. As the disabled person also experiences a visual impairment, a third support worker assists with reading information and figures from the payroll service. Together they provide a useful interconnecting network of support to enable the disabled person to continue their work as an artist and creative poetry composer.

Example supplied by NCIL

6 How would you set up a direct payments scheme?

- A large number of local authorities now have direct payment (DP) schemes. For a scheme to be successful, one of the key messages seems to be that it is extremely important to get elected members, senior managers and finance managers on board. They need to understand the implications and requirements, including the financial ones, to run a direct payments scheme properly.

One of the main issues for councils is to understand the wider implications of DPs for council processes. Offering DP is the easy part. The infrastructure to support this – from the setting up of the DP with the individual and the ongoing support required, to the monitoring of how DPs are used and the adjustment of the budget structure to allow for DPs in areas that have traditionally been block contracts – is all important. An easy guide to setting up would be useful, but the key is to find champions in the organisation to take the issue forward.

Leicestershire LA

- The evidence from the practice survey shows that differing models of practice regarding direct payments are operating throughout the country, despite government guidance seeking to create consistent practice.
- Perhaps two of the key differences are whether or not there is a direct payment support scheme and the level of partnership that exists.
- If there are no existing local direct payment support schemes, the local authority should take action to promote and fund a service user-led group to provide these services.

You've got to be bold. Those of us who have made progress on direct payments have done so because we've taken risks and been bold. This was especially so in the early days, as Coventry made the decision to go with direct payments when other authorities were very uncertain about the legality and practicality of the approach, but we felt it was the way forward. We are now well established as a result. We also found a way of making direct payments available to a person with learning disabilities via a direct payment support organisation at a time when it wasn't clear how this could be done without incurring some risk. It's a balance between being bold to enable people and building in safeguards.

Coventry LA

- Many authorities have established 'champions' in social work teams who have responsibility for development and promotion of direct payments. This work is being done not just within their teams, but also within their local communities, service user groups and voluntary organisations.

In the short term, this has been an effective way of embracing direct payments, but in the long run, direct payments need to be supported both financially and as part of the infrastructure by senior managers and elected members.

- This support could also include the cost of purchasing independent advocacy and direct payment support and advice.

Introducing direct payments requires effective leadership to drive the process of implementation from national direction and guidance through to local leadership, at both a strategic and an operational level.⁴

- Other suggestions from the practice survey have included the establishment of regular liaison/meetings between senior managers, service users, voluntary organisations and social services staff, to ensure on-going communication and the resolution of any issues that arise.

All of our senior managers were very committed. Regular meetings between DP users, voluntary sector, social services staff, senior manager from each customer group attended each meeting and a DP champion was introduced. [DP champion is a local authority expert on DPs who could be contacted during working hours.]

Hounslow LA

Provided a briefing for elected members and offered a workshop on DPs. Used a video presentation of service users explaining the difference that DPs had made to their lives. Members have since been sympathetic to requests for additional funding and refer service users to us if they come to their surgeries with complaints about care agencies.

East Riding of Yorkshire LA

- In a paper¹⁴ for the Social Services Research Group conference (2000), Hasler stated that successful implementation of direct payments is based on: outreach – so people get to know about the option; local support; enthused and informed care managers – so that referrals are made for direct payments; holistic and realistic community care assessments – so that the overall package is workable.
- In an article¹⁵ in *Community Care* entitled 'Direct to the client', Alison Miller reported on a Cumbria-based direct payments scheme that had won the older people/intermediate care category in *Community Care's* awards 2001:

Fred Wilenius is the service manager. He says: 'We realised it was going to be hard to get people to take on direct payments if we didn't have some sort of support systems in place. People were asking, "Will there be support available to help me?"'

The main barriers preventing people from using direct payments were that many older adults were worried about the responsibility of becoming an employer, and that social services would abandon them once they took on a direct payment. There was also a dearth of information about direct payments for older adults, and many professionals in the statutory and voluntary sector were not telling their clients about direct payments because they believed they were very unlikely to be interested.

Wilenius says: 'We set up consultation groups – two coordinators were set up to look at direct consultation with users, which seemed to be the best way to find out

how to go about promoting direct payments and find out what we needed to put in place for it to work.'

- Both the content of the Strategy Unit report 'Improving the life chances of disabled people'⁷ and the green paper 'Independence, well-being and choice: Our vision for the future of social care for adults in England'¹⁶ have reinforced the future of direct payments in social care.
- Nevertheless, they require the backing of local authorities across the board to ensure they are embraced by social care staff. This also requires senior managers to give their staff permission to test out the guidance, be creative and take some risks.

7 How can the money for schemes be secured when it's tied up elsewhere?

... Of course, this will mean you have to change the way you manage your budgets – and this won't always be easy. You cannot tell people that they cannot have a direct payment because all the money is tied up in block contracts.

*Dr Stephen Ladyman, former Minister for Community,
Department of Health,
26 January 2004*

- One of the issues raised in the practice survey is the 'postcode lottery': some areas promote and deliver payments where others do not; some provide sufficient funds and others state that the money is tied up elsewhere.
- Nevertheless, the practice survey identified several examples across the country where budgets have been secured.

Provision needs to be standardised. At the moment you get different things on offer depending on where you live. In some places you get a good support service and in others you might not get direct payments at all.

Direct payment service user

- One suggestion is 'top slicing' of the entire budget across all local authority services to create a direct payment pot. What is clear is that funding needs to be specifically allocated, and budgets must include dedicated costs for administration, publicity and promotion.

In physical disabilities, we have freed up money from modernising day provision and used it differently. DPs predominate in this service area and it is free from in-house services and block contracts. We need to develop further, contracting in-house provision and decommissioning in other areas so we can increase the flow of money and flexibility of budget.

Gateshead LA

We established a budget for the direct payment support organisation by top-slicing operational budgets on the basis of anticipated usage – this will be adjusted in the light of actual take-up. Funding for the DPs themselves does, and will continue to, come from operational assessment teams purchasing budgets as DPs replace traditional methods of arranging services.

South Gloucester LA

Each customer care group has its own budget – e.g. learning difficulties, they were awarded a target of 40 users this year. First of all, we would monitor progress – evaluate the response in our quarterly report. If figures are very low, we then try to identify problems that exist and look at ways to encourage users in different ways. It would be addressed at monthly meetings attended by the DP champion, DP coordinator and DP advisers.

Hounslow LA

Day centres for physical disabilities closed and budget transferred to day care services, where individual advised of community resources. Direct payments fund these activities.

Cambridgeshire LA

"Communication with the finance section is enabling the virement of funds from the home care budget to reflect the growth of direct payments.

Wakefield LA

Pay rates for DP support workers in direct payment support services need to be equalised around the country. Support workers are coming close to doing the job of a social worker without the training/recognition.

Independent Living, Norfolk

- NCIL¹⁴ reports that the evidence showing direct payments to be cost-effective seems to have led some authorities to assume direct payments must always save them money. This is despite all the advice from good practice authorities, stressing that direct payments represent an effective, targeted use of resources, whether or not they actually save money ... Budget issues also have an effect on individual assessments, and thus on the design of viable direct payments packages.
- The argument for cost effectiveness was tested again by Dawson in 2000.¹⁷ It concluded that:

A direct payment scheme that involves disabled people from its inception and throughout its operation can provide a very positive alternative to direct service provision and one which empowers disabled people to live their lives as they choose with no additional cost to the Social Services Department.

Evaluations have been made of a number of other direct payments schemes. Most have not been published. Similar themes emerge in them all – for instance, that payments are cost-effective.¹⁴

- Clearly, money is a significant issue, both for the local authority and the direct payment service user. For the latter, the local authority needs to consider if they are setting up the service user to fail by not providing sufficient funds – for example, for them to employ a personal assistance with suitable experience.
- Many service users have argued that they should be able to offer a personal assistant a minimum of £10 per hour, although it is likely that this amount will have geographical variations. Nevertheless, recruitment is not an easy process, and is made that much harder with insufficient funds.

It is up to the local authority to decide on the amount of a direct payment, but it must be enough, taking into account any contribution which the individual is expected to make to the cost of his or her care package, to enable the recipient legally to secure the relevant service to a standard which the local authority considers is acceptable.¹⁸

8 What are direct payment support services and how can local authorities develop effective partnerships with them?

As a recipient of direct payments there are significant administrative tasks to be undertaken, including the employment and management of care staff, taxation and accounting issues. There are differences in the level and standard of support offered to direct payment users by councils in respect of these issues. The quality of the support provided has a significant impact on the experience of using direct payments. Some councils have commissioned independent agencies to provide a support service to direct payment users. People said that they prefer an independent body to provide the support service.⁷

- Direct payment support services (DPSS) can comprise local groups of direct payment (DP) users solely led and run by disabled people who work with local authorities to provide free and independent support services to direct payments users.
- Evidence from the practice survey suggests that a good relationship between the DPSS and local authority is essential in the continued development of direct payments locally.

We run bi-monthly direct payment user group meetings. We have a DP service user as chair of our local implementation steering group.

Brighton Direct Payments Advice Service

The evidence has shown that councils working in partnership with the voluntary sector, especially organisations run by disabled people themselves, are often the best way to deliver direct payments.

Dr Stephen Ladyman, former Minister for Community, Department of Health, 26 January 2004

- In addition to locally run user-controlled organisations, support organisations can be run nationally – for example, by the Penderel, Rowan or Shaw Trusts, who provide support services to direct payment users through contracts with a number of local authorities.

The scheme is managed by a committee of DP recipients who guide the direction of the scheme and support and direct the staff. The PA User Group meets regularly and has an opportunity to feed views to management committee and staff.

Kingston Centre for Independent Living

A support service needs to offer ongoing support throughout the life of the DP, not just [in the] initial stages. As a support service, it is important not to take over someone's DP but support them and assist them in all aspects of the process. It is also important to remain unbiased and impartial when dealing with social services and the service users.

Sandwell Ideal for All Ltd

- Local authorities should make the most of the DPSS expertise and agree on the most effective ways to ensure communication. Local authorities could also employ the DPSS to deliver training and coordinate service user feedback.
- This could be directly through the DPSS, through partnership boards or direct payments user and consultation groups.

A user-controlled best-value review of direct payments¹⁹ concluded that:

Developing more appropriate independent support mechanisms and improving internal management and financial processes within the Social Services Department would improve disabled people's experience of direct payments use and therefore the quality of their lives. The knowledge and confidence of care managers is crucial to the information and messages given to service users about their choice of direct payments and therefore its uptake.

Social services listen to and rely quite heavily on our opinion. We suggested they use a 'fast-tracking protocol' for users who already receive community care packages instead of having to wait sometimes up to one year while they are referred to a different care manager. Social services listened to us and the system was adopted.

Croydon Direct Payments Support Service

Direct payment users have influenced the way we work. We have a direct payment support worker contract with a local voluntary organisation and one of the challenges for them is delivering the business of the contract and advocating on behalf of service users. The relationship between the two organisations is positive and this is critical to the successful working relationship.

Hampshire LA

We are an organisation of disabled people, 100% run, staffed and controlled by disabled people. We are all service users.

Independent Choices, Northamptonshire

All our management committee are disabled people. We consult with disabled people. We work to the social model of disability. Our service aims to promote disabled people as experts in their own lives.

Nottingham and Nottinghamshire Direct Payments Support Service

We work with our user groups with DP Partnership Board. Any decisions that have to be made about direct payments can only be made at these meetings. Decisions cannot be made without their guidance. Meetings are held on a monthly basis. Council have confidence in user-led groups, user-led managed. I am involved step by step but they are in charge.

Gateshead LA

Support services were crucial in enabling older people to use direct payments. The major difficulty lay in meeting audit and administrative demands, necessitating ongoing assistance from support services. Local authority funding does not always account for this.⁴

It is important that local people should be consulted fully as local arrangements for making direct payments are set up. The best direct payments schemes have been developed by local authorities and users working together to draw up a scheme that meets local needs. Local authorities will wish to take care to avoid focusing on one group of potential users to the exclusion of other groups and should not make the assumption that organised groups necessarily represent all users and their carers in the locality who might benefit from the flexibility offered by direct payments.¹⁸

9 How can schemes be promoted and publicised?

- Promotion and publicity is clearly essential if the take-up of direct payments is to improve in the way Stephen Ladyman, former Minister for Community, set out:

Let me make it very clear. I want direct payments to play a central role in the future of adult social care. I don't want them reduced to a bit part, as they still are in too many places. I'm concerned that direct payments are not taking off as many of us had first hoped. Numbers were and are rising, but nowhere near as quickly as they should be or as they need to be ...

I want care managers and social services staff to become immersed in the way direct payments can work for people, to find out what the advantages are, to address the challenges, to find solutions to the support needs and the very reasonable concerns of potential recipients. I want social services to think laterally, not think literally. I want them to explore and push the boundaries of the possible and come up with flexible and innovative ways for meeting the support needs of these individuals ...

I want to see a future where social services work more effectively to produce the range of services and options that allow people to make meaningful choices about their lives.²⁰

- The Department of Health figures for 2003-04²¹ show that 17,300 direct payments were made in England.²¹
- While there has been an increase on the year before, this amount is still disappointingly low. Promotion of these payments has primarily been directed at service users but also their families and carers, as well as the community whose members may be interested in pursuing a career in social care.
- Promotion has been extremely successful when done in partnership with a direct payment support scheme or other user-led organisation,
- These are examples from the practice survey:
 - > the appointment of a development manager to produce literature and publicity
 - > clear, jargon-free publicity leaflets in accessible formats, such as Braille, audio-cassette, video/DVD with sign language and subtitles. These should also be available in local community languages, and there should be a version suitable for users with learning disabilities.
 - > accessible website on direct payments including advice sheets. This can be for specific local authorities, as well as national resources such as <www.valuingpeople.gov.uk>, <www.icesdoh.org/article.asp?Topic=110> or <www.changeagentteam.org.uk/>.
 - > using the media – for example, publicising direct payments in the local press, in regular articles in the borough-wide free magazine, via advertisements on local radio
 - > radio interviews and open forum sessions, when professionals talk about direct payments, then the phone lines are opened to the public.
 - > GP surgeries (leaflets, drop-in sessions, health visitors, etc.), post offices, posters
 - > briefings and promotions at planning forums or meetings of user groups
 - > presentations at conferences by direct payments users

- > working with county learning disability teams on a drama presentation
- > information days: for example, during Learning Disability Week, stalls can be run by direct payment workers
- > road shows
- > direct payment surgeries such as information sessions to reach all isolated users
- > promotion to specialist voluntary groups, such as joint meetings with Mencap and attendance at community events with information available in a range of formats: CDs, tapes in different languages, large print.

Looking at the development of the direct payment service in Peterborough, it was clear that, to maximise the benefit of the service, we would need to widen the style in which we informed individuals of its potential. We had already made the decision to invest in the independent support service in order to increase capacity, so it was decided, after consultation with service users, that the best way of promoting the service was directly to those who would use it, and from an independent perspective. We then specified that part of the increased support service budget be used to employ a part-time member of staff to promote direct payments with users, carers, and user groups. By doing this, we are able to inform many more individuals about the local direct payment service than simply via our own information, or through social workers and other direct workers.

Greater Peterborough Primary Care Partnership

- Care managers should discuss direct payments with all eligible people at the time of assessment or review. It should be a specific question on the community care assessment form.

We are commissioned to offer road shows to specific user groups in each authority area which publicises direct payments.

West of England Centre for Inclusive Living

A social work manager in community mental health was funded to conduct a four-month project on direct payments (DPs) and mental health. She arranged a stakeholders' conference and initially hoped to set up a DP users group but was unable to achieve this. She then turned her attention to improving the awareness of social workers within the department of DPs. She found that the general training on DPs was not particularly helpful to mental health workers as did not cover their very specific legal constraints and something more specific was required. Next she conducted a survey within the department to identify social workers who were already engaged with mental health DP packages. These workers became the DP champions in their respective teams. They built up a body of expertise. The worker promoted DPs at team manager meetings and arranged for consideration of DPs to be included in the standard care assessment form. She made contact with the local direct payment support service and acted as a link between them and the social work team and explained departmental procedures. She devised a new referral form with a tear-off slip for social work managers to specify to the DP support service what further information would be needed to progress cases they referred – e.g, GP referral.

Tameside LA

- It is clear that publicity and promotion should not be limited to informing service users. Local authority staff also need to be included and kept up to date with developments, new ideas, and changes in legislation.

One authority set up a focus group, predominantly for staff working with people with learning disabilities and the direct payment support service, Rowan. They also consulted with the advocacy organisation, and a direct payment (DP) service user attended a couple of meetings. Through the group they identified some of the barriers to people with learning disabilities accessing direct payments, and looked at ways of addressing these, particularly methods of raising awareness and knowledge. Through the group they:

- established lead practitioners in teams to support other care managers with the process of direct payments
- produced a simple plain English/supportive pictures service user leaflet produced a leaflet explaining what trusts are so [that] carers/relatives knew what the options were for people with higher support needs reissued Department of Health material to all teams
- arranged for direct payments to be the subject for one of the Service Users Parliaments ([comprising] 30 'MPs' – users elected to represent their areas) where presentations on what DPs are were held and a panel of LA and Rowan staff answered questions. This included a presentation by a person with a learning disability who was setting up a DP scheme. arranged for DPs to be discussed at locality groups (local groups where representative service users/carers/voluntary organisations meet to focus on issues of local interest) fed back to the management team about some of the issues, etc.

Cambridgeshire LA

10 How can you ensure that the process runs as smoothly as possible?

Monitoring and review of direct payments

- If a service user is struggling with a direct payment, the first issue to be considered is whether additional support can be provided. Different options need to be considered before the direct payment is stopped.
- Direct payment service users should have reviews with their care managers at regular intervals, or at their request, to ensure that the package is still suitable for that person's needs.

Legislation allows for the local authority to seek repayment of money, if it has not been used to obtain the type of service or equipment for which it was intended. However, DH [Department of Health] guidance explains that this provision is not intended to penalise genuine mistakes, as opposed to wilful misuse of the money ... the legislation and policy underpinning direct payments clearly establishes arms-length arrangements in which the local authority will inevitably exercise more control ... for local authorities to be over-prescriptive about how the care package works might threaten to undermine the very purpose of the payment.¹²

- In 2000, Scope²² reported that, so far, monitoring and guidance had been more about finances than the quality of services. This perhaps reflects the concerns that people will run off with the money or misuse it. However, accountability and safeguards are built into the process.

People want to be trusted to spend their direct payment money on the things that they need. They want flexibility and control.⁹

I was told by my social worker: 'Your care package is not fixed in stone – get in touch if you need to inform us about any changes.'

Direct payments user

... In Scotland, practitioners were deterred by perceived expenditure and workload implications ... and by a fear of loss and control. Others were concerned that service users would misspend their payments on drugs or alcohol ...¹⁹

- The Valuing People support team have produced an extremely practical document entitled *A guide to receiving direct payments from your local council*.²⁴ In the section 'What do I need to do before I start receiving direct payments?' (pp 25–27), there is a comprehensive list of all of the issues that should be agreed between local authority and service user, and is written for the latter. Adapted for this guide, it includes:

- > how often and in what form payments will be made
- > the information the local council needs to receive about how the money is spent
- > what the money may and may not be spent on, and how much flexibility will be allowed

- > what needs the direct payments relate to
 - > what services the direct payments are meant to cover
 - > the value of direct payments to be received.
- If the service user decides not to carry on with direct payments, then the local council should arrange services instead. If the council does not think the service user can manage direct payments any more, it might decide to stop giving the money and to arrange services instead.
 - The local council should involve service users in any decisions being made about support and care, and ensure that they know what is decided. Ideally, good practice would require this to be a collaborative and person-centred process.

Difficulties can be minimised by good assessments, clarity (e.g. about what the money can be used for), monitoring, effective support arrangements and by discussing potential areas of difficulty, and how they will be handled, with the user before direct payments begin.¹⁸

- The arrangements made about how direct payments will be used should be reviewed in the same way as traditionally received services. This will establish whether needs are being met and whether they have changed in any way.
- Many social care staff are concerned with risk. This was picked up in an article by Sian Vasey in *Community Care* – ‘Our way or no way’²⁵ – which states:

From what is known, most individual direct payments schemes work well, but, perhaps inevitably, some probably don't. And when this happens it can create conundrums for social services. Could they or should they intervene, and if so, under what circumstances? With the exception of corruption or other abuses of funds, do they even have the right to ‘interfere’ in what is an essentially private arrangement between disabled people and the staff or agencies they employ?

- The article discusses how this was a dilemma faced by one practitioner in a particular case. Sian Vasey concludes:

This case has put the system to the test, but it shows that allowing people autonomy is the right thing to do. When a direct payment is in place, the buck must stop with the disabled person on the issue of employing people and on the issue of making sure their own needs are met.

- On one level, it is inevitable that, for some, direct payments will not work for a variety of reasons. However, the same principle can also be applied to the provision of traditional services.
- The relationship between the service user and local authority/care manager is key. If it is one of partnership and collaboration, with the proper reviews and checks in place, the risk of things going wrong would be greatly reduced.
- There is undoubtedly a role for direct payment support services in this process. They have a part to play in both protecting the rights of the service user and also feeding back issues to the local authority to enable schemes to develop.
- This may appear idealistic, and it may not always be possible to achieve. However, these are principles on which independent living and the success of direct payments

depend. In many ways, the guidance and legislation is encouraging staff to take risks, be flexible and creative and learn from the experience.

Councils should follow existing guidance on carrying out reviews. The fact that the council is making direct payments rather than arranging services itself does not affect its responsibility to review an individual's care package at regular intervals. As with all services, the projected timing of the first review should be set at the outset. The purpose of the review remains to establish whether the objectives set in the original care plan are being met. It should therefore cover whether the person's needs have changed, whether the use of direct payments is meeting assessed needs, and how he or she is managing direct payments.²⁶

Criminal Records Bureau (CRB) checks

- If direct payment recipients are employing an individual to care for a child, the local council should carry out checks under the Protection of Children Act through the Criminal Records Bureau. The council must carry out the check free of charge. The same regulation should be applied to disabled 16- and 17-year-olds.
- Disabled adults who want a similar degree of reassurance about the suitability of their personal assistants will need to enter into a contract with an approved agency who can request the CRB check. The local council or direct payment support service should be able to offer more advice about vetting potential workers.

11 What training might give me more confidence in working with direct payments?

- Good practice is not only about the mechanisms of direct payments (DPs), but also about disability rights and how to promote independent living.
- Training is needed at senior levels and for practitioners and should include material on independent living, the social model of disability – <www.ncil.org.uk> – and person-centred planning: <www.valuingpeople.gov.uk> and <www.personcentredplanning.com>.
- Training about direct payments should be included on social work training courses and in inductions for new staff, as well as for those undertaking specialist roles (e.g. a DP champion, people working with people with mental health impairments, assessment).
- All training should be continuously reviewed and developed. There are good examples of training delivered by service users, who can talk first hand of their experiences and the differences that direct payments have made. The National Centre for Independent Living (NCIL) also offers consultancy and training on how to do direct payments.

The knowledge and confidence of care managers is crucial to the information and messages given to service users about their choice of direct payment and, therefore, its uptake.¹⁹

- The following examples are taken from the practice survey:

We are introducing a new style of training where we have a day's training followed by half-day slots to deal with the specialities – e.g learning disabilities, older people, mental health impairments. There is a revamping of the course content, from the general overview to the specific case-focused work, with direct payment service users who have personal experience.

Hampshire LA

We provide a day on policy and procedure, practice guidance and updates on DH guidance for social workers including briefings on legislation and guidance and duty clauses. Via partnership board we do briefings on issues like trusts, independent living, etc (practitioners invited). Briefings are also regularly sent to senior/middle managers.

Gateshead LA

There is good take-up of the training – high demand, always people waiting for the courses. Coordinated by the council but involves the user network and support and advocacy services – they have also helped design the training. Social work staff were also consulted.

Essex LA

- Several people in the practice survey suggested that joint training between the local authority and the direct payment support organisation would be an ideal method of delivering training.

- This would enable participants to hear the perspectives and experiences of recipients of direct payments with expertise and of colleagues who have successfully implemented them.

Direct payments coordinator provides training, meets social workers on an individual and group basis. Example case loads are used to show how to deal with different issues that can occur. Independent Living Trust (ILT) coordinator develops training to suit care managers. They all seem to be able to promote DPs, as numbers have greatly increased.

Hounslow LA

12 What about promoting direct payments to minority ethnic and other marginalised groups?

- It is recognised that, so far, few direct payments (DPs) have been made to people from minority groups. However, there are examples of work that has been done to promote payments and encourage take-up.

We are working to make good contacts with black and minority ethnic groups and encourage members of these communities to take up direct payments. We started initially by inviting representatives from ethnic communities to the launch of our new website on direct payments. Through this, we recruited some service users to the scheme which then gave us the opportunity to reach further into the community. We would ask them and their family members for ideas about places and groups we could go to make presentations on direct payments. We would encourage the DP user to talk about her experience of the scheme to others in their community.

Brighton Direct Payment Advice Service

- The Equalities National Council <www.encweb.org.uk> has produced a video entitled *Breaking the barriers*. It is aimed at service users and is also a useful tool for practitioners and their managers.
- Although the following examples of methods to promote direct payments relate specifically to black and minority ethnic groups, it appears that some principles can usefully be applied to other marginalised groups:
 - > targeting people to attend specific events where information is being provided, such as community events
 - > recruiting service users to schemes/local authorities and using their knowledge and expertise in informing others
 - > outreach work in the community
 - > encouragement of service users to share experiences
 - > use of educational material in accessible formats, such as Braille, video, easy read <www.valuingpeople.gov.uk and www.nimhe.org.uk>
 - > employment by the local authority of specialist workers from specific community groups.

Direct payments offer greater independence and flexibility in support arrangements and, for people from black and minority ethnic communities, this can mean improved access to culturally sensitive support. For people experiencing mental health problems, direct payments can facilitate social inclusion, through providing support to access mainstream activities that are not stigmatising or mental health-focused ... Targeting specific groups and taking information to them was identified as essential – for example, targeting people before they leave hospital, outreach work with black and minority ethnic communities, as well as ensuring that the options are discussed with all potential recipients. Undertaking this work adequately would require resources and training being made available but is vital if take-up for these communities is to be increased.²⁴

The Essex Coalition of Disabled People put a successful bid together to the Direct Payment Development Fund, which Essex Council supported. This bid was successful and part of the funds have been used to appoint a full-time Direct Payment User Network (DPUN) coordinator. One of the key objectives for DPUN is to broaden the representation within the network to include traditionally under-represented groups including direct payment users from B&ME [black and minority ethnic] communities. DPUN now has representatives for older people, people with learning disabilities and people with mental health difficulties, as well as people with physical and sensory impairments and parents of disabled children. It is hoped that strong links can be established between the B&ME advocates to inform disabled people from these communities of direct payments and the existence of the Direct Payment Users Network, hopefully resulting in broader representation of these under-represented communities.

Essex LA

A specialist worker was appointed in October 2003 to work with black and minority ethnic groups, who is funded by the Department of Health. He has been making links with service users in minority ethnic communities and promoting direct payments in a number of ways. By working with 'Carers Bucks' he has been able to go on joint visits to minority ethnic service users and promote the idea of direct payments to them. This has increased take-up from these communities. He has also visited mosques and community centres and did a particular promotion during the Eid festival when local imams publicised the existence of direct payments and recommended it as a form of help available to families who have members who are disabled or have mental health needs and gave him as a contact. This helped to increase enquiries and take-up of DPs. He has also publicised DPs to mosque committees, worked with the race equality officer, the town mayor and social services care managers. The mental health sector has not produced many candidates for direct payments so far, but via home visits with people from Carers Bucks, applications are starting to come through.

Buckinghamshire People's Voices

... Having access to an accountancy service through the direct payments support service to deal with the banking and administrative requirements was essential in overcoming the language and literacy barriers faced by the older women. None of the women spoke English and some experienced difficulties in dealing with bills and official letters. A link between Somali community workers and the direct payments support service helped to bridge the information gap between social services and the community, as well as give the older people access to direct payments.⁴

- There is still much work to do, both in terms of informing communities about the opportunities that direct payments can bring and in making the process accessible and culturally sensitive. Yet there are undoubtedly examples of good practice as well as subsequent evidence of an increase in the take-up of direct payments from people from black and minority ethnic groups.

13 How do you introduce the idea of direct payments to service users? How does the assessment process work?

- The care manager needs to be very clear about what direct payments are, who is eligible and what can be offered. This may well have implications for training, particularly where people's needs are more complex (see pp 31–32).
- Having confidence in your own knowledge and how the process works is essential, but the latter will differ across authorities, which can be confusing.
- The local authority should think about developing information for staff and service users alike that is clear and accessible, about all aspects of direct payments, and ranges from assessment through to monitoring and review.
- This information should address issues such as advocacy and the responsibilities of becoming an employer, and should reflect the Department of Health's Fair Access to Care Services (FACS), which covers the assessment of all adult users of social care, including older people. It says that assessments should include:
 - > sustaining social support and relationships
 - > sustaining family roles and other social responsibilities
 - > life and health including risk of abuse or neglect
 - > choice and control over day-to-day environment
 - > ability to carry out personal routines
 - > ability to take part in work, education or learning.²⁷
- The Department of Health *Circular LAC (2002) 13 Fair Access to Care Services (FACS) guidance*²⁷ provides a framework for local authorities to use when making decisions on how they can provide support to adults of any age. They are required to be consistent in setting priorities that meet people's needs in order to promote independence and quality of life. The assessment for direct payments is the same as for other services. This means looking at the need for support and what social services sees as possible risks to the person's independence if they do not get a service.
- According to suggestions made during the practice survey, care managers need to be relaxed and have more faith in the direct payment approach.
- Care managers need to be flexible and move away from the traditional methods of doing things, *always* discussing the possibility of direct payments instead of deciding who it may or may not be suitable for.
- Direct payments should be part of a person-centred community care assessment, which should offer the person a positive choice that needs to be fully explored before a decision is made.
- It should also be remembered that just because someone does not want a direct payment at a particular time does not mean that the option should not be reconsidered at a later date.

The judgement as to whether someone is able to manage direct payments, and how much help is appropriate, can sometimes be difficult and will need to be made on an individual basis. Local authorities should consider what assistance would enable a

prospective direct payments user to manage, rather than assuming that the person is unable to manage.¹⁸

- The assessment may well require several sessions to complete. In addition, it may be a complex situation requiring the support of advocates, family members, interpreters, and staff from the support service, as well as the service user and care manager. However, this is no different to completing a traditional needs-led assessment.
- Take the fear factor away by giving simple and clear information.
- Part of the assessment relates to a person's ability to manage. The FACS guidance is very clear that, where necessary, support should be provided to facilitate this process, rather than seeing it as a problem or reason to exclude someone.
- Support can come from a variety of sources, including family, friends and local support services that have been established to provide experience and expertise.
- There is always the option of maintaining or contracting traditional services while this happens.
- *The good practice guide for support workers and personal assistants working with disabled people with communication impairments*²⁸ discusses different methods of communicating and provides examples from service users that may be useful for the assessment process.
- Methods vary from so-called 'low-tech' aids such as pictures or books, to 'hi-tech' equipment such as voice output communication aids. The guide goes on to provide some useful tips – for example:
 - > Slow down and listen.
 - > Pay attention to body language and facial expression.
 - > Don't be embarrassed if you don't understand at first.
 - > Treat the person with respect, in the same way you would want to be treated if in that position.
 - > Take time to find out how to communicate with the person.
 - > Check out that you have got it right.
- When working with people with learning disabilities and those with mental health issues, make use of *advocacy services* and other recognised supportive approaches to ensure that they have equal access to direct payments.
- For information on person-centred approaches and planning there are numerous websites and training materials available – for example:
 - > Person Centred Planning & Approaches <www.personcentredplanning.com>
 - > British Institute of Learning Disabilities <www.bild.org.uk>
 - > Valuing People Support Team <www.valuingpeople.gov.uk>
 - > North West Training and Development Team <www.nwtdt.com>
 - > Circles Network <www.circlesnetwork.org.uk>
- If a person has mental health problems, this also needs to be integrated with the care programme approach.

Handling money is known to be a problem area for individuals with dementia and their carers, which often worsens as the condition progresses. However, progressive

agencies offering dementia care and advice, such as Alzheimer Scotland Action on Dementia, advocate the making of plans while the person with dementia can understand and discuss matters. This would suggest some scope for involving people with dementia in considering cash payments instead of services, even if this has to be at the earliest stages of dementia.²³

I had the ins and outs and pros and cons explained to me and was told all about the direct payments scheme. It was good because it took into account my social life as well as my personal needs.

Direct payment service user

On the whole, people with learning difficulties need exactly the same sort of information, support and advice as other potential direct payments users – that is:

- information
- support in accessing direct payments
- support in managing them, including payroll, managing staff, etc.

However, they may need this support provided in a different way (for example, written information may not be so useful or timescales for discussions and decisions may need to be longer). They also often have the hurdles of assumptions around consent and ability to manage a payment to overcome too.²⁴

- Andrew Holman²⁵ refers to several pointers in the successful assistance and management of direct payments for people with learning disabilities. He says that those who assist with direct payments should:

- > show how this help maximises an individual's participation in decision-making about their direct payment
- > recognise and respect the way in which an individual expresses himself or herself
- > incorporate centrally, in the care plan, the ways in which someone makes their preference known in decisions made about the use of direct payments
- > provide the service user with a range of opportunities and experiences in order to further facilitate informed choice
- > document evidence that decisions about a direct payment are being made in this way, including evidence of outcomes and their desirability.

Care managers carry out joint visits with advisers from the support service during the initial stages.

Croydon Direct Payments Support Service

- Self-assessment is an important aspect of this process, and applicants should be able to identify their own needs. This can be facilitated through an advocate/family member/friend, and can be done in advance of meeting.
- The process can also be facilitated by involvement from the direct payment support services (DPSS). DPSS are generally staffed by service users, and it can be helpful to have someone with first-hand experience to explain the process and deal with any concerns.

It was good as I had support to do my own self assessment in advance and felt well prepared and supported.

Direct payments service user

In considering whether people's proposed arrangements will be adequate, local authorities should not be constrained by existing patterns of service provision. By exploring innovative and creative options, it may be possible for users to identify alternatives which both cost less and meet their needs more effectively. Where the user's needs fluctuate over time, it will be important to discuss in advance how the direct payments will be used to secure a package of assistance which varies according to need.¹⁸

One participant of a focus group, who was an Asian person and had mental health issues as well as physical impairments, commented that she was not allowed to have her advocate from the mental health advocacy group there in the assessment. This clearly breached accepted good practice and there was a general consensus that DP users must be given the option to have advocates present during the assessment.

Direct payments service user

- Assessments should include six main categories:³²
 1. personal and social care
 2. health care
 3. accommodation
 4. finance
 5. education, leisure, employment
 6. transport and access.

The initial assessment as a couple was good – the social worker kept in contact and adjusted the requirement as my husband's condition deteriorated. We were both consulted and consent requested.

Direct payments service user

- Assessments should include plans to cover for emergencies/sickness and holiday cover. For some people, such as those with mental health problems, an advance directive can be put in place for times when they are feeling distressed or their mental health has fluctuated. This will enable the person to retain some control over their life and the response of others around them. For more information, contact NCIL and request a copy of *Direct payments for mental health users/survivors: A guide to some key issues* <www.ncil.org.uk>

... Implementation relies on an understanding of a social model of mental health, which emphasises capacity and recovery.²⁴

We are currently working with the local People First group to make all of our DP material accessible to people with learning disabilities. There is a section on having an assessment with the social worker and the importance of the person telling them about their needs. It also promotes self-advocacy and the involvement of the family or people close to the person during the time of assessment.

Sandwell Ideal for All Ltd

Understand that independent living is so much more than having a shower and your bum wiped of a morning and half an hour back to bed. It's about socialising, working, housework whatever the disabled person wants.

Direct payments service user

- Remember that direct payments are not set in stone. Just because the assessment has been completed, it does not mean that that is the end of it. Flexibility is essential to take account of the changing needs of service users, carers and families.
- For example, direct payments can now be used for short periods in residential care if it is agreed that that is what is needed, as well as providing an alternative to residential care or hospital admission <www.dh.gov.uk/assetRoot/04/06/92/62/04069262.pdf>.

14 What about gaining consent?

- One part of the assessment involves being clear that the service user is able to consent to a direct payment (DP). This needs to be approached creatively and with an open mind by the assessor to ensure they are able to communicate with people who may have a variety of impairments (see Chapter 13).

Under current legislation, as well as under the Mental Capacity Bill, each decision has to be assessed separately. It cannot be assumed that a person generally lacks capacity to make decisions; nor can it be assumed that a person will be unable to agree a direct payment simply because they may previously have been thought unable to make other decisions in their lives.^{27, 33}

- Gaining consent is a gradual process and should involve the individual direct payment user, social services, the family, advocates, friends and the direct payments support services (DPSS).
- The process can also be supported through the use of other tools, such as videos and pictures.
- The Department of Health (DH) has an easy-read guide to direct payments, which was developed by Swindon People First and can be downloaded from the DH website <www.dh.gov.uk>.
- Other useful tools and information can be found on the websites of the Valuing People Support Team <www.valuingpeople.gov.uk/DirectPayments> and the Joseph Rowntree Foundation <www.jrf.co.uk>.

We took this step by step. I first sat down with Jack and his mother and talked about the possibility. I took literature – the DH have a leaflet and a tape (now CD) about direct payments (for people with learning difficulties. Later we watched the *Values into Action* video together, it is really good, but most of the people in it have physical impairments, there are few with learning disabilities. All this gave him a flavour and made him aware of the possibilities, and gave him information to help him make his decisions ... The thing people need to remember is that they have to do an assessment anyway, whatever services people are having. Yes it takes time. I reckon it took four or five visits to complete the form. I took one section at a time and made sure Jack understood it all, understood what I was writing down, read it out, made changes. Consent was as much a process as a moment, though obviously there was a point when both Jack and his parents said: 'Yes.' This happened at a meeting of Jack, his mother and Ranjit in the family home. Once Jack understood that DP would enable him to do a variety of things that he wanted to do – go to college, the horticultural work and leisure activities – he was excited about the possibility. However, while Jack's mother could see the potential DP had to increase Jack's independence, she also had a number of anxieties about the responsibilities involved with DPs. She was concerned about the tax, National Insurance, employing the PA [personal assistant], etc. The support of the Direct Payment Support Agency was crucial in allaying her fears.

Nottinghamshire LA

We have money from the DP development fund to run a 'support network' project aimed at building on the circles of support model and applying it to DP users.

Independent Living, Norfolk

Our advocacy service is involved on many occasions and we have a worker identified within the support service to provide the extra support that may be needed by people with learning difficulties. Referrals can be made to us, and some care managers involve us at an early stage for this group.

Independent Choices, Northamptonshire

- Assumptions about consent and ability to manage direct payments can block people with learning difficulties from accessing support. These assumptions can be held equally by independent support schemes as by statutory services.⁴⁴

We are using DP development fund money to create a specialist post to work with people with learning disabilities to develop new ways of supporting people who need assistance to use and run their DP scheme.

East Sussex LA

- Assuming the assessment is user-centred, the service user can show consent retrospectively through satisfaction with the arrangements³¹

Measures local authorities were taking to maximise the potential for people with learning disabilities to make an informed choice included: providing accessible information, giving people time, reducing the formalities, respecting the ways in which people communicate, lessening the pressures and enabling people to make decisions in their own familiar environment.³⁴

- The key message for staff is that consent does not need to mean that the person understands the intimate details of how direct payments work, but they understand the options and how direct payments might make a difference to their lives.

What is a trust?

- A trust is a commitment made by one or more people to manage someone else's money and act on their behalf.
- Generally family members or friends, trustees have a duty always to exercise their powers in the best interests of the person receiving the direct payment.
- Trusts are legally binding and can be designed to facilitate supported decision-making, maximising the person's own control.

Susan, who is in her 20s is severely disabled. She makes her views known through her actions, verbal responses, facial expressions and moods. Susan's circle of support realised she was unhappy with existing services and put together a package to enable her to live independently. Direct payments was part of the package. The circle formed itself into a user-controlled trust fund, which manages the direct payment. Susan's expressions and views guide how the money is spent, so she is in control of the use of the money. Direct payments mean Susan can live

in her own house, with her own rota of support workers. She is relaxed, confident and content with a full social life and is very much part of the community.

Valuing People Department of Health, 2001

- More information on trusts can be found by contacting the National Centre for Independent Living <www.ncil.org.uk>.

Local authorities will need to consider how to treat someone with a fluctuating condition which affects his or her ability to manage direct payments. In many cases, people with such conditions may nevertheless be able to cope with direct payments if a friend, relative or some other third party is willing to provide greater assistance when their condition worsens. If the person's condition is likely to deteriorate to the point where he or she is unable to manage even with assistance, the local authority might consider ways of enabling him or her to receive direct payments to ensure that support continues to be delivered in the manner preferred by the user.¹⁸

- Advance directives are an opportunity to discuss in advance what should happen if a crisis develops or health deteriorates. This can ensure the wishes of the service user are always represented. For an example, have a look at the booklet *Direct payments for mental health users/survivors: A guide to some key issues*,³⁵ available from the National Centre for Independent Living (NCIL, www.ncil.org.uk).³⁵

15 Is employing a personal assistant complicated?

- A personal assistant (PA) is someone employed to provide some of the personal help and support a disabled person requires both at home and in the community.
- PAs need to have a range of skills and abilities to take on this work, as well as a positive attitude to supporting and empowering disabled people, according to their own wishes and needs.
- Sian Vasey's *Rough guide to managing personal assistants*³⁶ provides expert advice on a variety of issues ranging from interviews to disciplinary action.
- Direct payment (DP) users have identified that they need a wide range of commitment and collaboration from services to help them make a success of employing PAs.
- The local authority should ensure that these services are available. This can be provided directly by the local authority (LA) or through specific funding to a local direct payment support scheme.

Authority works with carers' centre to provide a wide range of support service including payroll service. Holds consultation meetings with service users in relation to the training needs of recipients and personal assistants.

Sefton LA

- PAs can be employed to do a great variety of tasks, ranging from personal care to walking the dog, watering the plants, reading correspondence, parenting and going on holiday.
- Direct payments support schemes have helped DP users considerably in breaking down the barriers and complications in employing PAs. Jobcentre Plus has also got in on the act to help this process in some areas:

We have also been working in partnership with Jobcentre Plus who provide us with a free accessible building to hold interviews and give us advice on recruitment procedures. Still developing good guidance handbooks on this process. These will be developed with Jobcentre Plus and ourselves. *But* will be user-led, as they [users] know what they want and what to look for.

Gateshead LA

- Additionally, there is literature available from the National Centre for Independent Living (NCIL) about the employment of PAs – *Everything you need to know about getting and using direct payments*,³⁷ to be revised October 2005 – with useful examples of job descriptions, interview schedules, contracts and disciplinary procedures.³⁷
- Direct payment recipients have suggested that PA registers would be useful resources to help with recruitment. These are now being set up in some areas.

We support with any aspect of employment and hold a database of PAs who apply for employment with other users of DPs.

Salford DPSS

- The practice survey includes more examples of innovative practice that support the employment of personal assistants:

- > Local authority offers links with Inland Revenue to provide support.
 - > Direct payment support scheme offers use of accountants.
 - > Direct payment support scheme provides every DP recipient with an information session with a representative from Acas (Advisory, Conciliation and Arbitration Service) to cover employment law.
 - > Local authority offers links with local Jobcentre Plus personnel.
 - > Local authority can provide DPs with a list of useful contacts for advice and expertise, including named contacts in human resources and legal services at the authority.
 - > Direct payment service users can be employed as mentors on employment law.
 - > Some direct payment support schemes issue a handbook to DP users that details the full procedures for and guidelines concerning employing staff.
 - > Many local authorities, direct payment support schemes and voluntary organisations now offer DP service users a payroll service to manage the tax, national insurance and payments of the scheme. In some cases, this is a free service; in others, a fee is payable.
- Direct payment service users have identified a need for training for themselves on their responsibilities as an employer and also, following their recruitment, for the PAs concerning their responsibilities.

Two people reported favourably on their local Inland Revenue office providing an outreach worker to help in the completion of their tax returns.⁹

We are shortly commencing a Community Fund project to research skills that PAs need to work with people with learning disabilities and will produce a training pack. Also a DH project which will produce a DVD college course for using DPs and will also train seconded social workers in DP to become ambassadors to improve practice.

West of England Centre for Inclusive Living

- The payment of personal assistants is a crucial factor in being able to employ the right person for the job. It should be remembered that they are offering a skilled service to vulnerable people. Local authorities should consider what constitutes appropriate levels of pay for such a job.

People have to be able to offer staff an 'attractive package' if they are to compete with other bigger employers. People who use direct payments are not always able to do this, as the amount they can pay staff is not enough.⁹

The direct payments advice service works with potential DP users to help with all aspects of becoming an employer including recruitment, payroll issues, etc. We also organise training for both service users and their PAs on an on-going basis (some of our training we offer through our local SS at a reduced rate).

Brighton Direct Payments Advice Service

Employing a PA through direct payment is not the same as having a care worker. They are a different type of person; in a way it is a new profession because people have to have different skills. If users understand this they will get more from their PAs. Otherwise it just reverts to the old way and people become dependent again.

Direct payments service user

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Direct payments: answering frequently asked questions

This resource guide aims to offer creative and innovative examples of how the legislation on direct payments can successfully be applied to achieve positive outcomes for service users.

It is hoped that the guide will inspire health and social care staff to embrace the principles of independent living and think more freely in applying direct payments to a wider audience.

The guide is designed to answer specific questions on direct payments easily, as well as provide access to numerous useful websites and give practice examples.

This publication is available in an alternative format upon request.