

Making Direct Payments a reality for people with learning disabilities

Ali Gardner

Working with local services in Cheshire, Greater Manchester, Lancashire, Merseyside and South Cumbria in moving towards better futures for people with learning disabilities.

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ISBN No: 1-898385-23-8

Acknowledgements

The research carried out by Values Into Action (VIA), London, in particular the report *Funding Freedom Direct Payments for People with Learning Difficulties (1996-1999)*, significantly aided the development of this report. For those interested in this subject, I must stress the value of the material produced by VIA on Direct Payments and would recommend exploration of this work, which is produced in several forms.

Catherine Bewley from VIA kindly read and commented upon a draft of this paper.

Thank you to Paul Clarke from the North West Training and Development Team for the material he supplied for this publication. Thank you also to all the social service departments who responded so promptly to my requests for information and enabled me to provide an overview of work currently being carried out in the North West. The specific information relating to individuals is invaluable in demonstrating that people with learning disabilities have already accessed Direct Payments. I thank those individuals for allowing this information to be used in this report.

A special thank you also to Martin Routledge for his continued support and the belief he placed in me throughout this publication.

Ali Gardner

Contents

Introduction	1
The experience so far	4
Research by the North West Training and Development Team.....	6
Overcoming the obstacles	10
A note on consultation	23
Appendix 1: NWTDT questionnaire.....	26
Appendix 2: Update questionnaire	29
Appendix 3: References	30
Appendix 4: Further help and advice.....	31

Introduction

It is not a new experience for people with learning disabilities, their families or those working with them, to find themselves at the margins of legislation or policy. Neither is it new, however, for committed people to find ways of understanding and interpreting legislation to ensure that people with learning disabilities take full advantage.

It is with this in mind that this report aims to provide practical advice and support to those involved in the development, co-ordination and delivery of Direct Payments to people with learning disabilities.

The report will begin with an up-to-date overview of legislation, policy guidance, thinking and current developments relating to Direct Payments for people with learning disabilities. The next section will review the extent to which people with learning disabilities are accessing Direct Payments throughout the country, focusing in particular on the North West. This will be followed by an examination of some obstacles faced by social services departments. Finally the report will give practical advice and guidance on how to overcome such barriers in order to make Direct Payments a reality for people with learning disabilities.

Direct Payments – The National Picture

The National Health and Community Care (Direct Payments) Act¹ 1996 which was implemented in April 1997 in England and Wales and Northern Ireland in April 1998 is designed to promote independence and give service users greater choice and control in relation to community care services.

Key Provisions

- Local authority social service departments have a discretionary power to make Direct Payments to service users.
- The Department of Health have stated that should local authorities choose to make Direct Payments available to service users they would have to be:
 1. Aged between 18-65 years, (NB The recent Social Services White Paper indicates changes to include people over the age of 65. See below for more details).
 2. Disabled.
 3. Already assessed as having the need of community care services.
 4. Competent to give consent to agreed arrangements and take responsibility for Direct Payments with or without the support of others.

(This last point may be crucial for many people with learning disabilities who have greater support needs).

What does the Act allow?

- A Direct Payment(s) by a social services department for any domicillary service that would meet the service user's assessed needs, but not permanent residential care.
- An appropriate level of payment, determined by the social services department, that would allow the individual to purchase the required level of support to meet their assessed needs. The social services department will still have the power to levy a charge to the recipient of the Direct Payment towards the overall cost of their care.

What does the Act not allow?

- For Direct Payments to be used to employ relatives or partners, (NB. in recent months, consideration has been given to a possible change in the legislation which might allow people to employ relatives).
- For Direct Payments to be used to purchase local authority services, (an example might be the social services department's Home Care Service).

Since the introduction of the Act, a change in government has brought with it new thinking and initiatives which have further impacted on its implementation.

Perhaps the most overriding influence is the policy drive towards tackling social exclusion. With the establishment of the Social Exclusion Unit and initiatives such as Welfare to Work, the need for flexible service delivery to enable disabled people to take up work opportunities seems likely to become of central importance to social and health care purchasers and providers.

The current Government has stated the importance of integrating disabled people into society in its strategy to prevent social exclusion. In December 1997, the Government established a Disabled Rights Task Force to conduct a review into how to secure comprehensive and enforceable rights for disabled people. The first job of the task force will be to consider the role and function of a Disability Rights Commission, as part of government's commitment to disabled people.

Both the legislation itself and the establishment of the Social Exclusion Unit and the Disabled Rights Task Force rely on social services departments delivering services in a way which promotes independence and prevents people from becoming socially excluded. The Government sees Direct Payments playing an important role in meeting this challenge. In the recent Social Services White Paper, *Modernising Social Services*², clear messages were sent to social services departments that Direct Payment schemes should become mainstream, alongside a widening of eligibility for Direct Payments to welcome people over the age of 65 years.

In the Social Services White Paper² further guidance was given in respect of the development of Best Value. Briefly, Best Value requires local authorities to seek continuous improvements in service quality, matching the quality of services that local people want to the price they are prepared to pay. In an attempt to offer people more independence, choice, better quality care and better outcomes for individuals, Direct

Payments will be one way in which local authorities can demonstrate Best Value has been delivered.

A thorough understanding of legislation, policy guidance and literature around Direct Payments is a prerequisite for those working in the field of learning disabilities. Later in the report the potential discrimination faced by people with learning disabilities in receiving Direct Payments will be explored. To ensure fair access to the opportunities offered by Direct Payments, service providers and purchasers will need to continuously refer to the fundamental principles and provisions of the Act.

Local authorities must not discriminate unfairly between people who want Direct Payments. Authorities can decide which service will be covered by a Direct Payment but cannot discriminate between groups of eligible people. Therefore, if Direct Payments are available for support to people in their own homes this should apply to all people who wish it regardless of the service grouping or label a local authority places upon them.

The National Centre for Independent Living (NCIL) 1997 has said that when local authorities are implementing Direct Payments for all eligible groups, *'they must act reasonably. Although local authorities have discretion, they may not 'fetter' this discretion with blanket exclusions'*.³ Decisions about who is to receive Direct Payments must be made on an individual, not a group basis. It is only the Secretary of State who has the Authority to decide upon eligible groups as stated in the legislation itself.

The experience so far

A survey of local authorities to collect baseline information on progress in local authorities implementation of the Direct Payment Act was carried out by the Policy Studies Institute (PSI) in October 1997.⁴ This survey formed the first stage in a project which aims to:

- Investigate practical solutions for addressing some of the key concerns which local authorities and disabled people have raised about implementation of Direct Payments.
- Disseminate good practice on the management of payment schemes that will contribute to positive outcomes for both local authorities and users. (See report findings for more details).

Current provision of payments schemes

Findings from the survey indicated that in 1997 just under 50% of all local authorities were operating some form of payments scheme. These were mostly third party schemes, but a small proportion involved direct payments or some other combination of direct and in-direct payments and/or payments through trusts.

Plans to implement Direct Payments

Among the 88 local authorities that already operate some form of payments scheme, just under three quarters were planning to alter or extend their existing schemes in line with the Community Care (Direct Payments) Act 1996. 36% were planning to adapt their existing scheme in line with the Act and 38% were planning to introduce a completely new scheme. One in five local authorities were undecided about this as yet, but only 5% indicated that they definitely do not intend to make any changes.

Regional variations

The survey indicates some quite marked regional variations in the provision of payments schemes. Provision was very low in the North of the UK (apart from Scotland) and in Wales and Northern Ireland. Less than 30% of local authorities in these regions were providing any form of payments scheme, compared with 70% or higher in London, the South West and Scotland where Direct Payments have been legal since the 1968 Social Work Act.

Research from VIA

Research carried out by Values Into Action (VIA) in 1997, *Funding Freedom Direct Payments for People with Learning Difficulties*³, found little evidence of the involvement of people with learning difficulties in areas where Independent Living Schemes are established. In a recent review, of such schemes, including those claiming to include people with learning difficulties, VIA found very few with people with a

learning difficulty using them, and even less involvement by people with greater support needs.

Research by the North West Training and Development Team

In 1998, the North West Training and Development Team, carried out a survey to find out the extent to which Direct Payments were being used for people with learning disabilities in the North West region. The NWTDT wrote to social service departments using a questionnaire requesting information in the following areas (see Appendix 1):

- Actual numbers of people with learning disabilities receiving Direct Payments.
- The kinds of support being purchased.
- Intentions/plans to implement Direct Payments in the future.
- The extent to which Direct Payments were being used for in other service areas (e.g. for people with physical disabilities).
- Hopes around what Direct Payments may enable people with learning disabilities to do.
- Any fears attached to Direct Payments.

The results

15 responses were returned. The results showed the following activity in the North West:

- The vast majority of social service departments were moving tentatively towards Direct Payments and most were only at a working group stage at this time. Most of the targeting appeared to be at people with physical disabilities.
- Only two of the local authorities that replied expressed a strong interest to include people with learning disabilities in their pilot projects. Three others were clearly saying that they would consider extending it if the pilot for physically disabled people proved successful. The rest stated that they had no plans to develop Direct Payments for people with learning disabilities.
- In respect of hopes as to what Direct Payments might enable, people expressed comments about greater choice and control for people managing their own money. There were a few comments along the lines of promoting and developing localised and natural supports, and people having the flexibility of support that many of the larger agencies seem unable to currently provide. One respondent spoke about the need to increase flexibility and more creative approaches around respite/short term support and clearly saw opportunities for this to happen within Direct Payments legislation.
- The question regarding fears around Direct Payments elicited responses along the lines of people being unable to manage their monies, people being open to

exploitation, erosion of public sector services and setting up something that would be very hard to monitor or manage from the local authority perspective.

Update to the research

We have not yet gained an update from all the social service departments that were initially contacted. A follow up questionnaire was sent to 21 social service departments in the North West in February 1999, (see Appendix 2). Of those 21 contacted, 12 responses were received. Three departments were able, at that time, to cite examples of people with learning disabilities accessing Direct Payments.

Manchester Social Services

The Manchester Joint Learning Disability Team in conjunction with Manchester Social Services Direct Payment Scheme reported significant progress. The service states to date that five people with learning disabilities are being supported to access Direct Payments and four people are on the referral list.

Number of people	Style and Level of Support
1 person	A combination of a Direct Payment and Independent Living Fund money is being used to support this individual to access support during holiday periods from a residential college. Two personal assistants recruited from a local college specialising in learning disabilities support this individual.
1 person	A combination of a Direct Payment and Independent Living Fund money is being used to support an individual to access appropriate daytime activities. This person found traditional services unsuitable to his needs and chose to remove himself from them. Since employing a personal assistant, he is reported to be much happier.
2 people	This married couple use a Direct Payment to employ personal assistant to help them with many aspects of daily living.

In Manchester, care managers have used the support of the Manchester Direct Payments Support Service. The service is reported to have been very helpful in setting up the scheme with people with learning disabilities. They have offered people information in a way that is more accessible, for example using videos. It is noted that the success of the five people using Direct Payments has encouraged care managers to look at Direct Payments as a positive option for accessing support and several service users are considering Direct Payments or are in the process of applying for them.

In discussions with the Manchester social service Direct Payment Scheme, it was stated that people with learning disabilities were of high priority to them. It was also noted that the scheme has developed close links with Manchester People First and Values Into Action. Through this work the scheme have developed their skills in working appropriately with people with learning disabilities and making Direct Payments more accessible to them.

The scheme has also publicised information about Direct Payments within the Joint Learning Disability Service, Manchester. Their aim is to make more staff aware of Direct Payments as an option for people with learning disabilities.

They have used their skills developed through Direct Payments to support staff in writing applications for Independent Living Fund monies and also to support staff and service users in managing their Independent Living Fund monies in areas such as recruitment, managing finances and accountability of money.

Some of the staff working on the Manchester Social Services Direct Payments Scheme have experience of working with people with learning disabilities. In discussions, they stressed the value of this in supporting people with learning disabilities to access Direct Payments. They also identified training in this area of high priority.

The Manchester Social Services Direct Payment Scheme also support people from other local authorities to access Direct Payments. At present they are supporting one person with learning disabilities in Trafford to access a Direct Payment and have developed links with Rochdale Social Services.

Tameside Social Services

Tameside Social Services developed a pilot Direct Payments scheme in April 1998. It is funded by the social service department but set and managed by the Tameside Forum of Disabled People.

Referrals come from the care management team and the scheme then support the individual to set up and manage the Direct Payment. The care manager also remains involved throughout this process.

The scheme which has just secured funding for a further 12 months is presently supporting ten people to access Direct Payments and hoped to support another 15 people by April 2000. The team is made up of two workers, one full time and one part time. Further posts should have been filled in April 1999.

The scheme notes that of the ten people receiving Direct Payments, one man with learning disabilities recently received a Direct Payment for a care package that is 15 hours per week. The scheme supported the man in recruiting a personal assistant who supports him in managing household tasks. The scheme will continue to support this man in managing his direct payment. This will include support around employment issues and managing the finances attached to Direct Payments.

Tameside reported that it took 3 months to set up this Direct Payment. Some of this time was taken by sorting out an unforeseen financial issue. They hope to speed up this process to six weeks in the future.

One member of staff has previous experience of working with people with learning disabilities and found this useful in supporting this man to access a Direct Payment.

Oldham Social Services

Oldham Social Services are nearing the end of their pilot scheme that has been running for one year. Out of six service users who joined the scheme in April 1998, one man had learning disabilities. After showing initial interest in accessing a Direct Payment, the man chose to use services provided by the social service department.

Presently, a care manager from the Learning Disability Service is seeking to support a young woman with learning disabilities to access a Direct Payment via a Trust. In discussion with the care manager it became clear that a supportive network of family and supports has enabled the process to progress.

It has been quite a complex route to progress this case due to the severity of this woman's learning disability and the consequent need to ensure she is 'able and willing' to use Direct Payments. However the aim of the family and the care manager involved is still to secure a Direct Payment to ensure her needs are met effectively.

Of the 12 responses, seven social service departments responded that Direct Payment schemes were either at a pilot stage or in full operation. Two of these social service departments stated that Direct Payment schemes existed only in the Physical Disability section at present. Four social service departments stated their intention to establish a Direct Payment scheme within the next 12 months.

A number of additional issues were raised within the questionnaires. Some of these included:

- A general commitment towards developing knowledge and skills to enable people with learning disabilities to access Directs Payments.
- A desire to know more about how this can be made possible for people with learning disabilities.
- Some concerns around the issues of consent particularly for people with severe learning disabilities. Comments such as 'are these people truly in charge of the service they receive?' indicated such concerns.
- Comments about the government's intention to extend Direct Payments to older people were expressed.
- One social service department raised the issue of independent advocacy/support to assist people who may be interested in using Direct Payments. Another social service department stated lack of independent support available in the community as the main reason for people with learning disabilities in their area not receiving Direct Payments.
- In one authority a feasibility study had indicated such a low potential take-up for Direct Payments that the setting up of a scheme was abandoned due to the cost.

Many of these issues will be explored later in the report.

Overcoming the obstacles

Whilst Direct Payments potentially offer an exciting and flexible tool for delivering services to people with learning disabilities, evidence since the implementation of the Act has demonstrated the potential obstacles faced by all people eligible to use Direct Payments. For people with learning disabilities seeking to use Direct Payments the obstacles increase. A major challenge seems to be their ability to satisfy legal requirements in respect of their capability to use Direct Payments.

This next section will examine some of the pitfalls and how local authorities that have developed Direct Payment schemes have overcome these. Whilst giving an overview of the barriers faced by all groups, particular emphasis will be paid to those issues which have the greatest impact on people with learning disabilities.

Awareness of such barriers should assist those involved in the development of such schemes to plan and act to meet the challenge ahead.

The key obstacles to take up of Direct Payments so far detected and experienced can be listed as follows:

1. Is the person willing and able?
2. Care Management – How does it fit?
3. Budgets – ‘But it costs more’
4. Lack of appropriate support
5. Eligibility criteria

1. Is the person ‘willing and able’

Perhaps the greatest challenge to those involved in the implementation of Direct Payments for people with learning disabilities is the unravelling of this term ‘willing and able’. Unfortunately, for some, this term seems to have caused fear and has led to a justification for the exclusion of people with learning disabilities from accessing Direct Payments.

The Direct Payment Act states that ‘the Authority may, if the person consents, ‘make a payment’. The policy guidance that follows says that a person must be ‘willing and able to manage the payment alone or with assistance’. The practice guidance advises local authorities to assess whether a person is ‘willing and able’.¹

At first glance, such a statement could appear to exclude people with learning disabilities particularly those with complex needs or few verbal communication skills. An immediate response to this is that if the legislation intended to exclude people with learning disabilities, it could have clearly said so as it did for people over the age of 65 at the time of implementation. In fact, the underlying philosophy of the Act was to promote independence and give service users greater choice and control in relation to community care services. It would therefore be unfortunate to say the least, if discrimination against a section of the disabled population led to them being excluded from a piece of legislation meant to empower them.

How to make it easier

Rule 1 – Assume capacity

It is established in law that ‘*adults have full legal capacity and the right to make their own decisions unless it is shown they do not*’.⁵ For those working with people with learning disabilities this will be a common issue. The dangers of presuming incapacity are realised and in most cases avoided at all costs. Due to the continued lack of clarity in law about capacity however, much depends upon professional interpretation. One way of overcoming this hurdle is to ensure mechanisms are in place to avoid arbitrary decisions being taken on a person’s capacity. Energy should also be focused on creating as many opportunities as possible for people with learning disabilities to develop their ability to give consent.

In their research, VIA found that those local authorities with larger numbers of people with learning disabilities using Direct Payments, time and energies had been concentrated on the assistance needed to enable someone to use and successfully control a Direct Payment, rather than getting caught up in tests of capacity or incapacity.³

Use the test of consent

For those involved in assessing someone’s ability to give consent, the checklist developed by the Law Commission *Mental Incapacity (Paper 231)*, (1995)⁶, is a useful means of ensuring that the correct decisions are made for and with an individual. It says that regard should be given to:

- The ascertainable past and present wishes and feelings of the person concerned, and the factors that person would consider if able to do so.
- The need to permit and encourage the person to participate, or to improve his or her ability to participate, as fully as possible in anything done for and any decision affecting him or her.
- The views of other people (such as advocates, friends, relatives etc), whom it is appropriate and practicable to consult about the person’s wishes and feelings and what would be in his or her best interests.
- Whether the purpose for which any action or decision is required can be as effectively achieved in a manner less restrictive of the person’s freedom of action.

A careful examination of this checklist should encourage those involved in such assessments to realise the breadth of opportunities available to them in supporting a person to give consent to a Direct Payments.

Reading between the lines

The term *with or without assistance* in assessing whether someone is ‘willing and able’ is key to many people with learning disabilities becoming eligible to Direct Payments. In theory the term should prevent professionals from excluding most people with

learning disabilities from accessing Direct Payments, as there is no specification on how much assistance a person may have. Therefore we have the opportunity to take the view that with the right level of support and expertise, we as professionals can find ways of supporting a person to:

- make a choice about whether to use Direct Payments
- and to offer the appropriate support to make them 'able'.

Informed consent

Information has to be presented to people with learning disabilities in a meaningful way. The person needs to understand what Direct Payments can do for them. They also need to be made aware of any potential difficulties.

Examples in the form of videos and listening to people's accounts of using Direct Payments are often useful to people with learning disabilities. VIA have a number of useful leaflets and a video called *Make Your Own Move*. The Plain Facts guide and tape entitled *Direct Payments for People with Learning Difficulties* produced by the Norah Fry Research Centre also gives useful guidance.

In their research, VIA found that the most effective approach to offering information was sharing real life examples of the benefits people experience when using Direct Payments, and then helping individuals think about the potential benefits for their own life. 'A discussion of these benefits helps people with learning difficulties think about the possibilities before considering the nitty gritty of the practicalities. It would be all too easy to influence people with learning disabilities against Direct Payments by starting to talk about areas such as the legal responsibilities of being an employer'³.

More sophisticated means of communication will be required for some people with learning disabilities. Accessing support from communication therapists may be a useful means of working with people with few verbal communication skills or challenging behaviour.

Reducing demands

Those involved in assessing a person, as being 'willing and able' must ensure that the minimum amount of pressure is placed on the individual during an assessment. Adequate time must be given to the person being assessed. This will include time away from the assessment process to think about it and discuss it with family and friends.

Assessors must make people aware that they can receive as much assistance as they require and that using a Direct Payment can be gradual. It may be useful to make the person aware that they do not have to have all their care package provided through a Direct Payment, that they can change their mind at any time and that services will resume as before. Finally as with any assessment, the worker needs to consider the following:

- **Environment** Is the person in the most suitable surroundings for the assessment to take place? Ensuring the appropriate people are present or not present as the case may be is essential.
- **Timing** Is this the right time in someone's life to be introducing the option of Direct Payment? A breakdown of a care package is not necessarily the appropriate time for a person. The anxiety evoked by making a decision may prove to be detrimental to the person further down the line.

Respecting and understanding the way people communicate

It is important to respect the different ways people communicate. The use of communication aids, other people supporting communication, signing and even 'challenging behaviour' all give people opportunities to express their views and feelings. 'Making clear one's preferences about the ways in which needs are met can be regarded as consent to decisions and therefore enable consent to and control over a Direct Payment. Certainly the ways in which people express themselves must be respected and should be included in any assessment for a Direct Payment.'⁷

Wider circles

The involvement of significant others can contribute to the assessment of capacity. Whilst assessors have to be mindful of individual agendas and desired outcomes, useful information can emerge from a skilled discussion with those close to an individual about the person's capacity to express a preference and what that preference might be. In the same way Person Centred Planning can be particularly useful in exploring how a person indicates their wishes.

Consider a range of models

As with any package of care, tailoring it to person's specific needs is crucial if the person's needs are to be met effectively. Whilst some individuals will be able to manage a Direct Payment independently or with limited support some people will require more assistance. Remember the legislation allows for *with or without assistance*. In such circumstances it may be important that the right type and level of support is offered to the individual. There are a range of models presently being used to support people to access Direct Payments. These include:

- 1.1 Independent Living Schemes
- 1.2 Service Brokerage
- 1.3 Individuals and Trusts

1.1 Independent Living Schemes

Independent Living Schemes are used as a means of channelling money to the disabled person. The schemes are voluntary sector bodies managed and controlled by disabled people. One drawback of such schemes for many people with learning disabilities is their tendency to concentrate on providing a service to people with physical disabilities. Some schemes however do support people with learning disabilities and provide benefits that include:

- helping people to look at what they want and need;
- how to set up and run their own services with assistance.

1.2 Service Brokerage

There is little evidence of service brokerage being used in the UK.

Service brokerage works with individuals, at their request, to:

- Provide adequate and accessible information.
- Help assess and plan the support desired.
- Help negotiate individualised funding for support.
- Help purchase support services.

Essentially service brokerage involves social services making payments to a broker agency which is responsible for purchasing support for the person with disabilities. Workers are provided by an independent provider. In some cases the broker agency will give the money to the individual who can then purchase their own support from self employed support workers. The brokerage agency is then contracted to monitor and review the payment. Direct Payments could be used in a service brokerage arrangement provided that it was in keeping with the underlying statutory purpose of the 1996 Act of increasing the autonomy of the user. VIA's publication *Willing and Able* provides examples of how service brokerage has been successfully used for one woman with learning disabilities⁷.

1.3 Individuals and Trusts

A Trust is a legal structure establishing a framework which allows local authorities to provide funding for User Controlled Independent Living Schemes. A Trust will usually offer additional assistance and safeguards to the disabled person. Trustees can be chosen who will carry out the functions associated with direct cash payments that the disabled person cannot or does not want to undertake, such as the financial aspects of employment.

A Trust Deed which is a legal document sets out the rules and regulations governing the use of any money given to the Trust and on what terms the money will be given. It may also contain auditing requirements and financial regulations. VIA have published an example Trust Deed that is invaluable for any local authority supporting people using Trusts⁸.

2. Care Management – How does it fit?

Care managers should play a very important role in making Direct Payments accessible to adults with learning disabilities. As gate keepers to services and opportunities they are often the key source of information and access. In discussion with care managers from two social services departments, the author encountered wide-ranging attitudes towards Direct Payments. Some care managers/ team managers were very enthusiastic

about Direct Payments and could see ways to make it work whilst others were less convinced that Direct Payments could be a reality for people with learning disabilities. Concerns raised included the following:

- Questioning as to whether it was the role of a care manager to set up Direct Payments and support the person in receiving a Direct Payment.
- A worry about the additional work this would entail in terms of supporting people and also in understanding all the information required. Many felt they could not manage this within existing resources.
- A concern that parents and carers could be given more control and the wishes of people with learning disabilities would be overlooked.
- A belief that many people with learning disabilities would not be able to give consent and therefore would not be eligible to receive a Direct Payment.

How can we support the care management process?

- 2.1 Training and Information
- 2.2 Confident, informed management
- 2.3 Value base
- 2.4 Care management autonomy
- 2.5 Involving Providers

2.1 Training and information

Care managers need adequate information and training to enable them to explore the possibilities of Direct Payments. If the assessment process requires the care manager to draw on their knowledge and experience of possible options in creating packages of care, it is crucial they have the appropriate information at hand. It appears to date that too many social services departments have allowed Direct Payments to become the exclusive domain of people with physical disabilities sometimes causing professionals in the learning disability service to feel disconnected from the whole process.

One way to overcome this is to offer basic training on the legislation, policy and practice guidance to all care managers and to ensure staff from the learning disability sections are represented on any Direct Payment working groups within the department.

In Salford Social Service Department, the Learning Disability Service report that they have maintained strong representation from their staff in the departments Direct Payment scheme. They have accessed training and information from Values Into Action (VIA) and spent time considering the issues specific to people with learning disabilities in accessing Direct Payments. From discussion with staff, it is clear that the inclusion of people with learning disabilities in the Direct Payment scheme is of high priority.

2.2 Confident informed management

As with care managers, managers also need the relevant information and training to ensure the inclusion of people with learning disabilities when schemes are established

within social service departments. A confident and informed management will enable care management teams to experiment with Direct Payments with the knowledge that they have support from above. In some cases, it may fall upon those working directly with people with learning disabilities to encourage management to take on board the relevance of Direct Payments for people with learning disabilities.

2.3 Value base

Sound principles based on values of promoting inclusion will encourage wider use of Direct Payments for people with learning disabilities. There is a danger of such values being overlooked especially when working schedules become. In the development of any work relating to Direct Payments, it will be useful to start the process with an identification and agreement of the principles guiding your work. Once formulated into a mission statement, these can be referred to at a later stage when the focus may be lost. It is important that these principles are endorsed by departmental management.

2.4 Care management autonomy

There is something very creative about Direct Payments. Many of those who have been involved in the development of schemes or in accessing a Direct Payment will be aware of both the opportunities and frustrations of setting them up. An environment that has a good balance between risk taking and support/protection must be developed if ways are to be found of making Direct Payments a reality for people with learning disabilities. A lack of flexibility will stifle creativity and experimentation. Whilst managers are responsible for ensuring mechanisms of accountability exist they must also acknowledge the skills and understanding of those working directly with people with learning disabilities.

2.5 Involving providers

The development of Direct Payments is often kept within the Purchasing arena. Training and information is targeted at care managers and commissioners who will be responsible for setting up the Direct Payment. However, there are many people with learning disabilities who would be eligible for Direct Payments that may rarely or never meet a care manager. They may however have contact with providers such as day centre staff or supported living staff. Providers play a key role in disseminating information to service users.

It is worth investing time and training for providers in understanding the legislation and the process of accessing Direct Payments as they have such a direct link with people who may wish to do so. Purchasers must be mindful of the initial concerns providers may have with Direct Payments. The Direct Payment legislation has been criticised for its supposed potential erosion of the public sector. Some providers may see Direct Payments as a threat to their jobs as people using Direct Payments can only purchase support from independent agencies. An awareness of this issue will ensure any training and information is approached sensitively.

3. Budgets – ‘But it costs more?’

A major concern for many social services departments is the cost incurred in developing Direct Payment schemes. In a climate of pressurised budgets, the

development of a Direct Payment scheme with no additional government funding has been fairly daunting.

How then, can we justify spending limited resources on the development of Direct Payment scheme? These are a number of issues and arguments to present here:

3.1 It's about Civil Rights

3.2 It's the law

3.3 It can ensure 'Best Value'

3.4 It can be cost effective

3.1 Civil Rights

Disabled people have expressed their wish to have services delivered to them in a way that meets their needs and respects their dignity. Direct Payments is one way this can be achieved. It is important for social service departments to recognise the link between Direct Payments and civil rights and to place it as high priority when considering the issues affecting decisions about how services should be delivered.

3.2 It's the law

At the time of writing this report social services have a discretionary power to make Direct Payments available to disabled people. However, it may well only be a matter of time before this becomes a statutory duty. This being the case, it would seem sensible that social service departments begin planning for the implementation of schemes sooner rather than later.

3.3 Best Value

Best Value requires local authorities to seek continuous improvements in service quality, matching the quality of services that local people want to the price they are prepared to pay. Again the link between Best Value and Direct Payments is clear. If cost is not the only consideration in service delivery, social service departments must begin to identify the other important factors and develop services accordingly. Again legislation on Best Value is likely to emerge in the year 2000 when local authorities are likely to demonstrate how they have ensured that services are matching what local people want.

3.4 It can be cost effective

An accurate measure of cost effectiveness of any service can only be achieved by matching like with like. It is true to say that some services provided to people via Direct Payments could appear to be more costly in the short term. However an accurate measure must take into account the quality of the service and it's long-term benefits. Anecdotal evidence has indicated many long term benefits to Direct Payments including improved physical and mental well being, both of which have been brought about by the person having more control over the services they receive.

Evidence of Direct Payments being cost effective is also likely to begin to emerge particularly in the field of "challenging behaviour" where highly expensive services are being purchased to support people with complex needs. The creative development of a

very individualised package of care supported by personal assistants may be found to meet a person's needs at a lower cost.

Clearly there are initial expenses in setting up Direct Payments scheme. Social service departments, however, may find it useful to consider and identify the potential long-term benefits both in terms of quality and cost before reaching any decision about whether to proceed with Direct Payments. The establishment of monitoring systems that measure such benefits will also aid departments in assessing their effectiveness.

Some of the practical ways additional money can be generated in order to support the development of Direct Payment schemes include:

- Using the Government's modernisation grants as described in the White Paper, *Modernising Social Services*².
- Pooling the charge made to Direct Payments users and paying for a support service (as one English authority has).
- Carry out an accurate cost analysis of services. For example, it may appear to cost more to employ a personal assistant for a day compared to purchasing a day centre placement. However, the true costings must include all the on-costs such as staff recruitment, training and management. In VIA's recent research project *Funding Freedom 2000*, they found that:

'One authority, for instance, adds £10 to a Direct Payment to cover staff recruitment costs. When asked for the equivalent cost to the authority to recruit one home care assistant (including advertisements, personnel and finance section time, management time, interim agency fees, interview panel time, induction and training), the figure came to a hundred times more than what they were offering to the Direct Payment user'⁹.

Value Added Tax (VAT)

Some social service departments have encountered a problem with VAT. Essentially when a person has a direct payment and chooses to go to an independent agency and purchase their support, they are charged VAT. Local authorities are themselves registered for VAT purposes and are able to claim this VAT back from Customs and Excise. Individual people using Direct Payments are not able to do this. Thus the cost will rise by 17.5% for the individual buying the service from an independent agency.

VIA⁹ found evidence of how this issue has been overcome in some areas. Some of the ways include:

- local agencies offering a discount rate to Direct Payment users;
- user-controlled trusts successfully registering themselves for VAT purposes and therefore able to charge the local authority.

One unexplored possibility is that Direct Payments recipients might form a user group or a co-operative to collectively register and claim for VAT. For more details see *Funding Freedom 2000*⁹.

4. Lack of appropriate support

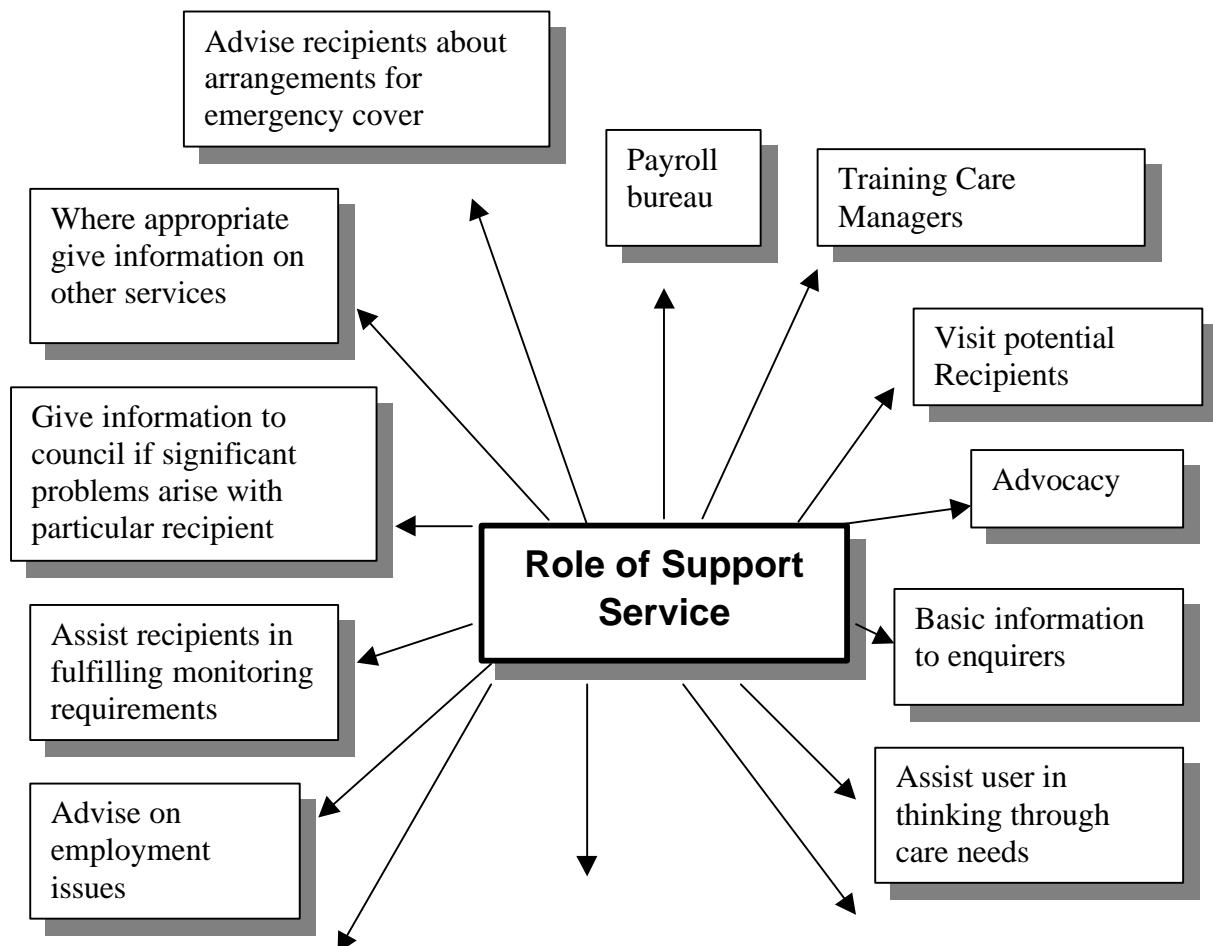
Support to people using any community care service is essential at all stages of the care management process. For people with learning disabilities support may have to be tailored in a way that takes account of any specific communication needs. This will often involve breaking down concepts to enable people with learning disabilities to understand services and to make informed decisions.

In the case of Direct Payments specific support is crucial to its success.

As Direct Payments aim to hand over so much control and responsibility to the service user, it is important the individual gains as much insight into the process to ensure it is an empowering experience and not a tokenistic gesture of promoting independence.

The care manager can offer much of this support to the service user, in the process of assessing an individual's needs and implementing a care package. However the receipt of a Direct Payment is likely to require support exceeding the role of the care manager, for example around recruiting staff, understanding employer's rights, account keeping and issues of health and safety. Many local authorities, recognising the breadth of support required, have responded by commissioning support systems/services offering this additional support. The diagram below highlights some of the typical roles of such a Support Service.

Typical roles for a Support Service



Assist in interviewing if required

Advise on recruitment process if recipient intends to employ own personal assistant

Advise on use of Direct Payments

In their research, the Policy Studies Institute found authorities with existing schemes stressing the benefits of setting up support systems and that this produced better outcomes for both the users and local authorities alike. Whilst there is an initial cost, as one case study authority with a well established scheme put it ‘you should look on it as an investment, not as a cost’¹⁰.

In their research, VIA criticise some of the existing support systems for a lack of evidenced inclusion of people with learning disabilities.³ The support required by people with physical impairments is likely to be in some respects different from that required from people with learning disabilities.

Insistence on inclusion of people with learning disabilities must continue at all levels. In the case of Direct Payments, politicians must ensure that legislation does not allow for overt or covert discrimination. Policy makers and commissioners within social services departments must address the specific needs of people with learning disabilities in setting up or commissioning support systems. Any tendering process should ensure that service providers can demonstrate their commitment to people with learning disabilities.

One possible approach for some social service departments may be to commission a support system that works solely for people with learning disabilities, although there are obvious potential pitfalls in establishing segregated services.

Another possibility would be to have an integrated support system with some staff with a background in learning disabilities. For example some workers to support people with learning disabilities in receiving Direct Payments and to support the scheme in becoming truly inclusive.

Who provides the support systems?

Most of the authorities that operate a Direct Payment scheme have commissioned local independent organisations to provide a support system for Direct Payments. Independent Living Schemes provide support in over 60 areas in the UK. Independent Living Schemes are managed and run by disabled people. Other voluntary organisations working with and for disabled people have also taken on contracts with social service departments for this purpose.

In their research, the PSI found the advice coming from those authorities with existing schemes, and from the NCIL suggested that Centres for Independent Living and similar organisations run by disabled people offer the most appropriate expertise for running a support scheme. ‘Working in partnership with disabled organisations underpins best practice within community care and embodies the ethos of Direct Payments, which intended to enable disabled people to take control of their lives’¹⁰.

In some cases the support system is provided ‘in house’ either as part of the care management system or by a separate team within social services. For example, Manchester Social Services have their own scheme managed and funded by social services whilst Tameside Social Services have a pilot scheme funded by social services and managed by the voluntary sector. All have their merits and the one most suitable to an individual Department will depend on a number of factors. PSI state the difficulties in being precise about the ratio of advisors to users, linked to the degree of variation in the way the job is organised. ‘The best guide we can suggest is that single worker can support thirty users: where numbers are higher than this, the depth, and to some extent the quality, of the support offered is less’¹⁰.

Whilst again it is difficult to be precise, PSI commented on the cost of providing a support scheme within the voluntary sector. ‘We suggest budgeting in tens of thousands of pounds, rather than the hundreds of thousands we have heard quoted from a few places’¹⁰.

5. Eligibility Criteria

In their research report, VIA found that whilst many authorities claimed to offer all service groups eligible in law access to Direct Payments, there was very little evidence of people with learning disabilities receiving Direct Payments³. Whilst at the time of writing this report, local authorities can make decisions about whether to implement Direct Payments and which services to cover, they cannot discriminate between groups of eligible people. It is only the Secretary of State who has the authority to decide upon eligible groups. In a recent speech (King’s Fund 23rd June 1999), the Under Secretary of State, John Hutton stated that his Department was working to ensure, amongst other things, that Direct Payments are made more accessible to people with learning disabilities, ‘In short we must make sure that these planned generic changes benefit people with learning disabilities’.

In order to ensure equity of access to services, social services departments must be aware of the potential discrimination faced by people with learning disabilities in accessing Direct Payments.

It is possible that pilot schemes may have contributed to the initial exclusion in some schemes of people with learning disabilities. In many cases this will not have happened intentionally but rather in an eagerness to develop schemes following the introduction of legislation. Whilst pilot schemes offer a great deal of flexibility to social services allowing experimentation and development, they must not be used as a means of excluding certain groups. As governmental monitoring of Direct Payments increases, it seems likely that such practice will be discouraged. However those working in the field of learning disabilities must be prepared to point out and address such discrimination where it appears.

In social services where pilot schemes or established schemes do not yet exist, it may be useful to involve professionals from the Learning Disability section from the beginning to ensure the needs of people with learning disabilities are not overlooked. This will require the proactive approach of finding out what is happening with Direct Payments in your social services department and ensuring strong representation from the Learning Disability Service from the start.

In their report, the PSI warn against putting people in touch with support schemes before their community care assessment. They note the importance of assessment for Direct Payments following the assessment of eligibility for community care. They state that payments are an option within the framework of community care, and the process of assessment needs to reflect this¹⁰.

A note on consultation

Legislation and guidance from the Social Services Inspectorate (SSI), emphasise the necessity of consulting with the public about the use of Direct Payments. According to government guidance on Direct Payments, consultation should take place prior to the implementation of any schemes within a local authority.

Although the Direct Payments Legislation remains permissive rather than mandatory at the time of writing the report, it seems quite possible that the government may place a statutory duty on local authorities to develop Direct Payment schemes.

With this knowledge, it would appear that social services departments who have not started the process of consultation need to move quickly. Those who have already begun need to consider service groups that they may not have included, which may include people with learning disabilities and people over the age of 65. As the future of Direct Payments becomes clearer, consultation needs to focus on giving people information about Direct Payments, enabling them to understand the process and listening to their views about how schemes can reflect their needs.

In any consultation strategy, the specific needs of people with learning disabilities needs to be addressed. This will require the involvement of those working with this service group to inform the process of consultation.

Consultation Strategy

The strategy adopted by individual authorities will vary depending on a range of factors including:

- the extent of consultation mechanisms already in place;
- the extent of knowledge staff have of Direct Payments;
- the level of interest and focus local voluntary organisations have on this subject;
- the political, economic and social climate of the individual authority.

Any consultation process or strategy must begin with a clear aim. For example, is it primarily to inform people about Direct Payments or is it to gather their views? The aim must then be communicated to the people who are being consulted.

What to include in a consultation strategy

Involve key voluntary organisations

Voluntary groups with an interest in disability issues have a key role to play in the development of Direct Payment schemes. Their contact with the wider disabled community means that information reaches many people quickly. The research report by the PSI in 1998 stresses the importance of working in partnership with local voluntary organisations. One scheme involved in the research stated 'You must consult

with organisations of disabled people. Direct Payments are about increasing choice and autonomy for disabled people, so start by involving them in all the planning and development'¹⁰.

The other benefit drawn from using voluntary organisations to disseminate information to the public is that it is less likely to be tainted by any political or economic motives the local authority may be seen to have. Voluntary organisations understand the mistrust and lack of confidence some disabled people have of social service departments and therefore may be in a better position to consult with the public.

Use existing consultative mechanisms

Many social services departments have established mechanisms for consultation. Some of these will be based within the role of planning, customer services or user involvement functions. Using these mechanisms, information can be shared and openly discussed with professionals and service user and carer representatives. The information can then be taken to people's networks and views can be brought back to the group.

Informing key staff

As awareness of Direct Payments grows, it is likely that service users will begin to ask staff questions about Direct Payments and how to access them. It is important staff have the necessary knowledge and skills to deal with any queries.

Using the right method

The process of consultation with people with learning disabilities requires specific focus and techniques. There is no disguising the complications in understanding Direct Payments. Those who have been involved in the development of Direct Payment schemes have continuously commented that they have struggled to understand and interpret all the information.

In researching information for this paper, one co-ordinator commented:

‘Although my enthusiasm for Direct Payments was maintained throughout the process, I could never have anticipated the enormity of the maze ahead. Whilst the legislation and policy guidance appears straight forward, logical and empowering to disabled people, the process of supporting an individual to work a Direct Payment feels like an assault course on the Krypton Factor. Just as you think you've cracked it, you are presented with the next obstacle’.

VIA in their research report ‘Funding Freedom’ offer a number of suggestions on making information on Direct Payments relevant to people with learning disabilities. Some of these techniques are also discussed on page 11 ‘*Informed Consent*’.

Advocacy Groups

Advocacy groups can be used as a means of giving people with learning disabilities an opportunity to discuss and think about the how Direct Payments might affect them

personally. A discussion in this environment might be very useful for those individuals with parents or carers who tend to take the decision-making role for the person with the disability.

Writing to service users

One way of starting the process of consultation/information giving is to write to current users of services giving very basic information about Direct Payments. A seminar or public meeting to allow people to find out more about Direct Payments could follow the letter.

In any process of consultation it is essential that information be fed back to those involved at the end of the consultation process. If people are being asked about a subject they need to know that their views have been listened to and where ever possible that responses and changes are made.

These are just a few ideas of how to get started with consultation. Most important is for individual social service departments to begin to explore how consultation can be achieved in their localities.

Conclusion

Direct Payments offer a real opportunity for people with learning disabilities to gain increased control over the way they receive services. If Direct Payments are to be successful for people with learning disabilities, service managers, care managers and others must recognise the potential benefits the legislation can bring in tailoring services to individual needs. The Direct Payments Act 1996 should be welcomed whole heartedly by social service departments. The potential discrimination must be acknowledged and addressed but should never be used as a justification to disempower people with learning disabilities. Instead the legislation must be used as a means of promoting independence, choice and control people with disabilities should have over their own lives.

Appendix 1: NWTDT questionnaire

Tel: 01254 821334
Fax: 01254 821329
E-mail: PLOClarke@compuserve.com

Calderstones
Whalley
Clitheroe
Lancs BB7 9PE

Dear Colleague,

Direct Payments and people with learning disabilities

NWTDT, in partnership with the National Development Team, are currently in the process of assessing the extent to which Direct Payments are being used in order for people with learning disabilities to purchase their own support or services.

As part of the process, I am writing to every social services department in the North West region to ascertain if any progress has been made or if plans are in place to enable people with learning disabilities (or family members/other supporters) to receive Direct Payments.

The results of this survey will be collated and published in a short report later in the year. We are particularly keen to hear of any examples where Direct Payments have been used to fill a gap in existing provision as we would like to be able to disseminate leading edge practice and creative approaches across the region.

I would be grateful if you could spend a few minutes completing the attached questionnaire and return it to me in the envelope provided.

With thanks in anticipation,

Yours sincerely

Paul Clarke

Name of local authority:

Name of person responsible for Direct Payments:

Address for correspondence:

n.b. no details of individual authorities or people will be divulged in the report

Is your local authority currently making
Direct Payments to people with learning disabilities? yes / no

If yes, please give brief details (approximate number of people, what kinds of support are being purchased, amount of money involved)

Are there plans to increase the extent to which Direct Payments are being provided?

If you are not currently making Direct Payments to people with learning disabilities, do you have any plans to do so in the future? yes / no

If yes, please give brief details

Are you currently making Direct Payments to other people? yes/no
e.g. physically disabled people, people with mental health problems, etc.

If yes, please state client group(s)

What do you hope that Direct Payments will enable?

Do you have any fears around Direct Payments?

Thanks for your help
Please return this form in the envelope provided

Appendix 2: Update questionnaire

28 February 1999

33 Hawthorn Grove
Heaton Moor
Stockport
SK4 4HZ

Dear Sir or Madam

Direct Payments

I am currently writing a report on the use of Direct Payments for people with learning disabilities. The report has been commissioned by the North West Training and Development Team. (NWTDT). You may have received a questionnaire in 1998 asking for information on this subject from the NWTDT.

The results of the questionnaire, which will also be published in this report, showed some evidence of people with learning disabilities in the North West accessing Direct Payments. In order to give an accurate up to date overview of the use of direct payments, I would like to give each social services department in the North West an opportunity to tell me about any progress they have made in this area.

The aim of the report is to give practical information and guidance about setting up Direct Payments for people with learning disabilities, the barriers social service departments have encountered and an overview of activity in the North West. This will be followed by a seminar in the late summer. (more information will be provided in the near future).

I would be very grateful if you could answer the following questions and send the information back to me no later than the 17th March 1999. I appreciate this is a very tight deadline. Nevertheless, highlighting good practice and sharing ideas with other social service departments is invaluable in progressing service delivery.

Questions:

1. Name of social services department
2. How many people with learning disabilities are you supporting to access a Direct Payment?
3. Is there an established or pilot scheme operating in your Department?
4. Do you have any comments to make about Direct Payments in relation to people with learning disabilities which you would like to see highlighted in this report?

If you wish to discuss this letter with me, please contact me after 6pm on 0161 432 9232.

Many thanks.

Yours faithfully

Ali Gardner

Appendix 3: References

1. DoH, (April 1997), *Community Care (Direct Payments) Act 1996*, HMSO.
2. DoH, (1998), *Modernising Social Services - The White Paper*, London, The Stationery Office.
3. Holman A & Collins J, (1997), *Funding Freedom - Direct Payments for People with Learning Difficulties*, VIA, London.
4. Zarb J, Hasler F, Campbell J & Arthur S, (October 1997), *Implementation and Management of Direct Payment Schemes: First Findings*, Policy Studies Institute (PSI).
5. Letts P, (April 1995), *In Their Best Interests*, Community Living Magazine.
6. The Law Commission, (1995), *Mental Incapacity (Paper 231)*, London, HMSO.
7. Ryan T & Holman A, (1998), *Able and Willing, Supporting People with Learning Difficulties to use Direct Payments*, VIA, London.
8. Values Into Action (VIA), (1995), *Independent Living for People with Learning Difficulties. Sample Trust Deed*, VIA, London.
9. Holman A & Bewley C, (1999), *Funding Freedom 2000 People with Learning Difficulties using Direct Payments*, VIA, London.
10. Hasler F, Zarb G, & Campbell J, (1998), *Key Issues for Local Authority Implementation of Direct Payments*, Policy Studies Institute (PSI).

Appendix 4: Further help and advice

Values Into Action

The National campaign with and for people with learning difficulties. VIA has been working since 1971 to end the injustice and misunderstanding which have impoverished the lives of people with learning difficulties. VIA promotes the rights of people with learning difficulties, and publicises good practice.

Address: Oxford House, Derbyshire Street, London, E2 6HG.
Tel: 0171 729 5436.

Age Concern England

The central co-ordinating body for local Age Concern groups throughout England. Offers national campaigning, information service and training. Equivalent bodies exist for Wales, Scotland and Northern Ireland.

Address: Astral House, 1268 London Road, London SW16 4ER.
Tel: 0181 679 8000.

Black Disabled people's Association

The Black Disabled People's Association offers training and advice on disability and racism issues.

Address: The Black Disabled People's Association, 336 Brixton Road, London, SW9 7AA.
Tel: 0171 274 0107.

CHANGE

An organisation run by disabled people for people with both a learning disability and a sensory impairment.

Address: CHANGE, First Floor, 69-85 Old Street, London, EC1V 9HY.
Tel: 0171 490 2668.

The Chartered Institute of Public Finance and Accountability

CIPFA provides education and training in accountancy and financial management for public services. It sets and monitors professional standards. It published the Direct Payments Accounting and Financial Management Guidance in 1998.

Address: The Chartered Institute of Public Finance and Accountancy, 3 Roberts Street, London, WC2N 6BH.
Tel: 0171 543 5600.

The Commission for Racial equality

The Commission for Racial Equality can offer advice and information on the law regarding discrimination on racial grounds, including the exceptions allowed under the Act which need accurate interpretation.

Address: Commission for Racial Equality, Elliot house, 10/12 Allington Street, London, SW1E 5EH.
Tel: 0171 828 7022.

The Disablement Income Group

DIG promotes the financial welfare of disabled people through a programme of advice, fieldwork, information, publications, research and training.

Address: DIG. Unit 5, Archway Business Centre, 19-23 Wedmore Street, London, N19 4RZ.
Tel: 0171 263 3981.

The Equal Opportunities Commission

The Equal Opportunities Commission can offer advice on the law regarding sex discrimination, including the exceptions allowed under the Act and the wording and placing of advertisements.

Address: Equal Opportunities Commission, Overseas House, Quay Street, Manchester, M3 3HN.
Tel: 0161 833 9244.

Health and Safety

Offers a range of free leaflets on Health and Safety issues for employers.

Address: Health and Safety books, PO Box 1990, Sudbury, CO10 6FS.
Tel: 01787 881165.

The National Centre for Independent Living (NCIL)

National centres for Independent Living was established by the British Council of Disabled People (BCODP). It is based in London but connected with a National Network of Local centres for Independent/Integrated Living and NCIL 'approved' consultants. The NCIL provides information, advice, training and consultancy to disabled people's organisations and local authorities to set up Independent Living Schemes. The NCIL focuses specifically on the implementation of Direct Payments and the development of Personal Assistance Schemes.

Address: National centre for Independent Living, 250 Kennington Lane, London, SE11 5RD.
Tel: 0171 587 1663.

Norah Fry Research Centre

The Norah Fry Research Centre is one of the leading centres in the United Kingdom for research into services for people with learning difficulties.

The NFRC produce 'Plain Facts', these are tapes and short papers aiming to make the findings of research easier to understand for people with learning difficulties.

Address: Norah Fry Research Centre, 3 Priory Road, Bristol, BS8 1TX.
Tel: 0117 923 8137.

Race Equality Unit

The Race Equality Unit (REU) promotes better social care for Britain's black communities. The REU does this through training, consultancy, research, publication and conferences.

Address: Race Equality Unit, Unit 27/28 Angel gate Road, London, EC1V 2PT.
Tel: 0171 278 2331.