

Cashing in on Independence

Comparing the costs and benefits of cash & services

By

Gerry Zarb and Pamela Nadash

A BCODP Publication

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## SUMMARY OF KEY ISSUES AND FINDINGS

Many disabled people require some form of support to enable them to live full and independent lives in the community. This can include personal assistance and domestic assistance, as well as other forms of practical help such as assistance with participation in social and leisure activities. In many cases, peoples' needs will involve a combination of these different kinds of assistance. Such support can be supplied in three ways: by relatives or friends; by direct service provision; or by individual workers controlled by disabled people themselves using either direct or indirect cash payments from a local authority or the Independent Living Fund, or - exceptionally - their own financial resources.

The focus for this report is on the costs and benefits of the last of these options - direct/indirect payments - and how these compare with the provision of services.

From the perspective of disabled people using such support, the key considerations are the quality of support available; how effectively it meets their own needs; and, most importantly, the extent to which it enables them to lead full and independent lives.

For the network of official bodies responsible for funding support, there are two linked decisions which need to be made: how much support should be available at public expense? and how should it be provided and paid for? In the context of debates about the relative merits of direct payments for personal assistance, this latter question can be boiled down to a simple choice: should the official agency provide/pay for services delivered to the disabled person by an organisation; or should it pay the cash directly to the disabled person so that s/he can hire personal assistance. Simplifying again, that choice can be seen to depend on two issues: which of the two approaches provides better support for the disabled person; and which of them is the more cost-effective.

### About the research

This research has been carried out on behalf of the British Council of Organisations of Disabled People (BCODP) following the award of a grant by the Joseph Rowntree Foundation with which to commission a study on the costs and benefits of direct payments for personal assistance.

This has been achieved by comparing the support arrangements of a sample of disabled people who receive payments for personal assistance with those of a similar group whose support needs are met by direct service provision.

This broad distinction includes a further differentiation between direct payments (ie. cash paid directly to an individual by either a local authority or the Independent Living Fund) and indirect payments (ie. payments administered by a third party such as a local disability organisation), and between support arrangements combining a range of services.

A total of 70 disabled people were interviewed for the survey. The sample was selected from four local authority areas in the Midlands, the South of England, and Inner and Outer London. Data from the survey has been combined with detailed budget data collected from local authorities which has been used to calculate the costs of payments schemes and services. Further information on the operation of local payment schemes has also been collected from Social Services Departments in these areas. We have also carried out a national postal survey of all local authorities in England, Scotland and Wales to assess current availability of payment schemes, and the extent of support for direct payments amongst local authorities themselves. The main findings and issues arising from the research are summarised below.

### Quality of support

Findings from the research highlight that payments schemes are associated with higher quality support arrangements than direct service provision. In particular, the payments option clearly offers disabled people a greater degree of choice and control and, consequently, leads to higher levels of user satisfaction. Most importantly, support arrangements which are funded through the payments option are almost invariably more reliable (and, therefore, more efficient) than those supported by direct service provision.

Payments schemes also meet a wider range of assistance needs than services. 80 percent of service users report a need for additional personal assistance hours compared to 40 percent of the payments group. Service users are also particularly likely to want more assistance with social and leisure activities.

Service users are also more likely to experience difficulty organising a suitable support package. For example, they are four times more likely to have difficulty obtaining back-up for their regular support, and three times more likely to have difficulty getting support workers to deliver assistance in the way they want them to.

### User satisfaction

People receiving direct or indirect payments have markedly higher levels of overall satisfaction with their support arrangements than service users.

The key factors determining overall levels of satisfaction are control and reliability. At the same time, there is often a marked contrast between the way in which service users and people in receipt of payments make their own assessments of these criteria. Reflecting the fact that they typically have little control over direct provision, service users tend to emphasise the interpersonal aspects of their support arrangements (ie. satisfaction with the individual support workers with whom they are involved). People who receive payments for personal assistance, on the other hand, typically place a much greater emphasis on the organisational aspects of their support arrangements (eg. when and how their personal assistance is provided, and by whom). This is important because, although service users may often be fairly happy with particular support workers, this should not deflect from the fact that they remain distinctly dissatisfied with the reliability of particular services and the degree of choice and control they are offered.

There were also some noticeable differences between the experiences reported by people who receive payments from local authorities and from the Independent Living Fund. People using local authority payment schemes are more satisfied with both the quality of the assistance provided, and the degree of control they have over their support arrangements. They are also more likely to have access to support and advice about organising their support - either from the social services or a local disability organisation. At the same time, reflecting the current uncertainty over the legal status of direct payments, people using local authority payment schemes have less confidence in the longterm viability of their arrangements compared to people funded by the ILF.

The relative costs of payments for personal assistance and service based support

The research has included detailed comparisons between the costs of support financed by direct or indirect payments and direct service provision. In making these comparisons, we have taken into account the administrative costs and other overheads associated with both the payments and services options. This includes additional costs which are not covered by direct or indirect payments and which disabled people have to pay for out of their own pockets (eg. recruitment costs, meals and travel expenses for personal assistants, and insurance). We have also included the cost of administration of payments schemes by local authorities. Similarly, the calculation of service costs also includes all identifiable administrative costs such as management and

supervision, transport, and central establishment costs (ie. personnel, legal, and accountancy services) involved with running particular services.

The findings indicate that support arrangements financed by direct/indirect payments are, on average, between 30 and 40 percent cheaper than equivalent service based support. The average hourly unit cost of support for people receiving payments is £5.18 compared to £8.52 for service users.

Part of this difference is related to the fact that payments from the ILF are typically cheaper than payments made under schemes operated by local authorities. The average unit cost for support financed by local authority payments is £5.95, compared to £4.53 for support financed by the ILF. Despite these higher costs, local payment schemes are still 30 percent cheaper than services.

However, the main factor accounting for the difference between the costs of direct/indirect payments and service provision is the administrative overheads involved. Administration of local payment schemes adds, on average, between 9 and 15 percent to the total costs. In contrast to this, administrative overheads for service based support add between 20 and 30 percent to the total costs.

Taken together with the findings on the quality of peoples' support arrangements, these cost comparisons indicate that direct/indirect payments are clearly a cost-effective option for meeting disabled peoples' support needs.

### Mixed support packages

The provision of 'care packages' tailored to individual needs and circumstances is intended to be one of the principle benefits of the new community care arrangements. Unlike the old ILF, the new Independent Living (1993) Fund is also based on disabled people receiving a combination of services and cash payments for the purchase of personal and domestic assistance. However, the findings from this research highlight that 'mixed' arrangements combining services and payments are both more costly and less efficient than either the payments option or services on their own.

### Current availability of direct payments

The results of a postal survey of all local authorities in England and Wales and Scotland indicates considerable support for payments for personal assistance. Just under 60 percent of authorities responding to the survey are already operating payments schemes. Although we cannot be sure whether

the same pattern would be found amongst non-responding authorities, this does mean that payments schemes are currently available in at least 38 percent of all local authorities.

It is also clear that there are marked regional variations in the availability of payments schemes. In particular, availability is progressively lower moving from the South to the North and the West of Britain. For example, 80 percent of authorities in the Greater London area make payments compared to only 17 percent in the North West and 25 percent in Wales. Not surprisingly, the exception to this trend is Scotland - where current legislation permits local authorities to make cash payments.

Nearly all of the schemes reported in the survey involve indirect payments. This is a reflection on the present constraints on local authorities (except those in Scotland) making cash payments direct to individuals and the measures they are having to adopt to stay within the law. Several authorities have had to take legal advice and/or change their payment schemes following the government pronouncements on the illegality of direct payments during the run up to implementation of community care. Amongst the authorities responding to the survey, 20 percent had changed from direct to indirect payments, and another 13 percent indicated that they had discontinued making payments altogether.

However, just over 90 percent of authorities responding to the survey indicated that they would make payments if legislation permitted. Only three authorities stated that they were definitely opposed to direct payments. The remainder indicated that they are unable to adopt any policy at this stage due to doubts about the legal situation and/or concerns about funding for community care.

#### Local authority management of payment schemes

The research also indicates that local authorities who wish to enable disabled people to have more control over their personal assistance arrangements are hampered by present legislation which prevents them from making direct cash payments. In fact, the need to work around this restriction and the uncertainty over the legal status of payments often leads to inefficiency and inequity in the way in which payments schemes are administered. Nevertheless, the study has also identified elements of good practice and a high degree of user satisfaction at a local level. This indicates that some local authorities at least are clearly capable of operating payment schemes in ways which are both efficient, and which give disabled people the kind of support arrangements they want. It is likely, therefore, that more would be able to do so if the present restriction on direct cash payments were to be removed.

## Access to support and advice for people receiving payments

The extent to which personal assistance users are able to manage their support arrangements efficiently is very much dependent on the quality of advice and support they receive when organising their support arrangements. Again, the research has highlighted considerable variation in the degree of back-up offered to people receiving payments for personal assistance under the various schemes we have observed.

In some cases there is only minimal support in the form of written guidelines or referral to other agencies who may be able to offer advice. The best run schemes, however, invariably involve ongoing support and advice either from a dedicated independent living scheme worker employed by social services, or a local disability organisation contracted to provide this service on behalf of the local authority. In a few cases, local authorities also sponsor places on independent living skills training courses for disabled people on their payments schemes.

Although this does add to the costs of support arrangements, the benefits in terms of quality and efficiency suggests that such support also represents good value for money. Further, even when these additional costs are taken into account, local payment schemes are still considerably cheaper than services.

## Employment issues

The research has highlighted some important issues relating to the employment of personal assistants with funding from payment schemes. First, it is clear that most disabled people who receive payments for personal assistance are acting as responsible employers. However, a combination of the level of personal assistance funding available, restrictions on the ways in which the money can be spent and, most importantly, present PAYE and benefit rules means that employment conditions for some personal assistants are less than ideal.

Second, the research has also highlighted a lack of clarity on the employment status of personal assistants recruited under the various payment schemes which are currently operating. Some are recruited by the personal assistance user but remain employees of either the local authority or, in some cases, a contracted care agency. Some are employed directly by personal assistance users who assume responsibility for administering PAYE, while some have their PAYE administered by a third-party arranged by the local authority as part of their local payments scheme. Others are acting as self-employed even



though it is doubtful that they would be recognised as such by the Inland Revenue and DSS.

The degree of variation which currently exists can lead to confusion for both personal assistance users and workers and is often a hindrance to recruitment. The situation also means that personal assistance users are not always able to offer their personal assistants the kind of stable and equitable employment conditions which are necessary for the security of both parties.

#### Demand for direct payments

Although this study has not attempted to provide any absolute measure of demand for payments for personal assistance, some indication can be provided by the experience of local authorities which have actively encouraged take-up. This suggests that take-up has, so far at least, been very low.

However, it is also clear that demand in most local authorities is restrained by a combination of lack of awareness, availability of funds, and uncertainty about the legal status of payment schemes (which prevents some authorities from promoting their schemes as actively as they might). Further, the experience of the original Independent Living Fund has shown that take-up is likely to increase as more people become aware of the availability of this option for meeting their support needs.

This is also reflected in the findings from this research. Amongst the group of service users in the study, two-thirds were unaware of the existence of a local payments scheme although just over half subsequently expressed an interest in using such a scheme. Given that this was a matched sample, with similar levels of personal and domestic assistance needs to those already receiving payments, their preferences do represent a more realistic (albeit very approximate) indication of the potential demand for payments for disabled people with higher levels of need. However, without more extensive research, it is obviously impossible to tell whether this level of demand would be replicated amongst disabled people as a whole.

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Finally - and most importantly - we extend our gratitude to the disabled people who participated in the surveys and without whom we would not have been able to complete the research.

Note: The bulk of this report was written by Gerry Zarb based on earlier drafts produced by Pamela Nadash, who also carried out much of the survey' design and analysis.

## Foreword

This study contains the most comprehensive analysis on the costs and benefits of direct payments to disabled people for personal assistance yet produced. The British Council of Organisations of Disabled People (BCODP) could not have known what to expect from the PSI's independent comparison of the circumstances of disabled people receiving cash payments with a control group receiving directly provided services. It is to BCODP's credit that it has, with the generous help of the Joseph Rowntree Foundation, sought a rigorous examination of the relevant issues.

The findings strongly support the case for the introduction of powers to enable local authorities to make direct cash payments to disabled people as opposed to the third party arrangements which currently exist. It is now confirmed beyond reasonable doubt that such powers, if wisely exercised, would be likely to result in greater choice and control for the disabled person and greater value for money and consumer satisfaction for local authorities.

The study also contains valuable information for local authorities on the reliability, accessibility and public lack of awareness of their directly provided social services.

The Association of Directors of Social Services supports BCODP and others, including the Local Authority Associations, in recommending that powers be introduced to enable the making of direct cash payments. From the material contained within this research study it is revealed that 90% of local authorities are wanting to introduce such schemes.

Roy Taylor

Director of Social Services - Kingston upon Thames and Chair of the ADSS Disabilities Committee.

## 1. INTRODUCTION

Many disabled people require some form of support to enable them to live full and independent lives in the community. This support can include personal assistance (eg. assistance with getting up/going to bed, washing and bathing); domestic assistance (eg. housework and cleaning, shopping); as well as other forms of practical help such as assistance with participation in social and leisure activities. In many cases, peoples' needs will involve a combination of these different kinds of assistance. Such support can be supplied in three ways: by relatives or friends; by organisations specialising in the provision of services; or by individual workers controlled by disabled people themselves using either direct or indirect cash payments from a local authority or the Independent Living Fund, or - exceptionally - their own financial resources (see box below).

The focus for this report is on the costs and benefits of the last of these options - direct/indirect payments - and how these compare with the provision of services.

From the perspective of disabled people using support, the key considerations are the quality of support available; how effectively it meets their own needs; and, most importantly, the extent to which it enables them to lead full and independent lives.

### Terminology

The following definitions have been used to describe the various forms of assistance available to disabled people which have been examined in this report.

Support: any form of practical help required by or available to disabled people. This may be delivered in three ways, as follows.

Payments schemes: support provided by a worker hired directly by (or for), and answerable to, the disabled person.

Services: support provided by a worker hired by (or a volunteer organised by) and reporting to a local authority, voluntary organisation or company.

Informal help: support provided by relative (or friend), usually without payment or formal contract.

For the network of official bodies responsible for funding support, there are two linked decisions which need to be made: how much support should be available at public expense? and how should it be provided and paid for? In the context of debates about the relative merits of direct payments for personal assistance, this latter question can be boiled down to a simple choice: should the official agency provide/pay for services delivered person by an organisation; or should it pay the cash directly to the disabled person so that s/he can hire personal assistance. Simplifying again, that choice can be seen to depend on two issues: which of

the two approaches provides better support for the disabled person; and which of them is the most cost effective use of resources.

In principle, direct payments would extend the range of provider markets to which disabled people have access, and so offer greater choice. This should, in turn enable people to have more control over who assists them, and what tasks should be undertaken.

However, very few disabled people have had the resources to pay directly for personal assistance out of their own pockets. In the past, statutory support has almost always been supplied in the form of services provided by a local authority or by the NHS, supplemented by voluntary organisations. The new community care legislation requires social services departments to pay for services, rather than supply them directly, but the contracts will usually be placed with service-providing organisations in the voluntary and commercial sectors, rather than with the 'clients' themselves.

Whatever the theoretical arguments about the potential advantages of direct payments, it has not previously been possible to base a comparison on actual experience of such a method of funding. However the rapid expansion of the Independent Living Fund, and the decision of some local authorities to offer direct payments on at least a limited scale, creates an opportunity to assess the advantages and disadvantages of this approach.

### About the research

This research has been carried out on behalf of the British Council of Organisations of Disabled People (BCODP) following the award of a grant by the Joseph Rowntree Foundation with which to commission a study on the costs and benefits of direct payments for meeting disabled peoples' support needs.

While the research itself has been carried out completely independently, the development of its aims and objectives has been a collaborative process between the researchers and BCODP. This has mainly been through regular consultation with, and feedback to the BCODP Independent Living Committee, some of whom have also been members of the wider project advisory group.

One of the key aims for the research has been to test the proposition - suggested by earlier local studies (eg. Oliver and Zarb, 1992) and advocated by the disability movement itself - that, making payments to disabled people to organise their own personal assistance creates higher quality support arrangements than direct service provision at no extra cost.



This has been achieved by comparing the support arrangements of a sample of disabled people who receive payments for personal and domestic assistance with those of a similar group whose support needs are met by direct service provision. This broad distinction includes a further differentiation between direct payments (ie. cash paid directly to an individual by either a local authority or the Independent Living Fund) and indirect payments (ie. payments administered by a third party such as a local disability organisation), and between support arrangements combining a range of services with either direct or indirect payments.

We have also attempted to place the findings in the context of current policy debates about how payments for personal assistance fit in with the new community care arrangements. In particular, debates about the compatibility between direct payments and the key community care principles of extending choice and control for disabled people; the relative advantages of direct payments and services for both disabled people and local authorities; the likely demand for direct payments and the implications for defining eligibility; and the relative cost-effectiveness of payments and services.

### Outline of the report

This chapter has outlined the background to why the research has been commissioned and the key questions we have attempted to address. The next chapter provides a more detailed discussion of the main background issues involved. Specifically, the development of payment schemes and, in particular, the Independent Living Fund; how payments for personal assistance fit in with the new community care arrangements; the arguments for and against direct payments in current policy debates; and the recent controversy over the legal status of existing payment schemes.

Chapter 3 outlines the methodology used in the research, including sampling, collection of data on the costs of payments schemes and services, the personal interview survey, and the surveys of local authorities. Further details are also given in the appendices.

The findings from the research are presented in the next four chapters. Chapter 4 contains findings on local authority policy and practice on payments for personal assistance. This is in three parts. First, we look at the general national picture on how many authorities operate payments schemes and how many would be likely to do so if the legal situation should change. Second, we summarise the essential features of the payment schemes operated by the local authorities from which our sample of disabled people were selected. Third, we

outline how disabled people who receive payments under these schemes actually use the money to purchase assistance.

The next two chapters focus on the comparisons between support arrangements financed by payment schemes and direct service provision. First, Chapter 5 presents the quantitative findings on the support needs of the payments group; how these compare with the needs of people who use services; and how effectively the two options meet these needs. We also look at the level of demand for payments amongst existing service users. Chapter 6 draws mostly on the qualitative interview data to consider what disabled people themselves have to say about the relative advantages and disadvantages of payments schemes and services and to examine the specific factors which determine the quality of their support arrangements.

Chapter 7 switches the focus from the quality of different support options to a comparison of their relative costs. The first part of the chapter outlines the conceptual and methodological issues which the cost comparison has attempted to address. The second part of the chapter details the results of the comparative cost analysis, focusing in particular on the gross and unit costs of payments and services, and how the various elements of these costs are distributed.

Finally, in Chapter 8 we discuss the implications of the research findings for the policy issues outlined at the start of the report. In particular, we consider the extent to which the findings support the various arguments for and against direct payments and the implications of the findings for the further development of payments schemes in the future.

## 2. BACKGROUND TO CURRENT POLICY DEBATES ON DIRECT PAYMENTS

This chapter sets out the main background issues informing the research and the questions it has attempted to address. First, we briefly trace the evolution of payments schemes and, in particular, the development of the Independent Living Fund. We also highlight the recent controversy surrounding the legal status of existing payment schemes and the effect this is having on their further development. Following on from this, we look at the arguments in favour of making direct payments more widely available put forward by the disability lobby, and the reasons why this has been resisted by government.

### Independent living and payments for personal assistance

The evolution of payment schemes enabling disabled people to purchase their own personal assistance is closely tied to the development of the independent

living movement. Ever since the first Centre for Independent Living (CIL) was started in California in the early 1970's, disabled people around the world have developed an increasing variety of assistance and housing options which enable them to live independently in the community (Crewe & Zola, 1983; Shearer, 1983; Barnes, 1993; Morris, 1993). The concept of personal assistants working under the direction of disabled people has been a central feature of independent living. While this option has always been available to a small number of people with sufficient private income to pay for it, the development of CIL's opened the way for much larger numbers of disabled people to start controlling their own support.

The first recognisable payments scheme in the UK was developed by a small group of disabled people in Hampshire during the early 1980's (Project 81, 1986). The same group were also involved in starting the first CIL in this country, and their experience of establishing the scheme itself has had a significant influence on the subsequent development of the independent living movement generally. The group were enabled to move out of residential care and live independently by persuading their local authority to use some of the money paid towards their residential care to pay for their personal assistants instead. In this pioneering scheme, the money was handled by the residential home the group had moved out of, who then made payments to directly each individual on behalf of the local authority.

Since then, there has been a steady increase in the availability of payment schemes throughout the country. Some of these have been similar to the original Hampshire scheme in that payments are administered by a third-party such as a local voluntary organisation or a trust set up specifically for this purpose. Until recently, several local authorities had also been making cash payments direct to individual disabled people. However, there is evidence that this practice has declined significantly following recent government guidance reminding authorities that direct payments are illegal. Consequently, most of the schemes currently available involve indirect cash payments.

### The Independent Living Fund

More recently, the setting up of a national payments scheme in the form of the Independent Living Fund (ILF) has had a dramatic impact on the availability of direct payments for personal assistance. Launched in 1988, the ILF was intended to be a purely temporary measure to compensate for the loss of certain disability related benefits following implementation of the 1986 Social Security Act.

The ILF represented the first large-scale opportunity for people to use cash to satisfy their support needs, rather than relying on the services provided by local authorities or on their own families. The fund covers the whole country and has no connection with local services. Further, although payments were originally intended to cover only domestic support, the criteria were subsequently changed to enable people to purchase personal assistance also (Kestenbaum, 1993). Most importantly, unlike local authorities who are only legally able to make indirect payments, cash from the ILF goes directly to individual clients.

In practice, the ILF has proved to be remarkably popular. Although it was initially estimated that there would only be around 300 new awards a year (with a maximum of 1,250 overall), these forecasts were soon overtaken by demand. By 1989/90 - after only a year of operation - applications were already being received at a rate of 900 per month and, by November 1992, this had risen to 2000 per month (Kestenbaum, 1993). By the time the original fund closed in spring 1993, there were a total of 22,000 people receiving payments and there is evidence that this figure may well have risen further had the Fund continued to operate (Lakey, 1994).

Studies on the experience of people using payments from the fund have demonstrated that enabling disabled people to organise their own support arrangements offers considerably more choice, control, and flexibility than direct service provision; consequently, direct payments are seen as greatly increasing disabled peoples' independence (Oliver & Zarb, 1992; Kestenbaum, 1993; Lakey, 1994). These studies have also highlighted ways in which having this degree of control creates opportunities for a wider range of benefits such as enabling people to take up employment, enhancing their participation in social and leisure activities, reducing dependence on assistance from friends and family, and providing a viable alternative to disabled people being forced to live in institutions. The research has also indicated that, in many cases, direct payments represent considerable cost-savings compared to both community based services and residential care (Oliver & Zarb, 1992; Phillips, 1993).

By demonstrating the benefits of disabled people controlling their own support, the experience of the ILF has given further impetus to the lobby for direct payments to be made more widely available. However, the very success of the ILF has proved to be something of a mixed blessing for the campaign for direct payments. From the government's perspective, the level of demand for payments from the ILF - and the tenfold increase in its budget - has also raised concerns that any similar schemes which might be developed would spiral out of control in the way that the ILF was seen to have done.

These concerns have also influenced the subsequent development of the ILF itself. In November 1992, the government announced that the original fund would be closed from the end of March 1993 to coincide with implementation of community care. Instead, the fund has been replaced with two new charitable trusts. First, existing clients will continue to receive payments from the Independent Living (Extension) Fund. Second, the Independent Living (1993) Fund has been set up to run alongside services provided or purchased by local authorities.

The new 1993 fund differs from the original ILF in a number of crucial ways. First, it is administered locally. Whereas applications used to be made direct to the fund, these are now processed by local Social Services Departments.

Second, payments from the new fund are tied to the use of services. Applicants are now required to be in receipt of services worth £200 per week before they can apply. Payments from the fund can then be used to purchase additional support to supplement these services. Third, the cost of support is strictly cash-limited with a ceiling of £500 for the total cost of payments and services. As £200 of this total has to be spent on services, this limits the ILF contribution to a maximum of £300 per week. Further, it is now expected that people whose support would exceed this £500 limit should go into residential care.

#### Direct payments from local authorities

The changes introduced with the new ILF underline the government's policy that, in most cases, disabled peoples' support needs should be met by the provision of local community services. Consequently, the restrictions on the use of the fund have served to intensify the call for local authorities to be empowered to make direct payments, both from the disability lobby and from local authorities themselves.

Despite some local authorities having made such payments in the past, direct payments are in fact specifically prohibited under the 1948 National Assistance Act. At the same time it is only recently that the government has taken any action to enforce this prohibition. Consequently, some authorities appear to have interpreted this silence as indicating tacit approval of such schemes or, at the least, that the government was willing to turn a blind eye.

However, the passage of the white paper on community care through parliament brought renewed attention to the issue. This, in turn, led to the prohibition on direct payments being made explicit in the policy guidance on community care issued by the Department of Health in 1990. The guidance stated that:

*'Authorities are reminded that Section 29 of the 1948 Act and Schedule 8 to the 1977 Act, as well as Section 45 of the 1986 Act, prohibit the making of cash payments in lieu of services'*

Since then there have been renewed attempts to secure changes to the legislation so that these obstacles to local authority direct payments can be removed. The most recent attempt was the introduction of the Disabled Persons (Services, No 2) Bill in 1993 (House of Commons, 1993c). The main arguments put forward by the Bill's supporters were that:

- i) direct payments give choice and control to disabled people by allowing them to determine how and when they use personal assistance, and who it is provided by;
- ii) direct payments give disabled people greater privacy and dignity than direct service provision by reducing the level of local authority involvement in their lives;
- iii) direct payments reduce dependency on unpaid informal support to the mutual benefit of disabled people, their families, and other informal helpers;
- iv) direct payments are the most cost effective means of meeting disabled people's assistance needs as they offer the best quality support, matched to individual needs, at the lowest cost;
- v) offering the option of direct payments would be consistent with the principles of extending choice and user involvement which are central to current community care policy;
- vi) direct payments have the support of a wide range of informed and involved organisations, including the major disability organisations, the Association of Directors of Social Services, the Association of County Councils and the Association of Metropolitan Authorities, as well as a large number of MP's from all the main political parties.

These arguments in favour of direct payments essentially revolve around cost and quality and the convergence between the principles of independent living and the new community care arrangements. The Association of Directors of Social Services (ADSS) have recently taken this argument even further by arguing that the restrictions on direct payments are actually holding them back from delivering on these objectives. The ADSS review of the first year of community care includes the recommendation that:

*A significant increase in user power and diversification would occur if Social Services had the legislative power to make direct payments to users to arrange their own services'. (ADSS, 1994, p. 10)*

The principle of making direct cash payments for personal assistance has also received qualified support from the House of Commons Select Committee on Health. In a recent report on the future direction of community care the Committee also concluded that direct payments are consistent with the key principles of choice and greater user involvement which are central to the community reforms. The Committee recommended that the principle of direct payments for some people (particularly young disabled people) should be investigated further, with a view to forming part of a Community Care Charter.

However, the Select Committee report also highlighted a number of specific issues which were felt to require further consideration before direct payments could be fully incorporated into community care arrangements. Specifically, the Committee recommended that:

*'the Government should review existing research and practice on enabling local authorities to make direct cash payments to purchase their own care, and commission any additional research study to identify.*

- i) the types of users who could benefit;*
- ii) the pitfalls which need to be avoided, particularly in relation to employment conditions of care workers and for service providers in the planning of services,*
- iii) ways to assure value for money,*
- iv) ways of avoid any risk of that cash substitution could be used by authorities to shirk responsibilities for people who would be better served by or would prefer direct service provision, and*
- v) what necessary legislative changes would be required.'*

(House of Commons, 1993a)

### Government objections to direct payments

The government's objections to direct payments are based around four main issues:

- i) the perceived complexities in the administration of direct payments and doubts about local authorities being able to manage payments schemes in addition to their existing responsibilities;
- ii) the fact that the new community care legislation is seen as already providing mechanisms for extending users choice and control over their support arrangements;
- iii) concerns that a commitment to make direct payments would reduce local authorities' flexibility in providing services and may divert resources away from other service areas and client groups;

- iv) concerns about the potential level of demand for direct payments and the perceived difficulties in keeping a check on expenditure.

First, while accepting the evidence on direct payments representing better value for money than services in individual cases, the formal government response to the Select Committee recommendations stated that:

*'the Government continues to have concerns about the viability of local authorities operating a general system of direct payments to individuals in lieu of services. It remains to be convinced that such a system would not put additional pressures on local authority resources which could only be met at the expense of other client groups and services.'* (House of Commons, 1993b)

This general concern about the administrative complexity involved in making direct payments is closely linked to more specific concerns about the difficulties in defining eligibility and setting up mechanisms for ensuring financial accountability (which are discussed further in Chapter 8).

Second, one of the main arguments presented against legislation during the debate on the Disabled Persons (Services) Bill was that the new community care arrangements already provide the means for enabling independent living and user choice. Provided these arrangements are used effectively, any further changes would, therefore, be unnecessary.

Speaking on behalf of the government, Baroness Cumberlege also emphasised that the new community care arrangements required local authorities to spend a large proportion of their resources on independent providers and that this was intended to *'stimulate innovation and encourage agencies which are imaginative and willing to pioneer new approaches.'* (House of Commons, 1993c, col. 1663)

While stopping short of sanctioning cash payments which would enable disabled people to employ their own workers directly, Baroness Cumberlege also pointed out that under the new arrangements local authorities *'are free to contract with anyone for the provision of care, including individuals acting as personal assistants'* Also, that - in arranging individual support packages - *'there is no reason ... why disabled persons should not take on the day-to-day management of their carers ... or to choose them in the first place. Many already do this and it could quite easily be written into contracts with care providers'* (House of Commons, 1993c, col. 1665)

The government response to the Select Committee report also proposed that more time should be given to monitor the operation of the new community care



and independent living arrangements introduced in April 1993 before making any decision about new responsibilities for local authorities. Taken together with the qualified support for the principle of individual contracting arrangements noted above, this appears to suggest that the longer-term possibility of cash payments for certain groups has not been ruled out altogether. It is less clear, however, whether or not such payments would be administered by local authorities or some other agency like the ILF.

On the one hand, recent government statements appear to suggest that - if there is any place for direct payments at all - they would have to be accommodated within the new community care arrangements. On the other hand, the government has always argued that any form of cash payment should be the province of social security arrangements which - by definition - precludes local authority involvement. This point was firmly reiterated during the House of Lords debate on the Disabled Persons (Services) Bill:

*'Social services departments arrange exactly that - services. The Benefits Agency provides cash benefits. ... It is not the business of local authorities .... They are providers, enablers and facilitators of care services. It would be difficult for them to manage a general system of cash payments, including defining eligibility, and to carry out the necessary monitoring to keep control over public funds. .... There is a real danger that all that would be achieved is the creation of a separate social security system within social services, with its accompanying rigidity.'* (House of Commons, 1993c, col's. 1664-65)

The third main objection raised by the government is that a commitment to make payments would reduce local authorities' flexibility in providing services and may divert resources away from other service areas and client groups. As noted earlier, local authorities themselves have argued that restrictions on making direct payments are an obstacle to their ability to extend user choice in the ways intended by the new community care arrangements. However, as Baroness Cumberlege pointed out during the debate on the Disabled Persons (Services) Bill, the government takes more or less the opposite view on this question:

*'I do not doubt that in individual cases disabled people may be able to use money more effectively than certain authorities, but we need to look not only at the particular but at the overall effects of making direct payments ... there is a risk that over time they will lead to a degree of inflexibility and adversely affect authorities' ability to match their resources to all local needs, not just those receiving payments.'* (House of Commons, 1993c, col. 1665)

This concern about direct payments diverting resources away from other groups and services is also a reflection of wider concerns (particularly from the Treasury) about being able to control demand.

In particular, there is concern that - once the principle of meeting personal assistance needs through cash payments is accepted - it may be difficult to limit the cost of support arrangements in individual cases. Beyond that, the fact that take-up of payments from the original ILF far exceeded the levels forecast has made the government wary of allowing a similar situation to develop in the future. Indeed, anecdotal evidence from discussions between lobbyists and Treasury officials indicates that their main concern is that legalising direct cash payments would 'open the floodgates' by creating an unknown (and, therefore, potentially unlimited) level of demand.

### Precedents for direct payments

Apart from the fact that several local authorities are already making cash payments for personal assistance, there are also a number of other precedents for direct payments which are actually incorporated into existing legislation.

For example, Part III of the Children Act 1989 enables local authorities to make cash payments to children in need or their families. Similarly, cash payments have been available to parents of severely disabled children from the Family Fund since as long ago as 1973. Indeed, the original Independent Living Fund was initially based on the same model. In addition, there are a number of social security benefits - notably the Attendance Allowance and Disability Living Allowance - which are explicitly intended to contribute towards the costs of disabled peoples' support; the regulations for Income Support also recognise the costs of purchasing personal assistance as legitimate expenditure in the calculation of 'allowable income'.

The most interesting precedent, however, is that - unlike their counterparts in England and Wales - local authorities in Scotland are allowed to make direct payments under the Social Work (Scotland) Act of 1968. Section 12 of the Act states that local authorities can provide assistance in kind or in cash:

*'where the giving of assistance in either form would avoid the local authority being caused greater expense in the giving of assistance in another form, or where probable aggravation of the person's need would cause greater expense to the local authority on a later occasion.'*

Despite the contrasting legislative framework not all Scottish authorities have adopted direct payments as a central part of their provision for disabled people.

One of the reasons for this is that the 1968 Act also specifies that payments in kind or in cash are only supposed to be made in 'exceptional circumstances'. Some authorities appear to have adopted a very cautious interpretation of this criterion. Others have not found that it presents a major obstacle as they still have fairly broad discretion in defining the conditions which constitute 'exceptional circumstances'. Similarly, they also have a degree of discretion over what constitutes 'aggravated need'.

This has encouraged some Scottish authorities to place payments schemes at the centre of their provision for disabled people. At the same time, the findings from our own survey of local authorities (see Chapter 4) indicates that a few Scottish authorities are not even aware that they are permitted to make payments under the 1968 Act.

Further, even those authorities who do make payments are still generally uneasy about the precise legal status of such payments - particularly in view of the recent government pronouncements on this issue. Consequently, as in England and Wales, most Scottish authorities still make payments indirectly through third-party organisations.

#### Legal constraints on direct payments

The fact that even local authorities in Scotland - where legislation permits direct payments - are still wary of following this option is indicative of the degree of controversy which surrounds the legality of existing payment schemes.

As noted earlier, the legal situation regarding direct cash payments to individual disabled people is unequivocal: such payments are illegal. Although there are a handful of authorities who appear to be continuing with such payments, most existing schemes incorporate a variety of mechanisms designed to enable payments to be made indirectly while attempting to stay within the law. This has created a somewhat confused situation.

First, the government pronouncements on the illegality of direct payments has raised the profile of this issue within local authorities, and prompted many of them to review their policies or suspend their schemes altogether.

Second, the situation is further complicated by the diversity of legal opinion on the status of the various indirect payments schemes set up as alternatives to straightforward direct payments. For example, different local authorities with more or less identical schemes have received conflicting advice about their legal status; some have been advised that their schemes are within the letter of the law, while others have been told they are illegal. In some cases, this has led to

payments schemes being suspended altogether, while many authorities are currently looking at alternative options which would allow them to continue making payments indirectly.

Third, there are also concerns about whether or not the various third-party arrangement which have been adopted by local authorities are simply 'laundering' operations. Most of these indirect schemes involve an independent agency handling payments on behalf of a local authority. In some schemes the payments are subsequently passed on to disabled people themselves, while other schemes involve the agency paying disabled people's support workers on their behalf. An alternative approach is for the local authority to assume responsibility for paying workers wages, even though they are working for individual disabled people. A few local authorities have also experimented with setting-up trust funds with disabled people receiving payments as the beneficiaries. Questions have been raised about the legal status of all of these options. The practice of paying disabled people via a third-party is probably the most controversial as this the cash still ends up in the disabled person's bank account. Some legal advisors take the view that this is indeed a laundering operation and, consequently, outside the letter of the law.

The controversy and confusion over the legal status of these various payment schemes is seen as a significant obstacle to making payments for personal assistance more widely available. Although we have not been able to explore these legal issues in any detail in this research, we have attempted to highlight some of the ways in which they have affected the operation of the particular schemes used by people in the study. These are also discussed further in the final chapter of the report.

### 3. METHODOLOGY USED IN THE RESEARCH

#### Identification of local authorities making direct/indirect payments

The overall aim of the sampling strategy was to identify two samples of disabled people: a sample of people receiving direct or indirect payments, and a comparison group of people using services. Our first task, therefore, was to identify local authorities operating payments schemes. We were assisted in this task by the BCODEP Independent Living Committee who, through their numerous contacts with local disability organisations, already had fairly extensive knowledge on areas where people were receiving payments. This enabled us to draw up an initial list of authorities to contact and, where necessary, this was subsequently revised in the light of new information picked up from local authorities themselves.

Table 3.1 Response to initial trawl of local authorities by region

(No. of Local Authorities)	Agreed to participate	Unable to participate	No payments scheme
East Anglia	0	1	1
London	10	7	0
Midlands	3	2	1
North West	1	1	2
North East	1	0	1
South/South East	5	0	0
South West/West	0	2	2
Country			
Totals	20	13	7

Altogether, a total of 40 local authorities who were thought to be making payments were contacted during the first stage of sampling. Of these, 7 informed us that they no longer operated any payments scheme (although 2 were planning to do so in the future) and 13 declined to participate in the research. In most cases this was because staff were too busy dealing with implementation of the new community care arrangements (sampling was carried out during April 1993). This left a total of 20 authorities who were willing to assist with identifying people for inclusion in the research sample. Of these, 5 were located in the South/South East of England; 10 in London; 3 in the Midlands; and 2 in the North.

#### Sampling (direct/indirect payments sample)

The next stage of the sampling process involved identifying a sampling frame from which to select disabled people receiving direct or indirect payments. Social Services Departments (SSD's) in each of the 20 authorities were asked to send an initial screening questionnaire to all disabled people whom they made payments to.

The purpose of the screening questionnaire was to identify those who were willing to participate in the subsequent interview survey, and to collect basic details about the people receiving payments (age, living arrangements, type of assistance used etc) so that they could be matched with the sample of service users.

A total of 325 screening questionnaires were sent to the participating authorities for distribution and replies were received from 131 people receiving payments. Of these, 83 agreed to participate in the interviews, and 48 declined (Table 3.2)

### Selection of authorities for participation in the research

Having obtained a sampling frame of people receiving payments, we then had to decide which authorities the final interview sample would be selected from. Given the available budget for the research, it had been decided that it would be feasible to carry out around 60 interviews in four local authorities (ie. 15 in each). We also attempted to ensure that:

- a) there was an even distribution of authorities across different parts of the country; and,
- b) the final sample would include people who received payments from the ILF as well as from local authorities.

However, the final choice was also limited by the number of respondents available in each of the local authorities. In some cases, the numbers were too small to form a viable sample. This was particularly the case with authorities in the north of the country and, consequently, the final sample did not include any people in these areas. In the case, of authorities in London, however, it was feasible to amalgamate a small number of similar boroughs into discrete sampling blocks to produce a viable sample. The resulting interview sample was drawn from the areas listed in the box below. (Note: in order to preserve anonymity, the authorities have not been identified by name).

#### Local Authorities selected for final interview sample

Authority A - a shire county in the South of England

Authority B - a shire county in the Midlands

Authority C - an amalgam of four Inner-London boroughs. (Note: where necessary, these are referred to separately as Authorities C1, C2, C3 and C4).

Authority D - an amalgam of three Outer-London boroughs. (Note: where necessary, these are referred to separately as Authorities D1, D2 and D3)

## Sampling (service users)

Sampling for service users was carried out in two parts. First, Social Services Departments in the selected authorities were asked to distribute screening questionnaires to local service users. A total of 480 questionnaires were sent to the selected authorities for distribution. The number of questionnaires sent to each authority was based on each SSD's estimate of the number of disabled people who were using services and had similar levels of support needs (in terms of average hours per week) to the group receiving payments. However, as this initial sampling produced only a very limited response, the second sampling stage involved a more targeted approach. A fixed quota of service users (based on level of service use, age group, sex, and household composition) was specified for each of the sample authorities. SSDs were then asked to distribute duplicate questionnaires with reminders to people matching these quotas. We also requested that, wherever possible, the questionnaires should be distributed direct to individual service users, rather than a general mailing.

This targeted sampling brought the total number of service users responding to the postal screen up to 91; of these, 70 agreed to participate in the interview survey, and 21 declined. Added to the direct/indirect payments recipients, this provided a total of 153 people from which to select a final interview sample (Table 3.2).

Table 3.2 Summary of response to postal screen

Payments No.	Group %	Service No.	Users %	All No.	%	
Total No. of Screening questionnaires sent out	325	100	480	100	805	10
Declined	48	15	21	4	69	9
Agreed to participate	83	26	70	15	153	19
Total No of replies	131	41	91	18	222	28

## Matching people receiving payments and using services

All respondents for the interview survey (ie. those in receipt of payments and services) were sampled from social services client lists in the same local authorities. Matching was based on the basic information from the postal questionnaires. This included information on age, sex, ethnic origin, household

composition, the level and type of payments and/or services used, and the total hours of weekly support hours from all sources (including informal support).

Wherever possible, service users and payments recipients were matched on an individual case by case basis within each local authority. Where no exact match was available, we used the closest match available, with priority being given to matching on the total number of support hours used (ie. without necessarily matching on all of the other criterion variables).

This process eventually produced a total of 86 respondents (out of the 153 available for selection) for whom we were able to identify a suitable match. A small number of these subsequently decided that they did not want to be interviewed after all. Some were also excluded after making initial contact to arrange an interview. This was because information given on the postal questionnaire proved to be incorrect as some of the questions had been misinterpreted; consequently, the individuals concerned no longer met the sampling criteria. This left a total of 70 people who participated in the personal interviews.

Of the 70 people interviewed, 27 are men and 42 women. Just over 85 percent of the sample are aged under 55, with the average age being 41; 46 percent live alone, with most of the remainder living with a spouse or partner/partner. (Full details of the interview sample are given in Appendix A).

How the different types of support arrangements have been classified

Although the interview sample is divided into two basic groups (ie. people receiving payments and service users), there is often a degree of overlap between these categories as several of the payments group also use some services. In view of this, the descriptive statistics presented in the report are based on classification of each case according to the degree to which support arrangements approximate to the 'pure types' of 'payments', 'services' or 'mixed' (ie. those using a combination of payments and services).

Classifications used for statistical data analysis

- i) Payments group: People with 80 percent or more of their support (excluding informal support) met through direct or indirect payments.
- ii) Mixed group: People with less than 80 percent of their support met exclusively by either payments or services (ie. 20 percent or more being met by a combination of the two).
- iii) Service users: People who do not receive either direct or indirect payments.



The criteria we have used to distinguish between these three types are as follows. First, where eighty per cent or more of an individual's support (excluding unpaid informal support) is provided through direct or indirect payments, they would be counted in the payments group. Second, where less than eighty percent of an individual's support is provided by either payments or services, they would be counted in the mixed group. Third, people who do not receive any direct or indirect payments are, by default, classified as 'service users'.

For example, if an individual uses a personal assistant (paid for from direct payments) for 85 hours per week but also uses 15 hour's worth of services, they would be counted in the 'payments' group for the purposes of comparative data analysis. On the other hand, if an individual uses a personal assistant for 60 hours a week and also uses services for 40 hours a week, they would be counted in the 'mixed' group as less than 80 per cent of their support is provided from either source.

On this basis, 15 out of the 70 people in the sample have been classified as having 'mixed' support arrangements. Of the remainder, 28 are counted in the payments group and 27 in the service users group. Amongst the payments and mixed groups, 26 people receive most of their payments from the ILF and 17 from local authorities. (A full breakdown of age, sex, household composition, and support hours for each of the three groups is given in Appendix A).

### Personal interview survey

The majority of the personal interviews were carried out by freelance disabled interviewers under the direction of the research team. The interviews were based on a semi-structured interview schedule covering factual information on the practical details of peoples' support arrangements, their views on how effectively these arrangements meet their needs, and the relative advantages and disadvantages of payments schemes or services.

As far as possible within the resources available, the research has attempted to include an appropriate degree of respondent validation of the data collected.

First, all respondents were sent an initial postal questionnaire and, in the case of people receiving payments for personal assistance, a supplementary questionnaire which asked for basic details about their personal circumstances and their support arrangements. The first stage of the subsequent personal interviews involved going over these details again so that respondents had an opportunity to clarify any particular points and, where necessary, make changes to their original responses.

Second, between one and two weeks after the interviews each respondent was contacted again by telephone and asked whether there were any issues arising from the interviews which they had subsequently reconsidered, or any additional points they wished to raise. Interviewers were also instructed to go over any points (particularly those made in response to open-ended questions) which required clarification to ensure that the record of the interviews reflected respondents' views as accurately as possible. Again, any changes or additions which respondents wished to make were included in the final interview records prior to submitting these for analysis.

### Collection of data on the costs of payment schemes and services

A combination of sources have been used to estimate the unit costs for the various support options used by people in this study. Wherever possible, the unit costs for particular services have been calculated from data on service budgets supplied by the individual local authorities concerned. Where this data is unavailable or incomplete we have substituted unit costs based on the estimates of national average costs. Calculation of unit costs for support funded by direct or indirect payments is based on a combination of data supplied by local authorities and data on expenditure on personal and domestic assistance reported by individuals receiving payments. Further details are contained in Chapter 7.

### National survey of local authorities

An earlier survey carried out by RADAR in 1990 found that almost 60 percent of local authorities were operating some form of payments scheme (Browne, 1990). However, there have been a number of changes since then which are likely to have influenced local policies on direct payments. Consequently, we felt it would be useful to update this survey to find out how many local authorities are currently making payments, the type of schemes they are operating, and how many would be likely to make payments if the legal situation should change.

Information required for the survey had already been obtained from 19 of the authorities contacted during the sampling process described above. Further questionnaires were subsequently sent to the remaining 109 local authorities in England and Wales and Scotland. Replies were received from 63 of these authorities, making a total response rate of 64% (ie. 19 plus 63 out of 128). The findings from the survey are summarised in the following chapter.

### Presentation and interpretation of statistical data

The resources available for this research dictate that the findings are based on a relatively small number of people. This means that some of the quantitative data needs to be interpreted with caution. First, with a sample of this size we are unable to make any definitive statement about the extent to which the people interviewed are representative of service users and people receiving payments in general. At the same time, given that the sample are all people with a high level of personal and domestic assistance needs, they are perhaps a slightly more homogeneous group than might be found amongst a general sample of all disabled people.

Second, the data presented - particularly the quantitative comparisons between sub-groups in the sample - are not necessarily generalisable beyond the particular group of people participating in this study. Rather, we have attempted to produce illustrative findings in order to inform the analysis of the various aspects of the main support arrangements we have examined. Hopefully, this will also help to clarify some of the specific issues which can be investigated further in future research.

Similarly, the data on the comparative costs of payments schemes and services cannot necessarily be seen as a completely accurate guide to the actual costs which might be found in other local authority areas. Although, most of the unit costs are still within the broad range indicated by existing estimates on national average costs. However, as with the individual level data, it has not been our intention to provide definitive generalisable conclusions on costs. Rather, the main aim has been to provide an illustrative analysis of the approximate cost differentials between payments schemes and services used by the people in our sample.

The same considerations apply to the findings on the association between the costs and benefits of the main support options we have examined. Again, the analysis produced by this research does not allow us to make definitive statements about cost-effectiveness as, clearly, we have not measured all of the outputs and benefits which might be involved. Rather, the main aim has been to examine the relative merits of payments and services by weighing up the quality of a limited (albeit important) range of benefits against the actual costs involved in producing them. It is also important to bear in mind that this research was never intended to rely solely on the analysis of statistical data. In addition to the illustrative quantitative figures, we have also drawn on detailed analysis of qualitative interview data in order to highlight and clarify particular factors influencing the quality of the main support arrangements examined. It is important, therefore, that both sets of data are viewed together as this provides a much fuller analysis than would be possible using either of these on their own.

#### 4. PAYMENT SCHEMES IN PRACTICE

The main purpose of the chapter is to give an overview of the current situation regarding the operation of payment schemes at the national, local, and individual level. First, drawing on the findings from the national postal survey of local authorities, we look at the general national picture on how many authorities operate payments schemes and how many would be likely to do so if the legal situation should change. Second, we summarise the essential features of the payment schemes operated by the individual local authorities from which our sample of disabled people were selected. Third, we outline how disabled people who receive payments under these schemes actually use the money to purchase personal and domestic assistance.

##### Findings from the survey of local authorities

The results of the postal survey of all local authorities in England and Wales and Scotland indicates considerable support for payments for personal assistance. Just under 60 percent of authorities responding to the survey are already operating payments schemes, most of which involve indirect payments - ie. either through a third party or through trusts (Table 4.1). While we cannot be sure whether the same pattern would be found amongst non-responding authorities, this does mean that payments schemes are currently available in at least 38 percent of all local authorities.

The proportion of authorities making payments is also exactly the same as that found in the 1990 RADAR survey (Browne, 1990). The main difference between the two surveys, however, is that far fewer authorities currently appear to be paying cash directly to individual disabled people (5 percent compared to 23 percent in the RADAR survey).

It is also clear that there are marked regional variations in the availability of payments schemes. In particular, availability is progressively lower moving from the South to the North and the West of Britain. For example, 80 percent of authorities in the Greater London area make payments compared to only 17 percent in the North West and 25 percent in Wales. Not surprisingly, the exception to this trend is Scotland - where current legislation permits local authorities to make cash payments. This also confirms our own observations during the sampling stage of the project, as we were unable to locate any Northern authorities with sufficient numbers of people suitable for inclusion in the sample.

However, it is important to bear in mind that many local authorities are making payments to only a handful of individuals. (This is certainly the case

with some of the schemes in the London area, for example). So, although there is a clear regional trend in the availability of payment schemes, the differences in the actual numbers of people receiving payments may not be quite as large as these figures would suggest.

The fact that nearly all of the schemes involve indirect payments is a reflection on the present constraints on local authorities (except those in Scotland) making cash payments direct to individuals and the measures they are having to adopt to stay within the law. Several authorities have had to take legal advice and/or change their payment schemes following the government pronouncements on the illegality of direct payments during the run up to implementation of community care. Amongst the authorities responding to the survey, 16 (20 percent) had changed from direct to indirect payments, and another 11 (13 percent) indicated that they had discontinued making payments altogether.

However, just over 90 percent of authorities responding to the survey indicated that they would make payments if legislation permitted. Only three authorities stated that they were definitely opposed to direct payments. The remainder indicated that they are unable to adopt any policy at this stage due to doubts about the legal situation and/or concerns about funding for community care.

Table 4.1 Current availability of direct/indirect payments from local authorities

	No.	
Direct payments	4	5
Indirect payments	44	54
Does not make payments	34	41
Totals	82	100

(Response rate = 64%)

Table 4.2 Local authorities who would make direct/indirect payments if legislation permitted

	No.	%
Would make payments	76	93
Would not make payments	3	4
Undecided	3	4
Totals	82	100

Table 4.3 Availability of direct/indirect payments by region

Proportion of LA's responding to the survey in each region who make payments:

Greater London	80
South	78
South East	50
South West	33
East Anglia	50
West Midlands	40
East Midlands	50
North West	17
North East	27
Scotland	64
Wales	25

#### Classification of local payment schemes

This section of the report describes the essential features of the payment schemes operated by local authorities participating in the study and the extent to which they deviate from the 'pure' type of direct payments. A full description of each of the schemes is contained in Appendix B.

When the research was initiated, it was envisaged that there were two main categories of support arrangements to be examined: direct payments schemes and services. However, this simple distinction disguises the variety of arrangements which exist in practice.

Some payment schemes (most notably the Independent Living Fund) involve paying cash direct to individual users. However, most local authority schemes involve making indirect payments through a third-party; some of these indirect schemes use existing agencies (eg. a local voluntary organisation), while others involve arrangements set up specifically for the purpose of administering payments (eg. a trust fund). The situation was further complicated by a number of local authorities changing their payment schemes while the research was in progress because of concerns about the illegality of direct payments.

Consequently, it soon became clear that we would need to define clear criteria for distinguishing between direct and indirect payments schemes and, in some cases, between indirect payment schemes and services. The criteria we have used for the purposes of this study are outlined below.

**Direct payments schemes:** The 'pure' form of direct payments scheme is where money is paid by either a local authority or the ILF directly to a disabled person, for the clear purpose of allowing them to purchase support in whatever form they choose - whether this be through recruiting their own personal assistants, or by purchasing support from other sources. For the purposes of the definition used here, the individual must retain complete control over the recruitment or selection process, the type of person hired, the hours they work, and the tasks they do.

The crux of the matter in classing a scheme as a direct payments scheme is not simply how the money is spent - for example, some people use payments to pay for personal assistants from private care agencies rather than recruit their own workers - but, whether a disabled person is free to choose how it is spent.

Some disabled people may also receive support or assistance with making their support arrangements (eg. help with recruitment, provision of a payroll service, or training in managing personal assistants) as part of a payments scheme. Such assistance is not seen as compromising independence - as long as it is their choice to use it. Consequently, this would not affect the definition of a scheme as a direct payments scheme. Similarly, making disabled people accountable for how the money is spent is not seen as compromising their control over support arrangements, provided that the mechanisms for accountability are not unnecessarily intrusive.

So, the key criteria determining classification of a scheme as a 'pure type' of direct payments scheme are:

- i) that the money is paid direct to the disabled person; and,
- ii) the person receiving payments has complete choice and control over how that money is spent.

Amongst the forms of payments schemes used by people in this study, only the original Independent Living Fund meets both of these criteria in full. Although three of the local authorities participating in the research used to operate schemes conforming to the 'pure type' of direct payments, all of the current schemes are classified as 'indirect' payment schemes. The reasons for this distinction are outlined below.

Indirect payments schemes: Indirect payment schemes also involve making payments for people to purchase their own support. The crucial distinction between these schemes and direct payments, however, is that the money is not paid direct to individual disabled people. Rather, there are a number of alternative mechanisms used for administering payments, some of which result in the money eventually being passed on to individual, and some of which divert payment to support workers on their behalf.

In some schemes the money is paid to a third party, which then passes it on to a disabled person who uses it to recruit their own workers, or purchase personal assistance services, in much the same way as they would with a direct payments scheme. In others, the third party actually pays the support workers' wages (or agency fees) on behalf of disabled people - even though the workers may have been recruited by individual disabled people themselves. Other schemes have a similar arrangement except that the local authority pays the support workers' wages and so, effectively acts as their employer.

Although there are a number of such schemes in existence, local authority legal advisers differ in their attitudes toward them. Some advise that these schemes are merely 'laundering operations', and the same legal objections apply to them as apply toward direct payments. Others suggest that the involvement of third party organisations to administer the schemes on behalf of local authorities is consistent with the requirements of the 1990 NHS and Community Care Act. Specifically, that they can be seen as contributing to local authorities' obligations to enable innovative forms of support provision in the independent sector.

The various indirect payment mechanisms employed in attempting to stay within the law can effect the degree of choice and control disabled people have



over their individual support arrangements. In particular, there are a number of potential problems which can result from preventing disabled people paying support workers directly.

For example, some indirect payment schemes still allow them to retain choice over recruitment, but others involve restrictions on which support workers can be recruited, and where from. Similarly, some schemes allow disabled people to retain a high degree of control over the day to day direction of their support workers, while others involve workers being answerable, at least partially, to whoever is paying their wages.

The fact that the disabled person is not the direct employer can also create confusion over support workers' employment status. This can, in turn, compromise the degree of control disabled people have over their support arrangements and, in some cases, may even jeopardise the continuation of the payment scheme itself.

For example, one local scheme we have looked at allows disabled people to hire, direct, and use a personal assistant in any way they choose, but the personal assistants are considered to be self-employed. Wages are paid on submission of a timesheet, signed by the disabled person for whom they are working, to the Social Services Department. This scheme has run into difficulties with the Inland Revenue who have ruled that the workers are employees of the person by whom they are engaged to assist (ie. individual disabled people). The Inland Revenue have also told the local authority that they must now supply them with details of the disabled people on the scheme so that they can ensure they are operating PAYE. As a result, the local authority concerned is now reviewing whether or not it is viable to keep the scheme running.

The scheme run by Authority D2 has met with similar objections to workers' self-employed status from the Inland Revenue. In this case, however, the authority has attempted to get around the problem by issuing employment contracts to workers recruited by disabled people on the scheme, thereby assuming responsibility for their PAYE arrangements.

The fairly wide degree of variation between these different arrangements makes the definition of indirect payments more complex than the pure type of direct payments described earlier. However, apart from the obvious difference in the way the money is actually paid, the other differences between direct and indirect payments are mostly a matter of degree; specifically, the degree to which they retain the other principle elements of choice and control over how the money is used to meet individual support needs. Consequently, for the

purposes of this study, we have adopted the following definition of the essential elements of an indirect payment scheme:

- i) money is either paid to the disabled person via a third-party, or to the support workers or agency of their choice; and,
- ii) the person receiving payments (or having payments made on their behalf) has control over their individual day to day support arrangements, even though they may not be the formal employer.

### Distinguishing payments schemes from user-led services

In addition to payments schemes several of the local authorities also operate other kinds of independent living schemes which incorporate similar features. However, applying the definition of the essential criteria for payments schemes described above makes it possible to make a clear distinction between these schemes and identify which are genuine payment schemes and which are still a form of direct service provision.

For example, an independent living scheme run by Authority C3 is regarded as an indirect payments scheme by the authority as disabled people using the scheme are involved in the recruitment of the pool of support workers and can also choose individual workers from the pool once they are employed. However, as this recruitment is done on a collective basis, individual disabled people are not necessarily able to use support workers which they have personally chosen. Further, although disabled people using the scheme have a big say in how the scheme is run, support workers' terms of employment are set by a standard contract rather than negotiated on an individual basis. This means that the scheme fails to meet one of the essential criteria for payments schemes as it does not give individual disabled people full control over their day to day support arrangements. Consequently, it has been classified as a service for the purposes of this study.

### How payments are used to purchase support

This section of the report looks at the ways in which disabled people in the study use the payments they receive to meet their support needs. First we present the findings on the amounts people receive; where the money comes from (ie. local authorities, the ILF, or benefits); how much of their own money they use on purchasing assistance; how many workers they use; how much workers are paid; and the use of private care agencies and volunteers. We also look at the differences between payments from local authority schemes and the ILF. Second, we look at particular issues which people experienced difficulties with in organising their own support arrangements, and the availability of

advice and practical assistance from social services and local disability organisations.

### Level and source of payments

As noted in the previous chapter, the interview sample has been divided into three groups: people using payments schemes; services users; and people using a combination of payments and services. The findings in the remainder of this chapter of the report relate to the first and third group only.

Amongst the 43 people in the payments and mixed groups, 40 percent receive payments from local authorities and 60 percent from the ILF (Table 4.4). The average weekly payments for people on different local authority payment schemes range from £162 to £384, with an average of £180 for the sample as a whole. There is less variation in the level of payments from the ILF. The average weekly payment for the sample as a whole is £209, with the average for people in different local authority areas ranging from £190 to £238 (Table 4.5a). In addition to payments from local authorities and the ILF, just over 40 percent of respondents reported spending an average of £38 a week from social security benefits on their support arrangements, while almost a quarter reported spending an average of £46 from other personal income such as earnings from employment (Table 4.5b). These 'top-up' payments brings the average total payment up to £260 per week. This means that people receiving payments are paying for between 15 and 18 percent of the total costs from their own pockets'.

In the case of people receiving payments from the ILF, a proportion of any Attendance Allowance or the care component of the Disabled Living Allowance is automatically treated as available for meeting part of the cost of purchasing assistance. Consequently, they would not have a choice about contributing this amount in any case. Although additional contributions from other personal income are made on a voluntary basis, these have also been counted as part of the total payments on the basis that they represent an essential component of the funds available for the direct purchase of assistance.

However, such contributions have only been included where the same (or similar) amounts are paid on a regular weekly basis. Other incidental or 'one-off' costs which are met from personal income (eg. recruitment costs) have been counted separately and these are included in the estimates of actual expenditure which are discussed later in the report.

Table 4.4 Source of payments

	Payments No.	group	Mixed No.	group %	All No.	
LA payment schemes	12	43	5	33	17	40
ILF	16	57	10	67	26	60
Totals	28	100	15	100	43	100

**Table 4.5a Level of payments from statutory and private sources**

	Average weekly amount	(Number of recipients)
Independent Living Fund	208.73	(26)
Local Authority payments	180.58	(17)
Benefits	38.49	(18)
Other private/personal income	46.23	(10)
Average from all sources	260.20	(43)

Proportion using payments from the following sources: (Percent)

Local authority and benefits	18	41
ILF and benefits	23	
Local authority and personal income	14	23
ILF and personal income	9	
Local authority or ILF only	20	

Note: Percentages do not round to 100 percent as some people use benefits and personal income in addition to local authority or ILF payments

## Amount of assistance purchased

People who are using payments to purchase the bulk of their support have an average of three regular workers and two occasional workers. Most have between one and three workers, although just over 30 percent use four or more regular workers, while a little under 20 percent have four or more occasional workers (Table 4.6). The total amount of assistance provided by paid support workers averages 67 hours per week. The majority of people in the payments group have between 25 and 100 hours per week provided by their regular workers, and between 5 and 10 hours provided by occasional workers (see Tables 4.7 to 4.9).

Within the payments group as a whole, those who receive their payments from the ILF use 30 percent more hours of assistance than people using local authority payments schemes (80 compared to 53). This is partly due to the fact that a far larger proportion of the ILF groups' workers are living-in. (Those whose workers live-out use, on average, almost 25 fewer hours a week than those with live-in workers). Consequently, while half of the ILF clients have between 25 and 100 hours provided by their regular workers, just over a quarter have over 100 hours (Table 4.10).

Most of those funded through local authority payment schemes, on the other hand, have up to 50 hours provided by regular workers, while none of them use over 100 hours per week. However, both groups have very similar amounts of assistance provided by occasional workers - with the majority of people using between 5 and 10 hours a week (Tables 4.10 and 4.11).

Not surprisingly, those who use a combination of payments and services use fewer paid workers (an average of 2 regular workers and 1 occasional worker) and less hours than the payments group (an average of 40 hours per week). The majority of people in this group use their regular workers for no. more than 25 hours a week, with between 1 and 5 additional hours being provided by occasional workers. There are, however, a significant minority whose workers provide 100 plus hours of assistance per week.

Table 4.6 How many support workers people use

(Percent)	Regular workers	Occasional workers
One	10	27
Two or three	59	55
Four or five	21	18
More than five	10	0
Totals	100	100
(Base)	(41)	(22)
(Average)		
Payments group	3	2
Mixed group	2	1

Table 4.7 Total number of hours provided by paid support workers (Average per week)

Payments group	67
Mixed group	40
ILF	80
LA payments	53

Table 4.8 How many hours regular support workers work each week  
(Payments and mixed groups)

(Percent)	Payments group	Mixed group
Up to 25	21	73
26 to 50	22	7
51 to 100	39	7
101 to 150	7	7
Over 150	11	7
Totals	100	100
(Base)	(28)	(15)

Table 4.9 How many hours occasional support workers work each week  
(Payments and mixed groups)

(Percent)	Payments group	Mixed group
Up to 5	62	80
6 to 10	23	20
11 to 20	8	0
Over 20	8	0
Totals	100	100
(Base)	(13)	(5)

Table 4.10 How many hours regular support workers work each week by source of funding

(Percent)	ILF	LA payments
Up to 25	23	65
26 to 50	14	23
51 to 100	36	12
101 to 150	12	0
Over 150	15	0
Totals	100	100
(Base)	(26)	(17)

Table 4.11 How many hours occasional support workers each week by source of funding

(percent)	ILF	LA payments
Up to 5	70	63
6 to 10	20	25
11 to 20	0	12
Over 20	10	0
Totals	100	100
(Base)	(26)	(17)



Table 4.12 Proportion of support workers living-in by source of funding

Percent	ILF	LA payments	All
Live-in	23	6	16
Live-out	42	77	56
Both	35	18	28
Totals	100	100	100
(Base)	(26)	(17)	(43)

### How much support workers are paid

Amongst the sample as whole, regular support workers are paid an average of £4.25 per hour, with an average rate for occasional workers of £5 per hour

(Table 4.13). However, the hourly rates for agency workers are higher than this with some people reporting rates of up to £12 per hour.

People using payments to purchase the bulk of their support report slightly higher pay rates than those using a combination of payments and services (£4.25 compared to £4 for regular workers, and £5.25 compared to £4.50 for occasional workers).

However, there would seem to be a much larger difference in the rates paid by people funded through local authority payments and the ILF. Average hourly pay rates amongst the former group are around one pound higher than those paid by people funded by the ILF. This probably reflects the fact that, while local payment schemes typically review hourly rates on an annual basis, ILF payments have not been uprated for the last two years. The higher pay rates which people using local schemes are able to offer also has implications for their relative 'purchasing power' which are discussed further below.

Average hourly rates for regular workers in different local authority areas range from just under £4 to just over £6; the rates for occasional workers range from £4.75 to £6.25 per hour. Some of this local variation can be accounted for by the regional weightings applied to ILF payments; at the same time, this also reflects the fact that some local payment schemes are funded at higher levels than others.

Just over 60 percent of the people in the payments group do not pay their workers' tax and National Insurance contributions (Table 4.14). There are several reasons for this. In some cases workers are technically employed by a local authority or a third-party agency for PAYE purposes; some people spread the hours worked so that their worker's wages are kept below the tax/NI threshold; some workers are treated as self-employed or, in a few cases, paid cash in hand.

Just under half of the payments group pay their workers holiday pay. However, this seems to be much more likely amongst people on local authority payment schemes compared to people receiving payments from the ILF (Table 4.15). Amongst those using a combination of payments and services, this proportion is lower still - with only 1 in 5 people giving their workers holiday pay.

Table 4.13 Support worker's hourly pay rates

	ILF	LA payments	All
Average hourly pay rate (regular PAs)	£4.00	£4.90	£4.25
Average hourly pay rate (occasional PAs)	£4.40	£5.50	£5.00

Table 4.14 Payment of support workers PAYE and NI (payments and mixed groups)

(percent)	Payments group	Mixed group
Workers self-employed	14	7
Pays workers tax and NI	39	13
Does not pay workers tax and NI	32	53
Don't know/missing	15	20
Totals	100	100
(Base)	(28)	(15)

Table 4.15 Proportion of support workers receiving holiday pay

	Percent	(Base)
ILF	32	(26)
LA payments	47	(17)
Payments group	46	(28)
Mixed group	20	(15)

#### Views on adequacy of pay rates

Overall, just under 60 percent of the payments and mixed groups consider their workers' pay rates to be adequate. However, this figure is noticeably lower amongst the former group - who rely on their own workers for the bulk of their assistance. People using local authority payments schemes are also more likely to consider their workers' wages to be adequate compared to people receiving payments from the ILF (Tables 4.16 and 4.17).

Respondents' views on the adequacy of current pay rates are also reflected in how they would chose to use an increase in the amount of funding they receive. Half of those receiving payments stated that they would pay their workers/helpers more money and/or increase the number of hours worked. Over a third stated that their main priority would be to purchase additional hours (Table 4.18). The main reasons given for this choice were that this would enable them to have cover for nighttimes or emergencies, and to have more assistance with social and leisure activities. Some of those using a combination of support workers and services also said that higher pay rates would enable them to have a larger proportion of their assistance provided by paid support workers rather than services.

Table 4.16 Views on adequacy of pay rates for support workers (payments and mixed group)

(Percent)	Payments group	Mixed group
Generous	14	29
Adequate	32	50
Barely adequate	38	14
Inadequate	14	7
Totals	100	100
(Base)	(28)	(14)

(Missing cases = 1)

Table 4.17 Views on adequacy of pay rates for support workers by source of funding

(Percent)	ILF	LA payments
Generous	12	18
Adequate	31	35
Barely adequate	50	24
Inadequate	7	24
Totals	100	100
(Base)	(26)	(16)

**Table 4.18 How people would chose to use any increase in payments**

	No.	Percent
Increase weekly hours	14	37
Increase workers pay	13	34
Increase hours and pay	6	16
Pay worker's Tax/NI	5	13
Totals	38	100

(Missing cases = 5)

These views on the adequacy of pay rates also highlight that, although some people employing their own workers feel they have had to cut corners in the way they organise their support, this is invariably out of necessity rather than by choice. Far from indicating any lack of ability or responsibility as employers, people in this position emphasised the importance of being able to finance their support arrangements properly, not only for their own peace of mind, but also in terms of providing better conditions for workers and ensuring compliance with social security and tax regulations. Some (particularly those receiving ILF payments) also specifically emphasised the need to be able to pay an annual cost of living increase with worker's wages:

*"I would like to pay people a decent wage, including holiday and sick pay, and still have enough to go on holiday and take a PA with me. I'd like some allowance for out-of-pocket extras such as meals out and theatre tickets. It would include insurance cover and PAYE payments ... tax offices don't like PAs employed on a self-employed status. ... It would give me peace of mind because it would all be above board. "*

*"Funding must be index-linked - you can't expect people to work forever for the same wage. There should be a margin built in for sudden illnesses and emergencies - I might be ill overnight - and to pay out of hours bonuses for weekends, nights, and bank holidays. Not having this limits the sort of people you can employ. "*

These restrictions mean that people can sometimes find themselves having to choose between purchasing extra hours and paying higher wages, or paying workers more and reducing their hours. Apart from the making it more difficult

to secure a sufficient amount of assistance, this situation also has additional implications for support workers which are discussed further later in this report.

### Problems people experience with organising their own support arrangements

Previous research on local personal assistance schemes has highlighted that such schemes work much more effectively if people have access to practical advice and assistance with setting-up and managing their own support arrangements. Also, that even people who are experienced in managing their own workers can benefit from being able to access this kind of back-up from time to time (Oliver & Zarb, 1992). It is useful, therefore, to look at the kind of difficulties people have with organising their workers and the extent to which they have access to support and advice.

Half of the people in this study have been using their payments schemes for two years or more and less than ten percent have been doing so for under six months. People funded by the ILF have been receiving payments for longer than people on local payment schemes, with almost three quarters having done so for over two years (Table 4.19).

The most commonly reported difficulties amongst all of those using payments schemes are problems with recruiting suitable workers, organising/obtaining funding, arranging back-up for regular workers, and interpersonal relationships with their workers (Table 4.20). Other miscellaneous difficulties mentioned during the interviews included problems with deciding how to advertise for support workers, finding workers who are willing to travel, and availability of workers during the peak holiday periods. One or two people raised the issue of other family members being unhappy about support workers 'taking over' the support which they had previously provided.

People who use a combination of payments schemes and services seem to have greater difficulty with most aspects of these arrangements compared to people in the payments group. The most noticeable differences are in the proportion of people reporting problems with finding workers, organising funding, obtaining information, working out their support needs, and developing their own self-confidence. Some of the mixed group also pointed to difficulties with co-ordinating the support provided by their own workers with the other services or agencies they use.

There also appear to be some noticeable differences in the level of difficulty experienced by people using local authority payments schemes and the ILF. In particular, people funded by the ILF are twice as likely to report having difficulty with recruiting workers, organising back-up, and with their own self-

confidence. People using local authority schemes, on the other hand, are more likely to report having difficulty with establishing eligibility for payments and with organising their funding (Table 4.21).

Table 4.19 How long people have been using their own support workers

(Percent)	ILF	LA payments
Less than 6 months	8	6
6 months to one year	15	18
One to two years	4	35
Over two years	73	41
Totals	100	100
Base	(26)	(17)

Table 4.20 Problems experienced with recruiting/organising support workers (Payments and mixed group)

Proportion reporting the following: Payments group	Mixed group
Finding suitable workers 43	64
Organising funding 32	50
Organising back-up 25	29
Interpersonal relationships 25	43
Building self-confidence 25	50
Organising/training workers 18	7
Getting information 14	64
Establishing eligibility for payments 14	7
Working out support needs/care plans 7	29
Dealing with Tax and NI 4	14
Working out employees terms and conditions 4	0
Others 14	21
(Base) (28)	(15)

Note: percentages do not total 100% as some people reported two or more problems



Table 4.21 Problems experienced with recruiting/organising support workers by source of funding

Proportion reporting the following	ILF	LA payments
Finding suitable workers	60	35
Organising funding	36	41
Organising back-up	32	18
Interpersonal relationships	32	29
Building self-confidence	40	24
Organising/training workers	12	12
Getting information	28	35
Establishing eligibility for payments	4	24
Working out support needs/care plans	12	18
Dealing with Tax and NI	8	6
Working out employees terms and conditions	4	0
Others	20	12
(Base)	(25)	(17)

Missing cases = 1

Table 4.22 Support and advice on organising support arrangements from SSD's or voluntary agencies (Payments and mixed groups)

	Payments group	Mixed group
General advice (eg. tax/NI)	26	14
Registration/vetting workers	15	29
Assistance with recruitment	33	29
Advocacy	15	7
Other	15	7
(Base)	(28)	(15)

Table 4.23 Support and advice on organising support arrangements from SSD's or voluntary agencies by source of funding

	ILF	LA payments
General advice (eg. tax/NI)	8	44
Registration/vetting workers	12	31
Assistance with recruitment	12	63
Advocacy	12	13
Other	8	19
(Base)	(25)	(16)

Missing cases = 2

The findings also suggest there is an association between the degree of difficulty people experience with organising their support and the availability of support and guidance.

This particularly applies to people using local authority payment schemes who not only report fewer difficulties than people funded by the ILF, but are also more likely to have access to practical support and advice. For example, they are more than five times more likely to report having access to general advice

about managing their support arrangements (eg. advice on dealing with tax and national insurance) and assistance with recruiting workers (Table 4.23).

People using a combination of payments and services also tend to have less access to general advice compared to people in the payments group. At the same time, they are more likely to report having assistance with vetting support workers. This reflects the fact that a larger proportion of this group are using agency workers who would normally be vetted by their employers.

This chapter has looked at the operation of payment schemes at national and local levels. We have also examined how disabled people use the money from these schemes to purchase assistance. In the following two chapters, we examine how these arrangements compare with service based support.

## 5. COMPARISONS BETWEEN PAYMENT SCHEMES AND SERVICES

This chapter compares support arrangements financed by payment schemes and direct service provision. First, we present the quantitative findings on the support needs of the payments group; how these compare with the needs of people who use services, or a combination of payments and services; and how effectively these options are in meeting disabled peoples' needs. Second, we look at the role of unpaid informal support; back-up arrangements; and past and present use of services. We also consider the differences between support arrangements financed by payments from local authorities and the ILF. The chapter ends by looking at the level of demand for payments schemes amongst existing service users.

### Amount and sources of practical assistance

The average amount of practical assistance for the sample as a whole is just over 100 hours per week. People using a combination of payments and services have the most assistance, while service users have the least (Table 5.1). The main difference between the comparison groups relates to the proportion of informal support. Service users have nearly 60 percent of their assistance provided by informal helpers, compared to 40 percent for the payments group and 30 percent for people using a combination of payments and services.

There is very little difference in the level of support used by older and younger groups in the sample (Table 5.2). This is not surprising given that the sample of service users (which contains a slightly higher proportion of older people) was selected to match the group receiving payments.

At the same time, age does make a difference to the use of paid support workers amongst those receiving payments. A higher proportion of the younger group are using their own workers, while the older group are more likely to use a combination of paid workers and services rather than rely exclusively on either source (Table 5.4).

There are also noticeable differences in weekly support hours according to household composition. On average, people living alone use 27 hours less than those who are living with others (ie. mostly a spouse/partner, children or parents). Most of this difference can be accounted for by the availability of informal unpaid support - only 11 hours per week for people living alone, compared to 66 hours for those living with others. Consequently, the latter group are more likely to rely on a combination of paid support workers and services to meet their practical support needs (see Table 5.2).

Table 5.1 Average weekly support hours

	Payments group	Services users	Mixed group	All
Paid support workers	67	na	40	35
Services	1 %2	46	51	29
Informal support	40	55	30	44
Total hours	101	96	116	102

Table 5.2 Average weekly support hours by age and living arrangements

	Informal support	Total hours	(Base)
Under 55	46	106	(58)
Over 55	41	101	(10)
Living alone	1 1	87	(31)
Living with others	66	114	(37)

Table 5.3 Combinations of support used from different sources

Proportions having regular assistance from:	Payments group	Service users	Mixed group
Support workers only	57	0	0
Services only	0	89	0
Support workers/services	39	0	80
Support workers/volunteers	4	0	0
Services/volunteers	0	1 1	0
Support workers/services /volunteers	0	0	20
Totals	100	100	100
(Base)	(28)	(27)	(15)

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Informal and unpaid support

Informal support amongst all of the comparison groups is provided mostly by parents or a spouse/partner. However, service users appear to be more likely to have assistance provided by their children than either the payments group or those using a combination of payments and services; the latter are more likely to have assistance provided by friends and neighbours (Table 5.5).

There also appears to be some variation in the use of volunteers. 20 percent of people using a combination of payments and services have some assistance provided by volunteers compared to only 11 percent of service users and less than 5 percent of the payments group. People living on their own also have a higher proportion of their assistance provided by volunteers compared to those living with others. This suggests that volunteers are, to a certain extent, providing support which would otherwise be provided by peoples' own families.

### Levels of service use

Not surprisingly, there are noticeable differences in the levels of service use amongst the different groups in the sample. Amongst the payments group, the only service used by any significant numbers is the district nursing service - with contact time averaging well under one hour a week.

The most relevant comparisons are between service users and those using a combination of payments and services. As noted earlier, the latter group tend to have higher levels of assistance than either the payments group or service users. This applies almost equally to support provided by paid support workers and services. In particular, people using a combination of payments and services are more than four times as likely to use private care agencies as service users (Table 5.6). However, they are also less likely to be using local care attendant services. This suggests that agency workers are being used to provide the bulk of assistance which is not already covered by their own workers.

At the same time, people using a combination of payments and services are twice as likely to be using residential based respite care than service users; they are also almost five times as likely to be using respite services compared to people using paid support workers for the bulk of their assistance. Given the lower level of informal support available to this group, this suggests that respite care is being used to fill gaps in support which might otherwise be filled either by paid workers or - more likely - by other family members.

There also seems to be a different pattern of use amongst the group of service users. Although the proportion of people using the home help service is almost identical amongst service users and the mixed group, almost 40 percent of

service users are using local care attendant services compared to 20 percent of those who use a combination of payments and services. Service users are also more likely to be using day care than people receiving payments. This indicates that, apart from support which is provided by informal helpers, most of their personal assistance needs are being met by these two services. The fact that service users have a greater proportion of their support provided by informal helpers is also reflected in their lower use of respite care services.

Table 5.4 Combinations of support used from different sources by age and living arrangements

Proportions having regular assistance from:	Under 55	Over 55	Living alone	Living with others
Support workers only	31	0	29	24
Services only	22	50	42	38
Support workers/services	19	50	13	32
Support workers/volunteers	3	0	3	0
Services/volunteers	5	0	10	3
Support workers/services /volunteers	3	0	3	3
Totals	100	100	100	100
(Base)	(58)	(10)	(31)	(37)

Table 5.5 Sources of informal support

Proportions having regular assistance from:	Payments group	Service users	Mixed group
Parents	35	40	31
Children	4	27	15
Spouse/partner	30	24	31
Friends/neighbours	39	40	62
Others	26	28	23
(Base)	(28)	(27)	(15)

Note: percentages do not total 100% as some people have assistance from more than one source

Table 5.6 Current Service use

(Percent)	Payments group	Service users	Mixed group
District Nurses	39	48	60
Private care agencies	4	15	67
CSV's	7	11	13
Home Help	7	41	40
Meals on wheels	0	7	0
Day care	4	48	27
Respite care (residential)	7	15	33
Care Attendants	7	37	20
(Base)	(28)	(27)	(15)

Note: percentages do not total 100% as some people use two or more services

#### Levels of support for people receiving local authority and ILF payments

There are some interesting variations in the level of assistance used by people within the payments group. People receiving payments from the ILF have around 30 percent more hours of assistance per week than those using local authority payments schemes (Table 5.7). (As noted earlier, this is partly due to the fact that a far larger proportion of the ILF groups' workers are living-in). Both have just over a third of their assistance hours provided from by unpaid informal helpers.

The number of hours provided by paid support workers also needs to be interpreted in the context of the earlier findings on the number of workers people use, the way in which these hours are spread between regular and occasional workers, and the amounts which workers are paid.

People using local authority payment schemes have fewer hours overall but they also tend to spread these hours between a higher number of workers than those receiving payments from the ILF. This is partly a reflection of the fact that hourly pay rates are almost one pound higher amongst the former group; in other words, each pound they spend buys proportionately fewer hours. At the



same time, the fact that they are able to pay higher rates indicates that they are able to recruit a larger pool of workers, thereby spreading their hours more evenly between regular and back-up workers. As we shall see later in the report, this is often seen as an advantage in terms of avoiding over-reliance on a single source of support.

Table 5.7 Average weekly support hours by source of funding (Payments group only)

	ILF	LA payments
Paid support workers	80	53
Services	1	2
Informal support	44	31
Total hours	124	86

#### Types of practical assistance needs

As noted in Chapter 3, the sub-groups in the research sample were selected on the basis of their using a similar amount of practical assistance. However, in order to draw any useful conclusions from the data, it is also necessary to establish what type of assistance needs the different groups have, and the extent to which they are comparable.

The various activities people have regular assistance with are summarised in Table 5.8. Needs are divided into three groups:

- i) personal assistance  
eg. assistance with getting up/going to bed, nighttime assistance, washing and bathing;
- ii) domestic assistance  
eg. housework and cleaning, shopping, laundry, meal preparation and other miscellaneous domestic tasks;
- iii) miscellaneous assistance  
eg. assistance which enables people to participate in social and leisure activities, assistance at work, driving and transport generally, DIY and gardening.

These findings suggest that the comparison groups within the sample have broadly similar support needs. The proportions having various types of domestic assistance are almost identical, although people receiving payments

tend to have a greater amount of personal assistance than service users. The payments group are also noticeably more likely to report having assistance with transport and driving.

At the same time, the level of assistance people receive does not necessarily give a completely accurate comparison of their actual levels of need. Using less assistance may indicate a lower level of need (ie. reduced demand); however, it may also indicate that certain needs are not being met in full (ie. reduced availability of support). Consequently, to complete the picture we also need to consider the extent to which the different support options meet the full range of needs by looking at levels of unmet support needs reported by people in the study.

Table 5.8

## Practical assistance needs

Proportions having assistance with:	Payments group	Service users	Mixed group
<i>Personal assistance</i>			
Getting up/going to bed	75	63	80
Nighttime assistance	57	41	33
Washing/bathing	89	85	93
Dressing/grooming	86	70	100
Toilet	61	41	60
<i>Domestic assistance</i>			
Housework/cleaning	100	93	93
Shopping	82	82	73
Laundry	89	89	93
Meals	82	82	87
Other domestic assistance	54	63	53
<i>Miscellaneous assistance</i>			
Social/leisure activities	57	52	40
Assistance at work	25	18	20
Driving/transport	89	44	53
Personal finances	32	33	40
Child care	7	4	0
Communication/facilitation	18	15	13
Other	32	26	20

## Unmet support needs

Findings on unmet support needs suggest that differences in the type and level of assistance received are linked to lower availability rather than to lower demand. In fact, service users and people using a combination of payments and services are twice as likely to report a need for additional personal assistance than people in the payments group. They are also noticeably more likely to report a need for additional domestic and general assistance (Table 5.9). There are two important implications suggested by these findings.

First, service users do not necessarily have a lower requirement for personal assistance than the payments group. Rather, the findings suggest that their support arrangements are not adequate to fully meet their needs.

Second, although people receiving payments also report some unmet needs, it also appears that payments schemes meet a greater range of needs compared to services.

At the same time, people receiving payments from the ILF also appear to have a higher level of unmet needs than people using local authority payment schemes - particularly in relation to domestic and general assistance (Table 5.10). Although these differences do not seem to be as marked as those between the payments group as a whole and service users, this does suggest that local schemes are meeting a wider range of needs than the ILF.

There are also some interesting differences in the level of unmet needs reported by older and younger people, and by those living alone and with others. First, older people are much more likely to report a need for additional personal assistance compared to the younger group. Second, although living arrangements do not make much difference to the demand for additional personal assistance, people living with others are noticeably more likely to report a need for additional domestic and general assistance than those who live alone. This suggests that, while the former group have a greater proportion of informal support, this may not be adequate to fully meet their needs.

Responses to open-ended questions about the specific kinds of additional support people require also help to give a clearer picture of these differences in unmet needs.

First, additional needs amongst service users seem to be fairly evenly distributed between personal, domestic and general assistance. The most commonly reported needs are assistance with getting-up/going to bed; nighttime assistance; housework and cleaning; help with meals; and assistance with social

and leisure activities - all of which are reported by around a quarter of service users.

Second, people using a combination of payments and services report a similar pattern of unmet need. Amongst this group, between 33 and 40 percent report a need for additional nighttime assistance, housework and cleaning, and assistance with social and leisure activities; other common needs include assistance with gardening or household DIY, and transport or driving - all of which are wanted by around a quarter of the people in this group.

Third, although some of the payments group want some additional personal assistance hours (particularly for nighttime assistance), very few report any need for additional domestic assistance. Rather, the most common needs amongst this group are assistance with gardening or household DIY, and transport or driving. However, the proportion of people wanting these kinds of assistance (less than 20 percent) would seem to be noticeably lower than that amongst the other two groups.

These findings on unmet needs suggest that payment schemes - and local authority payment schemes in particular - are not only meeting a greater range of needs than direct service provision, but are also less likely to leave gaps in basic personal and domestic assistance needs. They also suggest that once people's basic support needs have been met there is a tendency to look for ways of extending this support to meet other needs which - although they may not always be absolutely essential to day to day survival - can significantly enhance the quality of life.

Table 5.9 Unmet support needs

(Percent)	Payments group	Service users	Mixed group
Proportion wanting additional personal assistance	37	80	73
Proportion wanting other support	56	72	64
(Base)	(28)	(27)	(14)

Table 5.10 Unmet support needs by source of funding

(Percent)	ILF	LA payments
Proportion wanting additional personal assistance	54	44
Proportion wanting other support	68	44
(Base)	(26)	(16)

### Back-up arrangements

The reliability of individual support arrangements is strongly dependent on the "availability of cover for peoples' regular support. This is particularly important when usual sources of support are unexpectedly unavailable. This, in turn, is closely tied to the degree of flexibility which exists in individual support arrangements as this will often determine whether or not cover can be arranged at short notice.

People receiving payments appear to be more likely to have cover for when their usual sources of support are unavailable compared to both service users and people using a combination of payments and services. People in the payments group also report a markedly higher degree of confidence in their back-up arrangements (see Table 5.13).

People in the payments group also tend to have greater direct control over their back-up arrangements. When asked who provides cover for their usual support, the majority of the payments group reported that they use their pool of occasional support workers, or a combination of support workers and informal support. Most of the service users, on the other hand, rely exclusively on their families or, in a few cases, simply manage without:

*"I'd just do without. I know people who haven't had a bath for three or four weeks. "*

*"Do without - I settle down with some dry biscuits and a flask. "*

Some of the comments from the interviews also suggest that the lower levels of confidence are associated with services being unavailable at short notice, for emergencies, or at nighttime or at weekends:

*"If you are taken bad over the weekend, how do you get in touch with them? I have the number of (the service co-ordinator), but that would not be*

*appropriate over the weekend unless that is an emergency number as well, but I don't know that. "*

Husband: *"A couple of months ago, when she was very ill, /just stayed at home. "*

Wife: *"We wouldn't know what to do really. If there's a sudden change we have no cover then."*

Some also highlighted the fact that, even where services might attempt to provide cover for these times, it is not possible to rely on this actually materialising:

*"To be fair, our Care Attendant Organiser does say she will try and back you up with care attendants. But obviously, it is only if she has got the spare hours."*

*"I usually ring the head office and they say 'is it an emergency?' and / say 'of course it is' and they say 'we'll try and get someone round' and I wait all day and no-one comes. "*

*These kinds of difficulties indicate that back-up arrangements for service users are less reliable than those used by people who are able to purchase their own cover. At the same time, there are also differences in the degree of confidence in back-up arrangements expressed by people receiving payments from a local authority and from the ILF. Although both groups have greater confidence than service users, people on local authority payments schemes are often more confident in these arrangements than ILF clients. This, in turn, may be related to the earlier findings which suggested that they have greater 'purchasing power' than people receiving ILF payments. In particular, the fact that they are able to offer higher pay rates, and have a larger pool of workers to draw on, makes it easier for them to arrange adequate cover.*

Table 5.11 Availability of cover for when usual support is unavailable

(Percent)	Payments group	Service users	Mixed group
Usually has cover	89	75	79
Only sometimes has cover	11	21	21
Rarely or never has cover	0	4	0
Totals	100	100	100
(Base)	(27)	(24)	(14)

Table 5.12 How often people are left without support

(Percent)	Payments group	Service users	Mixed group
Never	52	52	62
Once or twice a year	30	13	8
Between 3 and 10 times a year	11	17	8
Between 10 and 20 times a year	4	4	8
More than 20 times a year	4	9	0
Unable to say	0	4	16
Totals	100	100	100
(Base)	(27)	(23)	(13)



Table 5.13 Proportion of respondents expressing confidence in their ability to arrange back-up for their usual support arrangements

Percent	(Base)
Payments group 74	(27)
Service users 42	(26)
Mixed group 33	(15)
<hr/>	
LA payments 71	(17)
ILF 52	(25)
<hr/>	

#### Past and present use of services

Previous research on personal assistance schemes (Oliver and Zarb, 1992) has indicated that direct payments are associated with a reduction in dependency on services. As shown in Table 5.14, this is also reflected in the findings from this study. As with the previous research, the largest reduction is in the use of the home help service. There also appears to be a marked reduction in the use of local authority or voluntary agency care attendants and the use of private care agencies. Where the use of these services is retained this is primarily to provide back-up for people's own support workers or, in some cases, because the level of payments are not sufficient to purchase enough hours to meet all their needs. Similar considerations apply to the use of Community Service Volunteers (CSV's) which are sometimes seen as a means of providing additional assistance at a reduced cost. However, the slight increase in the use of CSV's actually only applies to one local authority area. Further, this form of provision is now being reconsidered as it has not proved to be as inexpensive as the authority originally anticipated (see Appendix B).

The availability of payments also has an important association with reducing dependency on informal support and residential care. When asked what type of support arrangements they had in the past, just over a quarter of those receiving payments (or using a combination of payments and services) reported that they had moved out of residential care. The same proportion indicated that they had previously relied more or less exclusively on their families for the bulk of their support.

Table 5.14 Comparison of past and present service use  
(Payments group only)

(Percent)	Current	Past	Change
'District Nurses	39	50	- 11
Private care agencies	4	21	- 17
CSV's	7	4	+ 3%
Home Help	7	46	- 39%
Day care	4	11	- 7
Respite care (residential)	7	11	- 7%
Care Attendants	7	36	- 29%
(Base)	(28)	(28)	

Note: percentages do not total 100% as some people used two or more services

Table 5.15 Why people stopped using services (Payments and mixed groups only)

	No.	Percent
Wanted control over support arrangements	16	37
Services unreliable/inflexible	13	30
Unsuitability of support provided	8	19
Services withdrawn/introduction of charges	7	16
Wanted to move out of residential care	5	12
Changes in assistance needs	4	9
Lack of privacy	3	7
General dissatisfaction with services	4	9
(Base)	(43)	

Note: Percentages do not total 100% as some respondents gave more than one reason.

The most common reasons which people gave for choosing to switch from service based support to a payments scheme were wanting to have more choice and control over their support arrangements, and the fact that services had been unreliable and/or inflexible.

Several people also pointed out that services were unsuitable. In some cases this was linked to dissatisfaction with the way assistance was delivered by particular workers. However, as workers were not accountable to service users, they felt that they had little choice other than accepting an unsatisfactory service, or going without:

*"Some workers were very good, but there was the odd aberration. For example there was one nurse who wouldn't brush teeth. Then, one of the Home Carers said - 'You're very lucky, I wish I had someone to feed me and give me a shower'. I was very annoyed by this because I've got Multiple Sclerosis and I don't think I'm lucky at all. "*

*"One of the home helps was a lazy, awful, dreadful woman - a nasty person. The council has had many complaints about this individual - but they won't sack her. "*

*"I wasn't very keen on the meals on wheels. ... It used to be a dried piece of oily fish and mashed potatoes and a few grains. That is mutilation!"*

*".., they were horrible - I can't find a good word to say about any of them. "*

Others pointed out that the services they were being offered simply failed to meet their practical support needs:

*"I did have Crossroads but we don't have them anymore. I couldn't get on with that idea ... I got a bit fed up with somebody sitting there just talking to me for hour and a half, two hours, you know, it just bored me to tears. ... we just had nothing to talk about, I'd much rather just watch the telly or something, you know. ... It was nothing personal against the people. No, they were nice enough people but what I wanted was a good service, well it was a good service but it just wasn't for me, / think it was more for elderly people than it is for my sort of age. "*

As the example above illustrates, some services essentially provide 'supervision' which people do not feel they need, rather than the practical support which they

actually want. Consequently, apart from being unsatisfactory for the individuals concerned, some people also feel that these services are an inefficient use of resources.

### Organising support arrangements

The findings presented above demonstrate that payments schemes meet a wider range of assistance needs than services. This is also reflected in responses to questions about how easy or difficult people find it to organise a suitable support package.

For example, compared to people in the payments group, service users are more than four times more likely to report having difficulty with organising back-up for their regular support, and almost three times more likely to have difficulty getting support workers to deliver assistance in the way they want them to. Similarly, over 50 percent of service users report having problems with the competence and/or attitude of support workers, compared to only just over 10 percent of people in the payments group (Table 5.16).

The most common difficulty, however, is obtaining information about services and alternative support options - an issue raised by as many as two-thirds of service users, compared to less than 10 percent of the payments group. Apart from the practical obstacles to organising suitable support which this creates, lack of information also has implications for the level of expressed demand for payments which are discussed further below.

People using a combination of payments and services are also more likely to report having the same kinds of difficulties - although the differences are not as large as those between the payments group and service users. It is particularly interesting that more than half of the mixed group report having difficulty with organising back-up. As noted earlier, although they are more likely to have access to some form of back-up than service users, they are noticeably less confident in these arrangements than either of the other two comparison groups. There are two main reasons for this suggested by the findings.

First, people using a combination of payments and services are more likely to use private care agencies compared to those who use mainly their own workers or services. However, the extra costs involved can mean some people only being able to purchase less cover than they actually need.

Second, this group also appears to have a greater reliance on friends and neighbours for informal support compared to the payments group (who are more likely to use paid workers), and services users (who are more likely to

have help from within the family). Although there are potential problems associated with all these types of arrangements, using friends and neighbours can often be the most difficult as it is dependent on both continuing goodwill and availability - which is likely to be more variable than it is for family or paid workers.

Table 5.16 Problems experienced with organising suitable support arrangements

Proportion reporting problems with the following	Payments group	Service users	Mixed group
Obtaining information	8	65	27
Establishing eligibility for services	na	42	33
Agreeing appropriate care plan	0	27	20
Being assertive with support workers	8	23	13
Finding appropriate services	na	42	27
Competence/attitudes of support workers	11	54	27
Getting support workers to carry out tasks wanted	11	27	27
Interpersonal relationships	25	31	33
Organising back-up/cover	8	39	53
Others	4	27	7
(Base)	(28)	(25)	(15)

Note: percentages do not total 100% as some people reported two or more problems

#### Level of demand for payments schemes

We have attempted to assess the level of demand for payments schemes amongst existing service users. Also, for those who are currently using a combination of payments and services, we have looked at the proportion who might prefer to switch to using payments schemes for the bulk of their support.

However, expressed demand for payments is obviously dependent on both availability and the level of awareness people have about this option for meeting their support needs.

Although all of the local authorities operate some kind of payments scheme, this does not necessarily tell us very much about availability unless we also know whether or not this option is actually offered to people on an individual basis. One way of looking at this issue is through the outcomes of community care assessments. First, we asked people in the service users group whether or not they had had a community care assessment in the last 12 months. Second, we asked whether the payments option had been considered as part of the assessment, and whether or not they were satisfied with the outcome.

As shown in Table 5.17, less than half of the service users had actually had an assessment by the time of the interviews. This is not completely surprising, however, as the interviews were carried out only a few months after the start of the new community care arrangements (Summer/Autumn 1993).

The most relevant issue for our purposes is the proportion of assessments which included consideration of the payments option. In fact, less than a quarter of those having an assessment reported that this included any consideration of their using either the local payments scheme or the ILF.

Given that service users in the sample were matched with the payments group, most would have been eligible to apply to join one of the payments schemes. The fact that so few appear to have been offered this option could be due to a number of reasons. First, social workers carrying out the assessments may not be aware of payment schemes or how to apply. Second, most of the local schemes include 'ability to manage own support arrangements' as one of the eligibility criteria; it is possible, therefore, that some social workers may be making subjective judgements about this and ruling out certain people automatically. Third, budget constraints and the uncertainty surrounding the legal status of payments mean that some authorities do not feel able to promote their schemes as actively as they might; consequently, in some cases, the payments option might only be explored if disabled people raise the issue themselves.

Community care assessments are obviously not the only means by which people might become aware of the availability of payments schemes. For example, people who do not go through the formal assessment process might still find out about this option through a local disability organisation, by word of mouth from other people, or through other contacts with the local authority. However, the findings from the interviews suggest that this is not generally the case, as almost

two-thirds of service users reported that they had no knowledge of the availability of payments schemes at all (Table 5.18).

At the same time, over half of this group subsequently expressed an interest in this option. We also explored whether they would want to actually employ their own support workers directly, or opt for an indirect arrangement which would avoid them taking on the administrative responsibilities involved (eg. payroll). Although one third of the service users are willing to employ their own workers, almost half stated that they are unsure about this (Table 5.19). This is not particularly surprising in view of the fact that most had had little opportunity to consider this option before the interviews. However, just over 20 percent stated that they would definitely not want to be direct employers.

We also asked people who are currently using a combination of payments and services if they would prefer to switch to using directly employed workers to provide the bulk of their support. The response to this question suggest that 40 percent would in fact prefer to do this if they were able to. Bearing in mind that a large proportion of this group are using agency workers, this effectively means that they would prefer to use the same money to employ their own workers instead. However, one third of the group also stated that they would definitely not want to do this. In most cases, this is because they have deliberately chosen the option of using agency workers precisely because they want to avoid the responsibilities of becoming an employer themselves.

Table 5.17 Community Care assessments (Service users only)

	(Percent)
Proportion having an assessment in last 12 months	46
Proportion satisfied with outcome	64
Proportion of assessments including consideration of the payments option	21

Table 5.18 Knowledge of/demand for payments schemes (Service users only)

	Yes	No	Total
Proportion with knowledge of local payments scheme	36	64	100
Proportion wanting to use local payments scheme	55	45	100

Table 5.19 Willingness to employ own support workers (Service users and mixed group)

(Percent)	Service users	Mixed group
Willing to employ own workers	33	40
Not willing to employ own workers	22	33
Don't know/unsure	45	27
Totals	100	100
(Base)	(27)	(15)

This chapter has compared the practical support needs of people using payments schemes and services. We have seen that, payments schemes are associated with more reliable support arrangements and also meet a wider range of needs than direct service provision. We have also looked at some of the reasons why people choose to use payments schemes in preference to services and established that there does appear to be a demand for such schemes amongst current service users also. The next chapter examines the specific factors influencing the quality of different types of support options and identifies which of these are seen as most important by the disabled people in this study.



## 6. RELATIVE ADVANTAGES AND DISADVANTAGES OF PAYMENTS SCHEMES AND SERVICES

The first part of this chapter presents the findings on levels of satisfaction with different kinds of support arrangements and the factors which appear to have the most influence on satisfaction. The second part of the chapter draws on the qualitative interview data to consider what disabled people themselves have to say about the relative advantages and disadvantages of payments schemes and services and the specific factors which determine the quality of their support arrangements.

This analysis also attempts to highlight the reasons why particular aspects of peoples' support arrangements are viewed in either positive or negative terms. For example, where people have highlighted the importance of having choice and control over their support, we have attempted to unpick the data to identify exactly what it is about their arrangements which gives them more or less choice and control. We have also attempted to examine the kinds of 'trade offs' people make between the advantages and disadvantages in assessing their optimal support arrangements.

Similarly, where there are relative advantages or disadvantages associated with either payments schemes or services, we have attempted to distinguish between those factors which are inherent to these support options and those which seem to be related to the way in which particular support arrangements have been set up and organised. For example, in some cases, perceived deficiencies in personal assistance arrangements could be related either to general difficulties which people face in recruiting suitable workers, or to the fact that their payments do, not cover all of the support hours they need. The former problem might be interpreted as a structural issue, whereas the latter could be seen as a result of localised policies on how support needs are assessed and the level at which different authorities set their payments.

### Levels of satisfaction with support arrangements

The findings presented in the previous chapter give some indication of the reasons why people prefer to switch from service provision to payments schemes. Lack of control and unreliability of service provision have been highlighted as particularly important influences on this choice. However, we also need to consider how these and other factors influencing the quality of support arrangements are viewed by the different groups in the sample. Also, the extent to which quality of support arrangements are influenced by local variations in the organisation of services and/or payments schemes.

We start by looking at some of the objective indicators based on responses to a series of questions asking how people rate their satisfaction with particular aspects of their support arrangements. These satisfaction ratings have been broken down by type of support arrangements, source of funding, and age and household composition as shown in Tables 6.1 to 6.3. (See box below for details of how the ratings have been calculated). The small sample size for this study means that we have not been able to carry out any more sophisticated statistical analysis to determine the precise interrelationships between different elements of support. However, taken together with the more detailed commentary from the interview data, these ratings do at least give an approximate guide to the relative weight which people attach to the different aspects of their support arrangements.

#### Satisfaction/quality ratings

- i) Ratings are based on either a four or five point scale (eg. very satisfied = 5, fairly satisfied = 4 etc). The scales have been aggregated and ratings produced by dividing the total score for each item by the maximum possible score. Therefore, a score of 1.0 would indicate perfect satisfaction (ie. all' very satisfied).
- ii) Significance tests indicate whether or not the differences in the scores are statistically significant. Only those starred (\*) or (\*\*) are statistically significant; any differences in scores on the other items may be simply due to chance.
- iii) A significance level of 0.05 or less (ie. marked \*) **indicates** that the differences in scores are statistically significant at the 95% probability level. A significance level of 0.001 or less (ie. marked \*\*) indicates that the differences in scores are statistically significant at the 99% probability level.

First, the ratings clearly suggest that people receiving direct or indirect payments have higher levels of overall satisfaction with their support arrangements than service users. The differences in satisfaction appear to be most marked in relation to reliability and, closely connected to this, confidence in the viability of support arrangements.

Differences on other quality measures do not seem to be quite as important. Although the payments group tend to report higher levels of satisfaction than service users or people using a combination of payments and services, the differences recorded are not statistically significant.

The ratings for satisfaction with control over support arrangements are particularly interesting. Although people using payments schemes report a higher degree of satisfaction on this question, the differences are not as large as we would have expected and are not, in any case, statistically significant. This is

somewhat different from the impression given by the payments groups' detailed comments from the interviews which consistently emphasise the value of having control over support arrangements. This suggests that it is the particular factors which make this control possible (eg. reliability and flexibility) which are being picked up by the satisfaction ratings. At the same time, it is also important to take account of the different expectations associated with payments schemes and service provision which are discussed further below. The important point to bear in mind is that these are quite different types of arrangements, the contrasting elements of which cannot necessarily be adequately reflected in simple satisfaction scores. Rather, although such scores give useful pointers, identification of the actual nature of the factors determining the quality of support arrangements is only possible through detailed analysis of the interview data.

It is also interesting to note that people using a combination of payments and services report lower levels of satisfaction than people who use either payments schemes or services for the bulk of their support. This difference is most noticeable in relation to satisfaction with the reliability of their support arrangements (which is statistically significant). This finding is closely related to the fact that people using a combination of payments and services tend to have more complicated arrangements which require a greater degree of organisation. Consequently, they tend to be noticeably less confident about being able to organise cover for their regular support when the need arises.

Age does not appear to make very much difference to overall levels of satisfaction. Although older people in the sample appear to be more satisfied with both their relationships with individual workers and the quality of practical assistance they provide, none of the differences in the satisfaction ratings are statistically significant.

Similarly, although people living alone express lower satisfaction than those living with others on all of the items included in the ratings, these differences are not statistically significant.

There is a similar pattern in the satisfaction ratings recorded for people who receive payments from local authorities and from the Independent Living Fund. Although people using local authority schemes tend to report slightly higher levels of satisfaction on the majority of the items included in the ratings, most of the differences are not statistically significant.

The one exception to this is the score for satisfaction with the suitability of support workers. This may be linked to the fact that people on local authority payments schemes are typically able to offer higher rates of pay for their

workers; also, that they are more likely to have access to assistance and/or advice relating to recruitment.

It is also interesting to note that the only which people on local schemes appear to be noticeably less satisfied about than the ILF group is the long-term viability of their support arrangements. Comments from the interviews suggest that this may be a reflection on the current uncertainty over the legal status of direct payments as people receiving payments from a local authority are more anxious about the possibility of losing their funding as a result of cuts in local budgets and/or changes in local policies.

**Table 6.1 Satisfaction and quality ratings**

(Range 0 - 1)	Payments group	Service users	Mixed group
Satisfaction with reliability of support	.91	.61	.45
Significance = < 0.05 (*)			
Confidence in long-term viability of support	.78	.62	.61
Significance = < 0.05 (*)			
Satisfaction with interpersonal relationships with support workers	.77	.76	.70
Significance = 0.6			
Suitability of support workers	.71	.75	.70
Significance = 0.7			
Satisfaction with quality of practical assistance	.86	.88	.85
Significance = 0.5			
Control over support arrangements	.75	.72	.72
Significance = 0.5			
Overall satisfaction with support arrangements	.96	.76	.70
Significance = <0.001 (* *)			

Table 6.2 Satisfaction and quality ratings by age and living arrangements

(Range 0 - 1)	Under 55	Over 55	Living alone	Living with others
Satisfaction with reliability of support	.73	.50	.65	.74
Confidence in long-term viability of support	.68	.69	.65	.71
Satisfaction with interpersonal relationships with support workers	.72	.88	.69	.79
Suitability of support workers	.72	.73	.68	.75
Satisfaction with quality of practical assistance	.85	.93	.79	.92
(Significance)		(0.8)		(0.07)
Control over support arrangements	.73	.73	.66	.79
Overall satisfaction with support arrangements	.82	.85	.78	.86

Note: Significance levels have not been reported in the above table as none of the differences in satisfaction scores were found to be significant at the 95% probability level

Table 6.3 Satisfaction and quality ratings by source of funding

Range 0 – 1	ILF	LA payment schemes
Satisfaction with reliability of support	.92	.90
Significance = 0.9		
Confidence in long-term viability of support	.82	.73
Significance = 0.6		
Satisfaction with interpersonal relationships with support workers	.72	.83
Significance = 0.5		
Suitability of support workers	.64	.79
Significance = < 0.05 (*)		
Satisfaction with quality of practical assistance	.84	.88
Significance = 0.5		
Control over support arrangements	.73	.77
Significance = 0.9		
Overall satisfaction with support arrangements	.97	.96
Significance = 0.7		

## Local variations in levels of satisfaction

There are also some interesting variations in levels of satisfaction between the different local authorities included in the study.

First, we have examined the possible links between satisfaction with local payments schemes and local services. In particular, we have considered whether or not the high levels of satisfaction with local payment schemes might be a reflection on the standards of overall provision (including services) in particular local authorities. In other words, do local authorities who run good payment schemes also run good services which could meet disabled peoples' needs equally well.

As shown in Table 6.4, this only appears to be true in one of the local authorities (Authority D3). Other authorities where there is a high degree of satisfaction amongst the payments group also have considerably lower satisfaction amongst service users. This suggests that the higher levels of satisfaction in these authorities are linked to the existence of a payments scheme and are not simply a reflection on the overall standards of provision for disabled people.

Second, we have examined whether there are specific elements of good practice in particular schemes or services which might help to account for the variations in levels of satisfaction amongst local people who use them.

For example, it is interesting that the payments group in Authority B are noticeably less satisfied with their support arrangements than people using payment schemes in other areas. This scheme is the only one we have examined which requires people to use their payments to purchase personal assistance from an agency, rather than from wherever they choose. In fact, when we were deciding on the classification of payment schemes and services, this scheme was considered to be very much a 'borderline' case; its eventual inclusion as a payment scheme was decided on the basis that disabled people still retained control over when and how they used the agency.

It is also interesting to note that service users in Authority C3 appear to have higher levels of satisfaction than service users in most of the other authorities. Personal assistance is provided for this group by volunteers under a local

Independent Living Scheme which is run jointly by Social Services and the local organisation of disabled people. Although it has been classified as a service for the purposes of the study, the scheme does have certain features in



common with payment schemes. In particular, people using the scheme are directly involved in the recruitment and selection of the local pool of volunteers. The contrast between this service and the kind of scheme operated by Authority B illustrates the important point that payments schemes do not automatically ensure disabled people having greater choice or control over their support arrangements unless they are set-up and managed efficiently. On the other hand, it is quite possible to build a considerable degree of control into a genuinely user-led service.

Table 6.4 Satisfaction with control over support and overall satisfaction by local authority

	CONTROL		OVERALL SATISFACTIO	
	Payments group	Service users	Payments group	Service users
Authority A	.79	.65	.94	.60
Authority B	.80	.63	.75	.75
Authority C1	-	-	-	-
Authority C2	-	-	-	-
Authority C3	-	.90	-	.89
Authority C4	-	-	-	-
Authority 4D1	.75	.65	.95	.60
Authority D2	-	-	-	-
Authority D3	.75	.75	.93	.90

Note: A dash in the table indicates that there are too few cases to compute a satisfaction score.

#### Factors influencing satisfaction with support arrangements

The ratings discussed above have highlighted some important differences in levels of satisfaction between people using services and payments schemes. In order to get a clearer picture of why these differences exist, we also need to examine the specific factors which influence satisfaction, and the relative importance which the different groups attach to them.

First, although certain key factors such as control, confidence and reliability appear to be universally important, there is often a marked contrast between the way in which service users and people in receipt of payments make their own assessments of these criteria. Reflecting the fact that they typically have little control over direct provision, service users tend to emphasise the interpersonal aspects of their support arrangements (ie. satisfaction with the individual support workers with whom they are involved). Most of the responses to questions about the advantages and disadvantages of service provision are characterised by perceptions of the people who provide assistance, rather than the way in which this is organised.

As noted earlier, this may help to explain why the differences in satisfaction scores for control over support arrangements are not as large as we might have expected from examination of the interview data. Similarly, it may also help to explain why service users express slightly higher levels of satisfaction with the suitability of support workers compared to the payments group. Although another relevant factor might be that some people in the latter group (particularly people using payments from the ILF) have experienced problems with recruitment.

People who receive payments for personal assistance, on the other hand, typically place a much greater emphasis on the organisational aspects of their support arrangements (eg. when and how their personal assistance is provided, and by whom). This is important because - as we shall see from the qualitative data presented below - although service users may be fairly happy with particular support workers, they often remain distinctly dissatisfied with the reliability of particular services and the degree of choice and control they are offered.

Second it is also important to consider whether or not the levels of satisfaction expressed by service users might be a reflection of their having lower expectations than people who recruit their own workers. For example, as they do not control their own support arrangements directly, some people may feel less justified in placing too high a demand on the services they receive. Although, we have not been able to examine this issue directly, several of the comments from the interviews suggest that service users are in fact less inclined to be explicitly critical - at least as far as individual support workers are concerned. A few people also raised explicit concerns about not wanting to complain for fear of incurring sanctions from service providers:

*"I wasn't thinking about it prior to this conversation, like, whether or not I should be phoning up and saying that I want someone ... I don't like complaining, I don't want to get labelled as difficult. "*

People who control their own support arrangements, on the other hand, will often have chosen this option precisely because they wanted to avoid these kind of restrictions. Consequently, they are likely to tend to have higher expectations than people using services. By the same token, they are also more likely to be critical of their support arrangements if and when these expectations are not met.

Third, the analysis of the qualitative interview data presented below also indicates that several of the factors which determine peoples' satisfaction are interdependent. Reliability, for example, is dependent on both the degree of control people have over their support arrangements, and the degree of flexibility in the way their support is organised. Similarly, the degree of confidence people have in their support arrangements is, in turn, dependent on both of these factors - as well as external factors such as the level of advice and back-up available to people on particular payment schemes, and local policy priorities regarding provision for disabled people.

Fourth, it is important to bear in mind that the elements which determine high quality support arrangements can be delivered in a variety of ways. Well organised services, for example, can also provide reliability and flexibility for the people who use them. Similarly, services which incorporate mechanisms for extending the degree of choice users have over their support arrangements can also be associated with higher levels of satisfaction.

#### Perceived advantages and disadvantages of payments and services

Closer analysis of the qualitative interview data can help to unpick the ways in which the various factors outlined above influence the quality of support arrangements. In addition to questions about satisfaction with particular aspects of their support arrangements, the interviews also included open-ended questions about what people see as the advantages and disadvantages of these arrangements, and which of these are most important to them.

Findings from the analysis of their responses are summarised in the matrix of relative advantages and disadvantages below. (See Figures 6.1 to 6.5). The particular issues which people in the sample perceive as most important are discussed in more detail in the remainder of this chapter.

Figure 6.1 Comparison of advantages and disadvantages of payments and services

Perceived advantages of direct/indirect payments

Control over times support is provided

Control over who is employed

Control over type of assistance and how it is provided

Reliability

Flexibility

Perceived disadvantages of service based support

Lack of control over times support is provided

Lack of control over who provides assistance

Inability to control type of assistance and how it is provided Unreliability

Lack of flexibility

Uncertainty about future levels of local community care provision

Perceived disadvantages of direct/indirect payments

Managing/organising support arrangements

Recruitment and training

Interpersonal relationships with support workers

Restrictions on funding levels

Uncertainty over future availability of payments schemes

Perceived advantages of service based support

Convenience

Range of services available

Interpersonal relationships with individual staff

Reduced cost overheads

Figure 6.2 Perceived advantages of direct/indirect payments

Control over times support is provided

- o increases control over own time/enhances personal freedom
- o has beneficial impact on family life and social life
- o can free time for other productive activities (eg. employment)
- o greater reliability reduces anxiety
- o gives greater continuity to pattern of day to day life

Control over who is employed

- o greater choice over characteristics of support workers (eg. age and gender)
- o allows flexibility over terms of employment
- o availability of sanctions (including terminating employment) to ensure quality of assistance provided
- o enhances personal dignity

**Control over type of assistance and how it is provided**

- o reduces stress
- o greater efficiency
- o increases flexibility
- o enhances feeling of being in control of one's life

**Control as a value in itself**

- o enhances general quality of life
- o enhances personal dignity

Reliability

- o increases ability to control times when assistance is provided
- o increases control over own time
- o increases confidence in support arrangements
- o reduces practical demands on other family members

Flexibility

- o increases likelihood of securing back-up and emergency cover for usual sources of support
- o reduces reliance on respite services
- o reduces reliance on informal support

Figure 6.3 Perceived disadvantages of direct/indirect payments

#### Managing/organising support arrangements

- o increases workload and responsibilities
- o can be time-consuming
- o can be stressful for less experienced people (unless they have access to appropriate advice and guidance)
- o availability of practical advice and training is highly variable (and non-existent in some areas)
- o can involve extra costs (eg. recruitment costs, higher phone bills)
- o local availability of advice and assistance with tax/NI and payroll is highly variable

#### Recruitment and training

- o difficulties with vetting potential workers can increase vulnerability and risk (unless adequate assistance available)
- o need to take workers on a trial basis can lead to possibility of high turnover and extra costs for repeat recruitment
- o time and effort may be required for training support workers to be enablers

#### Interpersonal relationships with support workers

- o familiarity with workers can impose on personal privacy
- o relationships between support workers and other family members may need to be negotiated
- o potential difficulties maintaining clear employer/employee boundaries
- o extra responsibilities
- o can lead to over-reliance on a single source of support (unless adequate back-up is available)

#### Restrictions on funding levels

- o may lead to support hours being less than the number required
- o can increase reliance on family and friends to make up the shortfall
- o people in employment may be less likely to get funding (can be a disincentive to take up employment)
- o extra costs (eg. tax and NI contributions, recruitment costs, back-up support) may not be included in payments
- o some people may have to pay workers less than they would want to or recruit on a self-employed basis (may also lead to higher turnover of staff)
- o can lead to cutting corners (eg. paying cash in hand to reduce employment overheads)

### Uncertainty over future availability of payments schemes

- o increases anxiety over long-term viability of support arrangements
- o concerns about charging and means testing and possibility of having to make greater contribution from personal income
- o diversity of local policies on direct payments can create restrictions on personal mobility (eg. not being able to move house, change jobs etc)

Figure 6.4 Perceived advantages of service based support

### Range of services available

- o access to specialist skills if required
- o back-up for usual sources of support (although this is dependent on local availability)
- o reduces reliance on a single source of support
- o can offer a higher degree of flexibility in some cases

### Interpersonal relationships with staff

- o individual support workers may be highly valued
- o reduces isolation for people living on their own (particularly valued by some older people)
- o continuity of support

### **Cost and convenience**

- o no employment overheads
- o no employment responsibilities
- o reduces time and effort spent on organising support arrangements

Figure 6.5 Perceived disadvantages of service based support

### Lack of control over times support is provided

- o disruption to day-to-day routines
- o reduces personal freedom
- o unreliability

### Lack of control over who provides assistance

- o increases feelings of intrusion on privacy
- o reduces choice over characteristics of support workers (eg. age and gender)
- o no sanctions to ensure quality of assistance provided (other than complaints procedures adopted by service providers)

### Inability to control type of assistance and how it is provided

- o leads to inefficiency (eg. workers breaking things, putting household items away in the wrong place, not preparing food to personal tastes)
- o increases stress
- o reduces personal dignity and feeling of being in control of one's life

### Unreliability

- o increases stress and practical inconvenience
- o reduces ability to control times when assistance is provided
- o can disrupt family life, social life and other activities (eg. being made late for meetings, work etc)
- o limited sanctions available if services do not respond to requests for support
- o reduces confidence in support arrangements
- o increases practical demands on other family members

### Lack of flexibility

- o can create gaps in assistance provided
- o reduces likelihood of securing back-up and emergency cover for usual sources of support
- o reduces ability to increase support when needs vary
- o can increase vulnerability to breakdown of support arrangements
- o increases reliance on respite services
- o increases reliance on informal support

### Interpersonal relationships with staff

- o lack of choice over staff can lead to intrusion on privacy
- o difficulties with changing staff if interpersonal problems arise
- o limited sanctions available if unhappy with attitudes or behaviour of staff
- o larger number of staff to deal with can be inconvenient and/or stressful

### Other perceived disadvantages

- o increased vulnerability if service provision reduced or withdrawn
- o uncertainty about future levels of local community care provision
- o concerns about charging and/or means testing

### Choice and control

Findings from the qualitative analysis of the interview data indicate that having choice and control over their own support arrangements is seen as the most important benefit of payments schemes:

*"I am in control. I can decide when I want help. The way help is delivered -*



*I feel it is my life, not someone else's. You are not fitted in to other people's time table. Freedom - you can choose who you have. If you don't like them you can have someone else. You can choose the manner in which a task is performed, unlike when home care staff are used. It releases me to have family as family and friends as friends. "*

*"I don't have to put on my children. They can then try and live as normal a life as possible, in an environment where I am disabled and have a carer - you know, someone who is not a family member. Who has no relation to them, really. Who is just a carer for me. The children at least do get a continuity of life. I think that is the best aspect. And I get a continuity of life. "*

*"The choice and control. Flexibility. Being independent. Friends don't always have to pick me up, or cook and wash when they come for a meal. I'm out of dependency mode into independent mode. "*

As the above quote illustrates, the concept of control over support arrangements is in fact made up of a number of different elements: control over the type of assistance provided; how and when it is provided; and by whom. In addition, all of these different elements have wider benefits in terms of enhancing personal freedom, relationships with others, and the general quality of life.

Although people using direct service provision do not typically have this degree of control over their existing support arrangements, this does not mean that control is unimportant to them. In fact, when they were asked what their 'ideal' support arrangements would be like, service users often placed just as much emphasis on the importance of personal freedom and control as people in the payments group:

*"You want the freedom to get up late and stay up late if you want to...*

*A good emergency service. Arrangements which I have had plenty of say in. "*  
*"The most important characteristic would be to be able to have the flexibility of choosing who I want when I want... and to have more flexibility in choosing the hours that I want. "*

Control over the times support is provided

People using payments schemes highlighted a number of benefits associated with having control over the times support is provided. At the most general level, this aspect of control over support arrangements allows people to have more control over their own time and gives greater continuity to the pattern

of day to day life. However, the most important practical benefit of control over the times support is provided is that this makes peoples' support arrangements more reliable and, therefore, reduces stress and anxiety.

Some people in the payments group emphasised that having greater control over the times support is provided - and the greater reliability and predictability which this brings - also frees up more of their time for other productive activities like participation in voluntary work and paid employment:

*"... and this scheme is something that has helped me. It has helped me get a full time job. Without this scheme I wouldn't be able to work full-time. "*

Service users, on the other hand, often emphasised lack of control over the times support is provided as one of the least satisfactory aspects of their support arrangements. In contrast to people in the payments group, service users' comments on this issue are focused on the unreliability of their support arrangements and the adverse effects this has in terms of personal freedom and general disruption to their day-to-day lives:

*"This causes great stress. If I am late for a meeting, for example, it reflects badly on me. "*

*"That annoys me. I have to let other people down by being late or missing meetings and sometimes nobody comes to dress me. I once fell over in the shower and my attendant arrived 20 minutes late - by which time I was freezing to death, frightened, and angry. "*

*"I would like night nurses because I sleep very sound but only for about six hours and I've had enough when I'm lying down for six hours. I mean I've had nurses coming in here at half nine and ten o'clock and I refuse to go to bed then because I'd be awake at four and I've got to sit up - I refuse to lie there looking at the ceiling for hours, you know. I had a nurse come in here, quarter to ten, and I said 'oh its far too early for me, I'll sleep in the wheel chair' and I meant that. 'Come, come Mrs xxxx' she said, and I said, 'don't you talk to me in that tone of voice', I said 'I used that tone to talk to my daughter when she was four, I said 'don't come in and treat me like a child. I said I don't want to go to bed before ten'. I said 'I'm watching television, the only pleasure I have in the day is a few hours television' She said but its late enough' and I said 'not for me, no' - I said, I've never gone to bed in my life before half eleven and I don't want to go now"*

## Control over who is employed

Another of the perceived advantages of payments schemes is that they allow people to have much greater choice and control over who is employed to provide assistance.

People who employ their own workers directly obviously have a considerable degree of control over their terms of employment. This, in turn, increases the range of sanctions available for ensuring that assistance is provided in the way they want. Ultimately, this also includes the option of terminating a support worker's employment:

*"I can do what I want, when I want. I pay the people to come in at a certain hour if I want to change the hours I do that. "*

*"A difficulty too, with casual people, because, if it didn't suit them, they couldn't come - whereas if you employ people, they have to be here. "*

*"There are occasional personality clashes - but I don't employ people with the wrong attitude. "*

Some people also emphasised the importance of being able to have a choice about support workers' characteristics - particularly age and gender and, where applicable, ethnic or cultural origin:

*"They've got to be women, it's good that they respect me. PAs have to have a very good sense of humour. "*

*"I don't want personally a young seventeen year old, I want somebody my age, round about forty. Who likes the same sort of thing I like. With the Social Services scheme you got anybody. .... If it is somebody who is an old fuddy-duddy or somebody who is very young, who can only talk about her boyfriends all the time, or repeats the same thing all the time. If it's somebody who I'm not on the same wave length with, then for the whole time she is getting me up or putting me to bed, I'm automatically not speaking because we have nothing in common, it can be like having a brick waft there and it can be embarrassing. With me employing my own people, we get on well together."*

*"English being a second language can be a barrier. I have difficulty talking to people, for example, how to brush my hair and plait. "*

Having a choice over who provides assistance also helps to ensure that people have workers with whom they (and their families) can get along with:

*"Being able to choose the right person - personality, attitude to disability, how they fit in with family. I'm able to retain my self-respect in the current situation. "*

*"Presently I think it gives me the most freedom that I have ever had since I have been living independently. Other schemes have not come up with such good freedom. It gives me that independence to choose the people that I like to work with me, rather than the ones that get sent to me. "*

Most of those receiving payments are satisfied with this aspect of their support arrangements, although the degree of choice they have in practice is also dependent on both local availability of workers, and the pay rates they are able to offer. People on local authority payments schemes and those who living in metropolitan areas tend to have fewer problems in this respect, as they are generally able to offer higher wages (compared to ILF clients) and also tend to have a wider pool of support workers to recruit from.

As noted earlier, some indirect payment schemes involve local authorities employing support workers on behalf of individual disabled people. Some people are reasonably happy with these arrangements as they still have complete control over the day to day management of workers. Some, however, feel that the absence of a direct employer-employee relationship not only compromises their ability to direct what workers do, but is also less satisfactory for the workers themselves:

*"I want to employ my own staff, who I choose not who they choose for me, even if they say I am allowed to choose and they will pay that person, I still feel then, that I am not in charge, because I can't say to that person do it, because if they don't want to do it, they will not discuss it with me, but go to the people who are paying them. By me paying them if they have a problem, they come to me ... if they are not happy or clear about things we can straighten it out. "*

Similarly, people who use their payments to purchase assistance from private agencies do not necessarily feel that they have the same degree of control over staff as those who employ their workers directly. On the other hand, the commercial relationship involved does give them a certain degree of leverage if they are unhappy with the assistance provided. Further, if problems are not dealt with satisfactorily, they may also be able to vote with their feet by taking their custom elsewhere:

*"I'm going to be more assertive in getting what I paid for and if there's any monkey business I won't pay. I let it go on too long with the other agency and I'm now going to be a lot more wary. "*

Most service users typically have very little choice over the characteristics of staff providing assistance. Further, even where they do have a degree of choice, this would often appear to be dependent on the discretion of the service provider:

*"The disadvantage of the care scheme is that some members of the staff I don't feel very comfortable with and do not, therefore, wish to have them coming to me. ... With Care Attendant Schemes you haven't really got a choice. If someone is ill, the next one has to come, and if it happens to be the person you do not get on with there is not a lot you can do about it. "*

*"There's not enough choice of people who work with me. I'm sometimes sent people I have specifically asked not to have. I'm expected to get on with everyone. .. I don't always feel in control of what's done for me. ... Sometimes you get people with a bad attitude to disability and they keep sending them even when I ask them not to. "*

This lack of choice over who provides assistance can lead to people feeling that their privacy is being compromised - particularly where the assistance provided is of an intimate nature:

*"Someone offered to send a girl of 15 round to talk to me, have I got something in common with a girl of 15? I haven't, have I? I mean I've worked in an office for 40 years. "*

*"It's nothing personal, it's like, well when I come out of the bath for instance, it's embarrassing two women, other than your wife standing there. "*

Similarly, the lack of any direct sanctions to ensure that staff deliver assistance in an appropriate and acceptable way is also seen as one of the disadvantages of service based support. Although they may have the option to complain if they are unhappy with a particular worker, the outcome is still subject to the complaints procedures adopted by providers. Some people are also concerned about complaining for fear of reprisals from the workers involved:

*"One Home Carer changed her time to early morning - this was no use as it meant my wife was alone all day without anyone checking. When I phoned their office it turned out she'd done this without being authorised so that she*

*could get away in the daytime. The Home Carer was disciplined but afterwards she refused to speak to my wife - she sent her to Coventry, my wife was in tears ".*

*"We have had problems and we'll explain to them what's wrong and if they don't stop, then we'll put in an official complaint. Twice we've had to do that and they've been removed".*

*"The agency goes to pot if the co-ordinator is ill or on holiday. There's nobody to complain to about poor service except the council who don't want to know - they just refer you back to the agency. The attitude of the agency is that if she misses a bath, she just has to wait till next time (3-4 days). "*

Some services, however, do offer users a considerable degree of choice over who should provide their assistance. For example, people using the independent living scheme in Authority C3 are directly involved in recruiting staff and are also able to choose individual workers from the local pool. People using private care agencies also appear to be slightly more likely to be offered a choice over staff than people using local authority services:

*"Ah, the most satisfactory aspects are that if I don't like somebody I can say so and I then don't get that person again, but on a personal basis, the fact is that the people I do get are very willing to do just about anything that I ask them to do, which for me is very helpful and quite an important part of the care assistance. In other words they will do filing, they will do other small jobs that I require done, without complaining and are very happy to do so, it would seem. "*

*"I get on very well with the person who runs the nursing agency and she has settled basically on three people who deal with me. She's marvellous. "*

### Control over how assistance is provided

Having a choice about who provides assistance also allows people to have much greater control over the type of assistance and how it is provided. Again, this not only helps to ensure that assistance is provided in the most effective way (ie. matched to individual needs and preferences), but also has wider benefits in terms of enhancing personal freedom and dignity:

*"I am in control. I can decide when I want help. The way help is delivered, I feel it is my life, not someone else's. You are not fitted in to other people's time table. "*

*"I believe you have to have a quality and dignity to life and I don't believe you should be catheterised or wear incontinence pads if there is no necessity to do it. "*

Most of the people on payment schemes emphasised how much having this degree of control differed from previous experience with using services in particular, they highlighted the contrast with their earlier experiences of institutionalised care in residential homes and day centres:

*"Living independently has made a total difference to my lifestyle. I would only go back to an institution in a wooden box. "*

*"I went once (to the day centre) but they treated me like a little kid. ... they patted me on the head all the time and said 'are you alright' and I thought - I'm not a dog, don't pat me like that - so I only went the once, no more. "*

*"You are in control of your life. You eat what you want and do what you want .... you can go where you want. You are not controlled by the unbearable nursing or institutional regime where you do what you're told, eat what you're told, and are less free than you are in prison. "*

On a practical level, having control over how assistance is provided adds a greater degree of flexibility to peoples' support arrangements. For people who use service based support, however, restrictions on the kinds of assistance provided mean that their arrangements are more often characterised by inflexibility. Some people emphasised that this can lead to inefficiency as staff either cannot, or will not, provide the kind of assistance they actually need:

*"Like when I said 'can you borrow some ladders to take the curtains down, she said 'surely you can ask around, that's not part of my job' - I thought 'stuff you' Then the home help said she'll clean my windows but it's not in her contract"*

*"In my bedroom I'm getting cobwebs - the home helps don't do it because its not considered necessary. "*

*"Crossroads don't do sleep-ins. If I was ill, I would have to go to my mother's. "*

Others gave examples of ways in which their lack of control over how assistance is provided had led to conflict between themselves and particular support workers:

*"I've had a row with the bath lady because she insisted on washing me in a certain way. I just blow my stack and that's it. "*

*"There was one I've refused to use again because she tried to organise my house with the result I couldn't find anything. Some people impose their own ideas and I've still got my mine, even if I haven't got my legs. "*

Again, as most service users do not have access to any direct sanctions to deal with these kind of difficulties, some feel that they have little choice but to put up with unsatisfactory services:

*"It was agreed that I should have a home help three days a week and / only got two days. You don't have any come back. You have to be grateful for what you get, if you get a good home help, you're lucky, and if you don't, you just have to put up with it. "*

The lack of control which most users have over the type of assistance provided is, in turn, related to the fact that they do not generally assess their own needs. However, while the best run payment schemes typically place a high priority on self-assessment, some offer a greater degree of control than others. Consequently, even though they may still have greater flexibility than the majority of service users, some people also face restrictions on how they are able to use the money they receive:

*"I feel that sometimes the package is - when I first got onto the independent living scheme - it was the people that were deciding how much I should get. They were the ones really telling me what my needs were. Rather than what I felt they were myself. "*

### Interpersonal relationships with support workers

Although people using payments schemes place a high value on being able to control who provides their assistance, this also carries additional responsibilities which have to be weighed against the advantages involved. For example, while people who employ their own workers have the ability to dismiss workers who do not provide assistance to the desired standard, exercising this option is not without its disadvantages. Apart from the time, effort and expense involved in recruiting and training a replacement, several people pointed out that taking responsibility for terminating employment can also be fairly stressful:

*"One thing I did find very difficult, one personal assistant and I did not agree and we decided by mutual agreement that it would be best if she left at the end*



*of the month, ... But getting through that period was difficult, ... living with a personal assistant who wishes to leave, having personal things done for you by some one who does not wish to be there. And at the same time trying to find a replacement, but making sure you did not make another mistake - like taking the first person that applied. It was hard. "*

*"It's never easy telling someone that you don't want them to work for you any more. It puts you in a very vulnerable position. I've done it before, and its led to all kinds of problems. Again, I think I am getting better at handling it now than I maybe was in the past. And again, I think I have learned. But yes, that is one of the most negative drawbacks of it. "*

*"One staff member who left before it came to the crunch. Otherwise we would have had to tackle it by dismissing her. "*

However, although several people had had similar experiences at some time or another, most still felt that the advantages of having control over who works for them outweighed the disadvantages of having to deal with these kind of difficulties:

*"When its going well I prefer to control it all myself - I want to know who's here, rely on them to know what to do. I'm quite happy with being an employer. "*

Another relative disadvantage which some people find with employing their own workers is that the degree of familiarity involved can sometimes impose on their personal privacy:

*"When I want time to myself I can't often get it. "*

*"Well, its pretty hectic, always having people in the house. ... Sometimes you want to be quiet, and you've either got staff coming or going. Getting used to it is difficult, but its a matter of making up your mind. It can sort itself out, all this. "*

The degree of familiarity with workers can also create potential difficulties with maintaining clear employer/employee boundaries. This can be difficult for both parties. For the employer, there can be an obligation to deal with any personal problems workers might have. At the same time, people raising this issue also stressed that they wanted to try and avoid imposing on their worker's goodwill:

*"Workers can become familiar, you have to listen to their troubles. It is difficult to keep the demarkation between employer and employee. You have*

*to be careful about not abusing worker's willingness ... for example, asking them to do extra hours. "*

*"I am able to do exactly what I want to do, when I want to and how I want to do it - within the modicum of having thoughts of others who are helping so that I am not being total selfish in this give and take. "*

Some people also raised the issue of how support workers relate to other family members - particularly if they are living-in, or working for an intensive period (eg. accompanying someone on holiday). Although no-one reported having experienced serious conflicts between workers and other family members, managing these relationships may still require extra time and effort:

*"I do find - if we get back to holidays - having to take someone with me is a nuisance. But then I need it - I can't think of any other way of dealing with that. So a holiday companion is different from the sort of companion you need just for an hour in the morning to get you up. It's more difficult to choose someone you can actually live with for a week or a fortnight ... so it's not unsatisfactory, it's just practical, you wouldn't take every one of those people that you cope with for an hour, for a fortnight. "*

*"They're not part of the family so it's like having friends round all the time. No matter how good they are, they aren't part of the family unit. There are times when you feel vulnerable because you do something silly and people witness it."*

### Interpersonal relationships with service providers

As noted earlier, service users' satisfaction with their support arrangements is often very closely linked to the personal qualities of support staff: While comments from people in the payments group tend to stress the organisational aspects of their relationships with workers, service users tend to focus on the value of their personal relationships with individual workers:

*"They're very friendly, you know, now the evening staff are nice and friendly and have a laugh, you know, and the morning staff she's as good as gold, she's really a good friend now, more than just a home help. "*

*"The girl comes in the morning with a smile. I was a very independent and proud person and I can relax with her - it's a godsend really. She knows how to handle me and she knows my likes and dislikes. "*

*"I find the community care now excellent - very nice ladies as you can see, they're all like that. "*

A few service users - particularly older people living on their own - also stressed the value of company provided by support workers, either at home or at a day centre. This was seen as a particular benefit in terms of reducing their feelings of isolation:

*"I meet more people. ... because I used to get very lonely here sometimes"*

"Apart from the obvious - having myself and place clean - in the Day Centre there is companionship and the filling-in of time - I get a lot of enjoyment out of my pottery. "

At the same time, as discussed earlier, several service users have experienced problems with particular workers and had not always been able to do very much about this because of the limited sanctions at their disposal. Some also pointed to particular problems associated with workers who have negative attitudes to disabled people:

*"Their patronising attitude makes me angry. I'm quite tolerant but I have sometimes told them on the spot. I'm not so tolerant they can walk on me. I would ask for things and be offered an alternative as if I was senile. Some of them have a lot to learn about disability and treat me as a 'patient' "*

## Reliability

People using payments schemes have a higher degree of satisfaction with the reliability of their support arrangements. Service users and people using a combination of payments and services, on the other hand, are noticeably less satisfied. Analysis of the interview data suggests there are a number of related issues which influence satisfaction with reliability and which help to account for this difference.

First, there are various issues relating to the reliability of individual support workers, and whether they deliver assistance in a way which match peoples' expectations and requirements. For example, do they turn up at the right times? Are they easy to get on with? Do they follow instructions properly?

Second, the interviews included many comments relating to the way in which people's support packages are organised, and the extent to which this makes their arrangements more or less reliable. For example, how easy is it to find suitable support workers or services? how much effort is required to organise

and manage support arrangements? how easy is it easy to replace workers when necessary? Is back-up readily available and easy to organise, when one part of the system falls down?

Several people in the payments group stressed the reliability of their arrangements as one of the most significant advantages over service based support:

*"I'm happy with my arrangements. This is very important. Reliability is essential - if they didn't arrive / wouldn't be able to get up or get dressed. "*

*"It (the reliability) means everything to me because you are sure that they're here, and it gives you more confidence. ... they're there when you want them. "*

*"I can't think of any thing that would make it more positive. I like being on my own most of the time. I like to be able to call on people instantly - which I can - I can just ring them and they'll arrive. "*

*"The security of having a person around at night, an advantage in an emergency such as, fire, burglary, being able to deal with that emergency. "*

As noted earlier, people who control their own support arrangements can employ sanctions to ensure reliability. The reliability of service based support, on the other hand, appears to be more dependent on the organisation of particular services. As service users do not have direct control over this, there is often little they can do if services let them down. Not surprisingly, this can often be a source of considerable frustration:

*"The agency sometimes say they are sending relief staff but no-one turns up. ... I'm not satisfied with the reliability, or the buck passing between the council and the agency. It should be the council's responsibility to find cover if the agency fails. "*

*"If no one comes, I usually ring the head office and they say is it an emergency? 'and I say 'of course it is' and they say 'we'll try and get someone round' - and I wait all day and no-one comes. I get very annoyed because they wouldn't like it if they were in this position. "*

This kind of unreliability not only reduces peoples' confidence in their support arrangements, but also disrupts family life, social life and other activities. Some people also pointed out that it wastes a lot of their time as they often have to wait around for staff to turn up when they could be doing something more productive:

*"With one of the night staff, she just turned up when she felt like it. So, if me wife wanted go out somewhere in the evening, to a friend or something, she felt she couldn't go because she didn't know if they was going to turn up here to sort of help me and undress me or stand me up. "*

*"It would be handy if you could have them come in at the time you want, so that you can fill your life more. ... I'd like to do more things in the day. If they come a lot later then you cannot plan your day, you got to wait for them to come in. "*

Several people also pointed to the inconvenience and perceived inefficiency associated with a lack of continuity in the staff provided by different services. Apart from the practical difficulties this can create (eg. staff not knowing users' routines), having a larger number of unfamiliar staff to deal can be tiring and time-consuming:

*"The disadvantages - well, changes in workers I would prefer one permanent worker because chopping and changing is aggravating. "*

*"It gets a little bit tedious when I have had, as in the past week, six different care assistants because of holidays and sickness, and the one thing I would prefer is a little bit more continuity. "*

*"The worst thing about the revised Home Care service was that she constantly had new people. Its very frustrating always having to show new people around the flat. "*

These kinds of problems are obviously not universal, however, and some service users do feel confident that their support arrangements are generally reliable. Also, some people feel that being able to call on a range of services is one of the most important ways of ensuring reliability and/or continuity of support:

*"The agency are reliable and come when they say they will. "*

*"Actually being in the system, ... knowing if there is a crisis you've actually got somebody you can ring and something will be done, or at least you're not on your own.*

*"I get the right kind of care I need ... I get the right services I need, like a wash and getting up. Also I have somebody with me to help me throughout the day. "*

*"There is continuity of care - the workers are very well trained and know the needs of most of their clients. "*

## Flexibility

People who employ their own workers often emphasise the ways in which this increases the amount of flexibility they have in organising their support arrangements. Also, that greater flexibility has wider benefits such as reducing their reliance on their families or other informal helpers. At the same time, some also pointed out that the degree of flexibility they have is dependent on other factors such as the quality of their relationships with support workers, and how much assistance they can afford to pay for:

*".I've found that I have stayed friends with a lot of my PAs after they have left and many of them will cover in an emergency, so casual cover for illness and such is not usually a problem. My mother will come if I'm caught out, but I find we are such good friends now that I do not have to rely on her for all my care, as was once the case. "*

*"Paid workers come on time (generally). I choose the paid workers and we have a good relationship. I have flexibility with paid workers. However, at the moment I do not have enough income to cover all my support needs. "*

Service users views on the issue of flexibility are somewhat mixed. On the one hand, several people feel that the services they use are anything but flexible. Consequently they are concerned about the gaps in assistance which this creates - particularly at times when their needs might vary (eg. during a period of illness). Closely related to this, some are concerned about their support arrangements being vulnerable to breaking down if they are unable to arrange cover for their usual helpers:

*Husband. "She (wife) has bad weeks and falls a lot. ... The council wanted a guarantee that Crossroads would check her daily as she falls so frequently, but Crossroads said this was not their role. ... we didn't know what the hell to do or how to get help. "*

*"Maybe, its partly a feeling of being able to go to somebody within social services and say I need a more flexible arrangement with you. I am happy with the arrangements I've got at the moment and they work and they are flexible. But back to this business of when I get bad weeks, when I need more help going to the toilet or whatever, where I need more help then. I would like to say to social services I've got a bad week, so I need more help. Although to be fair, our Care Attendant Organiser does say she will try and back you up with*

*care attendants. But obviously, it is only if she has got the spare hours. So a more flexible arrangement within the whole system would help. "*

*"I would like to be able to, if there was an emergency, have somewhere that you could ring. ... I'm on lifeline, like if I fell, but now and again I need toileting when they're not here. I would like to be able to ring someone, so that there could be a stand-by emergency in place just in case. "*

Apart from these practical difficulties, some service users also stressed the restrictions which lack of flexibility places on their own personal freedom:

*"My present situation is the least satisfactory. ... I am using agency staff which - although the ones I have been using in the last week or so have been very good - it still leaves me in a regimented life. In other words, if I want to go back, I have to be back in time for the agency member who comes to put me to bed. And likewise I have to get up at the time predetermined, whether or not I wanted to lay in for another hour, or even want to get up earlier, I have to get up at a predetermined time. So my life is not terribly flexible at the moment. That is the worst part of it really. And the fact, of course, that I don't have anyone here at night should I need help. "*

The desire for greater flexibility in their support arrangements is also reflected in several of the service users' responses to questions about the characteristics of their ideal support arrangements:

*"The best characteristics, as far as I am concerned, would be the ones that enable me total flexibility with my needs - which are not regimented and, in fact, need to be totally flexible. "*

*"They'd be flexible so that I could change my needs from week to week. "*

At the same time, some service users clearly feel that having a range of different services enhances the degree of flexibility in their support arrangements. Some also pointed to the fact that particular service providers are able to offer the same characteristics of choice and control which are valued by people using their own workers:

*"The advantages include that my day timetable of care is overlapped by a little bit so, therefore, I am always covered. I have always got somebody in the house with me from nine until five, when my parents come back from work. "*

*"The main benefit of the current arrangement is that the agency workers are flexible and will do whatever needs doing. We used to use Home Carers who*

*were useless because the tasks that they would carry out at any given time were so restricted. "*

*"Getting domestic work done gives me freedom to go out and do other things. I have the same worker regularly so I've had a chance to develop a relationship."*

### Organising and managing support arrangements

Although people using payments schemes place a high value on being able to control their support arrangements, some also highlighted the responsibility and effort which comes with this control.

First, several people particularly highlighted the time and effort involved in finding and recruiting suitable support workers. Some also pointed to the fact that there is often no help available with vetting potential workers (although this varies between different schemes). This can increase the likelihood of making mistakes in the selection of workers, with the attendant problem of having to recruit all over again. However, this problem is often diminished as people gain more expertise over time:

*"I think any employer finds it difficult choosing the right person to come and do the job. Basically - I don't ask people to send in their CVs - it's very much on an 'as you see' basis. I think you get a feel for those people that are going to be right after a while, but it is difficult and you do make mistakes, and I think that I am learning all the time. But yes, it has its difficult moments. "*

*"I am having difficulty recruiting staff at the moment. But I guess that's something I am always going to have difficulty with - recruiting staff. I wish there was somewhere you could phone up and say, have you got anyone on your books at the moment who is looking for a position? if there is, I don't know of it. "*

*"... The most difficult thing is recruiting staff. I would just love to see a system where you could phone up somewhere and say, have you got something that might be suitable. To come and live in. "*

Second, some people also highlighted the time and effort required for training and managing workers after they have been recruited. Some also highlighted the fact that it is often impractical - or even impossible - to delegate this responsibility to anyone else. While this might be manageable in the normal course of events, it can be fairly difficult at particular times - for example, when someone is unwell:



*"...I have to make the phone calls, when one of them is sick. I would still rather do that, than that they phoned each other, but the fact that I even have to bother, it not that they're sick that often, but if they suddenly can't come for a perfectly good reason, it is my job to sort it and I can just do without the hassle ... but it isn't a problem. "*

*"I realise I will have a bigger responsibility when I am hiring all my own staff, when I interview people to take their (the Care Attendant's) place. I will make it quite clear that there are things I will need and will want doing. That is a disadvantage I can see, of making sure I get it right. I cannot give that responsibility to anyone else"*

*"There are times when I get very ill and require virtually constant support. Arranging my support leaves little time for leisure. "*

Third, a few people pointed to difficulties with training new workers to act as enablers. This is often linked to the issue of availability as, sometimes, limited availability might mean compromises having to be made at the recruitment stage:

*"I think there is a difficulty in finding the right type of person to do this job. It definitely takes a definite type of person to be able to do this, nursing, doctoring, whatever - a person with commitment, loyalty, that can focus on the job at hand without being too nurturing, shall we say. "*

*"You can't find suitable people and the stress of having to continually train people in your own routine, which is quite a big thing when you have to repeat things 500 times. "*

*"... you have got to interview them and give them a trial period... You'll put an advert in and stress the fact that you want somebody that's experienced, and they'll come and perhaps they've looked after an aunty, and don't know what it is to look after somebody ... You've got to terminate their employment, and its quite expensive to do that. You have them on a month's trial, and sometimes you can only have them a week, because they're just not suitable. Then you've got to try again. "*

*"It's difficult to find suitable workers ... some don't know the basics of independent living themselves. ... some will not do tasks to the required standard. "*

Fourth, some people highlighted the lack of support and guidance for people employing their own workers and the difficulties this can cause for those who

are less experienced. (Although this is in fact highly variable as some schemes do offer training and on-going support and advice if required). Some also pointed out that the viability of the payments option can often be dependent on whether or not this kind of support is available to those who feel they need it:

*"it worries me that some people don't have that confidence in themselves, or the back-up ... In that sense / think its a very tight arrangement. It concerns me now that a lot more people are being encouraged to go over to SOCS who I would say were borderline in having that ability to feel that the arrangements would be good for them. "*

*"I don't think there's any other things that you can do - unless I got in with other people, and listened to how they go about it - they maybe can do it better than me. "*

The single most common concern amongst people employing their own workers relates to the various problems which can occur when support workers leave or have to be replaced. Apart from the practical inconvenience and the additional recruitment costs involved, this can also lead to added stress as people balance the need to find suitable workers against the pressure to fill the gap in their support arrangements as quickly as possible:

*"I think my main fear is of every time a change happens and I have to get someone else. The hassle of advertising, going through the interviewing and getting to know them, someone again. As time goes on I am getting more used to that. "*

*"Having to advertise and interview new people when one person leaves, hoping you have picked the right one, the person you can live with. But it is worth it, to get the independence I mention before. "*

"I am currently having a problem getting a third carer in, so my husband is having to do extra work, which I don't like. But I am sure eventually I shall find someone and then it is a matter of training them. You can't be sure you've found the right person for probably a couple of months, until you've really got very used to each other. That can be a problem, sometimes you have made a mistake, but generally speaking, you have to pick them well, or try and pick them well. If you can do that you are O. K. I have made some mistakes there is no doubt about it. I had one, who I had for a long time, and it simply got to a point where she was doing what she wanted, instead of what I wanted, and she had to go. And that was very unsatisfactory but I have now solved that problem."

However, as discussed earlier, the fact that people using payment schemes (particularly local schemes) tend to have well-developed back-up arrangements often mitigates against some of this difficulty - at least in the short-term. Also, people tend to become more adept at managing this kind of

situation with experience. At the same time, as the quotes above and elsewhere in this chapter illustrate, most people clearly feel that the responsibilities and effort involved with managing their own support arrangements are outweighed by the advantages.

### Uncertainty over future availability of payments schemes and services

Many people's overall confidence about their individual support arrangements are strongly influenced by their perceptions of wider structural issues such as the level of funding for payment schemes and the policies adopted towards the provision of services and other support options for disabled people. When asked about their confidence in the long-term viability of their support arrangements, several people responded with comments about local policies on community care, or government policy towards direct payments and/or the future of the ILF. Several people were particularly concerned about what they see as a growing trend towards charging for local authority provision and the effects this might have on the viability of their own support arrangements:

*"The other thing is what the local authorities are doing about charging systems. There is talk about charging and how is this going to be done? Obviously there is concern about how this is going to work, because a lot of us now are putting our benefit money into things that at one time we would have been able to get from social services anyway. "*

*"Long term viability is a constant worry because social services are threatening charges if you have savings over £3,000. "*

*"I am worried about the Government's handling of the situation in regard to funding .... We are all reading that funds are drying up for independent living and they (ILF) are not taking any more applications for that, so what's going to happen when the funds dry up?"*

As noted earlier, the uncertainty surrounding the legal status of payments schemes has caused several local authorities to review their particular schemes and, in some cases, suspend them altogether - often at short notice. With such a potentially fragile state of affairs, it is not surprising that some people are extremely anxious about whether or not they will be able to maintain their current support arrangements in the future:

*"I never feel that this is permanent ... although the local authority have said verbally they won't cut scheme. Were worried that they may demand contribution of attendance allowance, but they haven't tried yet. We will fight tooth and nail if they do"*

*"I could worry myself sick over whether funding changes might devastate my plans. I try not to think about it because I feel that my life is in their hands. "*

Some people raised specific concerns about the uneven availability of payments schemes in different local authorities; others also highlighted the perceived lack of consistency in eligibility criteria. In particular, some people feel that the lack of consistency concerning local payment schemes effectively restricts their personal mobility as they are reluctant to move home or change jobs for fear of losing their funding:

*"Because the job that I do has quite a few vacancies - not in the recession, but at other times - there are quite well paid jobs in other parts of the country, but I am worried about the uniformity of the scheme. It's alright in xxxx, but what if I wanted to move to say xxxx, which is something that I would like to do - to move back nearer to my family and my friends from home. But if I move just because I have changed job what happens to my money? ... There doesn't seem to be any standard for moving from one place to another. "*

"I was fully funded at one time by an authority, and then I was sent a form to fill in for the Independent Living Fund. With the change of government, if there ever is going to be a change of government, is the fund going to be withdrawn? if so, will the authority that once sponsored me when I left the institution - will they honour the agreement. I have it in writing that they shall, but will that agreement change as people move on? - the people that gave the agreement won't always be there. "

The increasing accounting controls for payments schemes are also a matter of concern for some people using these schemes. Some pointed out that, the fact they are dependent on payments for personal assistance to survive already provides an effective check on accountability; consequently they feel that over bureaucratic controls are both unnecessary and divisive:

*"They put in place so many rules, its just... its not untenable but it is getting that way. Also they really regulate things to the point you have to be so accountable for everything ... and constant checking-up, which the ILF have started to do is ludicrous. There is no way after all their tests we could still manage to survive quite nicely and filch the government out of money. "*

*"The disempowering thing is that the system has to justify where the money is going and so we have to constantly account for our needs. Its as though they don't quite trust you and give you something with a bad grace, or as if they would rather you didn't ask for it at all. "*

Some people - both service users and people receiving payments -also expressed concerns about the ability of their support arrangements to cope if

they were to experience changes in health or if their needs were to change in any other way:

*"But I am worried about what happens if I need more ILF funding, I have a condition that will get worse ... what do I do then? I don't want to become a burden to my family, although they are very good, I wouldn't like them to have to cover for the extra help I may need, most of that would fall on my mother... if the worse did happen I can see me having to go into an institution and I would hate that. "*

*"...my needs will change because I have a progressive illness, which I shall need progressively more help, if that additional help is not going to be funded, or worse still, to be charged for, or in some other way penalised. Then I am going to be using my own money more, which may limit my ability to choose what I want to do ... given the present state of politics and the economy you don't know which way the centre is going to move. "*

Disabled people's views on the quality of their support arrangements are also strongly influenced by the level of funding - actual or perceived - for whichever support option they use. As we have already noted payment schemes - particularly the ILF - often do not cover the full costs of people's support packages. Consequently, some or all of the shortfall has to be met from personal income. Where people do not have sufficient funds, this can lead to their either having to make do with less support, or increasing their dependency on informal support.

Some people also pointed out that, if this option is not available to them, the only other alternative may be to use agency care. As this is typically more expensive than their regular support, the effect is to reduce their overall resources even further:

*"It would be nice to have more hours, so that if I wanted to go into town, shopping I could go, Where at the moment, having just a limited amount of money, I can't say to somebody take me shopping. Same with the cleaner, who comes in to clean the house, she comes in three hours per week, on a Wednesday, but if I need some extra cleaning that is not possible, some weeks I would like to have my cleaner twice a week. If I had more money I could tell her to come in twice, when I wanted her to do the extra jobs. "*

*"But there are times when you can't call on people. Weekends are the most difficult. And I think that's another thing - that this scheme doesn't provide enough to cover for weekends and that. Because people don't like working weekends, and when you have to resort to - like nursing agencies and things*

*like that - the price starts to become prohibitive, and you lose a lot of your money just for that essential few hours that you need. "*

Others highlighted that restrictions on funding levels, and the fact that certain essential costs (eg, tax and national insurance contributions) may not be covered by payments, can also create pressure on people to cut corners in order to meet their needs. For example, some people may feel that they have to pay workers less than they would want to, or recruit on a self-employed basis. This can also sometimes lead to other problems such as increasing the turnover of staff:

*"I would like to have more money so that I could pay staff more. I think for what they do, unreasonable hours, everything else, it would be nice to actually make it worth while. Also if they ever have a holiday, I can't pay them on holiday, because if I pay them on holiday, then I can't afford to pay someone else to look after me when they're gone. Which I think is wrong there should be allowances made to cover holidays for staff, where they should double what you get, for at least a month during the year, so that you can give people who work for you a holiday. That's not unreasonable, why they, people who wipe bottoms should be deemed not worthy of a pay cheque and a holiday at the same time. It is quite beyond me!"*

*"I wanted to keep my current carer and get an extra sum of money to meet my needs at the weekend, but the money offered is too little. Also some of the people who help me are friends who would not want payment, but I would like to be able to repay in terms of little gifts occasionally and the sum offered wont even cover that. Its quite hard and I don't want to break any rules.*

*"I would pay more for good people if I could - and I'd get better people. "*

A few people also raised the issue of the impact of employment on funding levels and eligibility. As the ILF as well as some local payment schemes involve means testing, this is seen as an inbuilt disincentive to employment as any excess income above subsistence levels is taken as being available to pay for assistance:

*"I think the best package I could think of would be to have all-round cover... it would give me night-time cover which I think at the moment I can't afford, and it does worry me being on my own. I also think that cover should be based on what you actually need, rather than what your means are, because sometimes I think that I am being unfairly - punished is maybe too strong a word, but - unfairly penalised for actually working. ... I work - and whereas a lot of people are able to spend their earnings on other things, I have to then consider*

*spending mine on help, and even things like extra transport costs, and things like that. And extra helpers for drivers here and there. So my ideal picture of help would be much more all-round cover. "*

These various concerns about the viability of support arrangements highlight that, whatever the inherent advantages of particular support options, these can only be maximised if there are appropriate structural supports (ie. policies and resources) in place. In the final chapter of the report we return to the policy issues outlined at the start and consider the implications of the findings for the future development of payments schemes. Before that, in the next chapter we will examine the comparative costs of payments schemes and services.

## 7. THE COSTS OF PAYMENT SCHEMES AND SERVICES

### **Overview of how the cost comparisons have been made**

The overall aim of the cost analysis has been to compare the costs of support financed by payments with the costs of direct service provision. Data on the weekly support hours provided by different sources has been combined with expenditure data to estimate the unit costs of personal assistance and service based support arrangements at both individual and aggregate levels. The calculations have been done in three stages.

First, details on all expenditure (direct costs and overheads) associated with services used by people in the study have been compiled from local authorities, independent sector providers and, where local cost data has not been available, using proxy data from secondary sources. Data has also been collected on the direct costs and overheads associated with administration of local payment schemes.

Second, the interview survey has collected details on all expenditure associated with each individual's support arrangements. These include the amounts paid to personal assistants (both regular and occasional workers) and/or private agencies; any charges paid for statutory services; recruitment and management costs (eg. employers national insurance contributions); and, where applicable, any incidental costs related to their support arrangements such as support workers' travel expenses.

This expenditure data has been used to estimate the gross weekly costs of individual support packages on a case by case basis. However, given the variation in the total number of hours involved in individual support arrangements and in the proportion of the total amount of assistance provided from paid and unpaid informal sources, the gross weekly costs have also been converted into two sets of standardised hourly unit costs.

The first set of standardised hourly unit costs have been calculated by dividing the gross weekly costs of individual support packages by the total number of hours provided from formal paid sources only (ie. services or directly employed support workers). This is the most meaningful cost unit for our purposes as it allows direct comparison between the costs of providing equivalent amounts of assistance through payments and direct service provision. However, as informal support clearly forms a significant component of many disabled peoples' support arrangements, the second set of standardised unit costs include unpaid support. This allows us to examine the influence which unpaid support has on variations in the costs of different types of support arrangements.



Third, the costs of individual support arrangements have then been aggregated to produce average weekly and hourly costs for the various sub-groups in our sample. We have also compared the average costs of support arrangements financed through local authority schemes and the ILF.

Full details of the sources and calculations used to compile the unit costs are contained in Appendix C. There are also a number of important issues concerning the definition of costs and the way in which the cost data has been compiled which need to be taken into account when interpreting the cost comparisons. These are discussed below.

### Estimating the unit costs of direct service provision

Local authorities were asked to supply a breakdown of the budgets for the particular services used by people in the study. In addition they were also asked to supply details of the overall number of users and annual service hours delivered by each service. These figures were used as the denominator required to calculate the hourly unit cost of each of the services used.

**Standardisation:** The data on service budgets was collected according to a standard format to try and ensure that all of the unit costs were calculated in the same way. The format for data collection was also designed to take account of the guidelines produced by the Chartered Institute of Public Finance and Accountancy (CIPFA) which local authorities are now required to follow in costing community care budgets. According to the CIPFA guidelines, net expenditure is defined as staff and running costs less any income from sales and fees (eg. charges to clients, payments from other local authorities, and joint finance from District Health Authorities). This is essentially the basic definition we have used in this study with one important difference regarding the treatment of charges to clients which is outlined below.

**Cost subsidies:** While deducting revenue from charges from net expenditure is entirely appropriate for the purposes of estimating local community care budgets, it does present difficulties for comparing the costs of direct service provision and support financed by direct or indirect payments.

This difficulty arises because income from charges is effectively a form of 'subsidy' on local authority expenditure. Although this is not a problem in itself, other types of support arrangements also include other forms of subsidy which may be costed in completely different ways. For example, if a payments scheme does not allow for the purchase of additional cover for emergencies disabled people might have to pay for this out of their own pockets. In this case, the amount they spend is also effectively a form of

subsidy on the cost of their support even though such expenditure would not appear in the budget for their particular payment scheme. Similarly, some service users pay charges direct to independent sector agencies.

One way of dealing with these potential anomalies would be to simply ignore all forms of cost subsidy and base cost comparisons between different support options on net expenditure only. However, this approach would significantly distort any comparisons between the various support options as it would not reflect the actual costs involved. For example, payments schemes are often based on hourly pay rates which are lower than the rates paid to personal assistants/helpers. Therefore, taking net expenditure as representing the cost of the payments option inevitably increases the relative costs of services. By the same token, ignoring the subsidy from charges for services systematically increases the relative costs of payments schemes. Consequently, wherever it has been possible to identify quantifiable subsidies (including charges) these have been counted as expenditure for the purposes of calculating actual unit costs.

Capital expenditure and administrative overheads: Variations in the way different local authorities treat capital expenditure and administrative overheads in their budgets have also presented problems for compiling cost data for this study. For example, although local authorities were asked to include central establishment costs (eg. the cost of legal services or personnel) in the breakdown of their budgets, most were unable to identify what proportion of these centralised costs should be applied to particular departments. Similar problems were encountered with capital expenditure (eg. on buildings and equipment). Some authorities included capital expenditure in their budgets; others provided a 'guesstimate'; and some simply left this item out.

Where this data has been omitted we have re-contacted the local authorities concerned to establish whether this is because there is no capital expenditure involved with a particular service, or simply because the costs are unknown. If it is because the costs are unknown we have estimated the capital element of particular service budgets on the basis of average proportion allocated to capital expenditure in other local authority budgets.

Missing/incomplete data: A further complication with calculating unit costs is that most local authorities have not been able to supply complete budget data for all of the services used by people in our sample.

In most cases, the main problem has been that, although we may have been able to obtain details of the overall budget for particular services, the local

authorities concerned have not been able to supply sufficient detail on levels of service use which would be necessary to calculate accurate unit costs. In some cases, there were also gaps in the data provided which meant that costs could be calculated for some services, but not for others. Overall, it has only been possible to calculate accurate local unit costs for 16 out of the 35 different services provided by the local authorities in the study (ie. 46 percent). Collecting budget data on the administrative costs involved with running local payment schemes has proved easier however, as 6 out of the 9 local authorities were able to supply this information.

In view of these difficulties, gaps in the expenditure budgets for particular local services have been filled by using proxy data from other sources. In some cases (eg. with capital expenditure) we have estimated the missing costs based on the average expenditure under the relevant budget heads reported by other local authorities in the study. Where the data on particular services is missing altogether, we have substituted unit costs based on the estimates of national costs compiled annually by the Personal Social Services Research Unit (PSSRU) at the University of Kent on behalf of the Department of Health (Netten and Smart, 1993).

#### Estimating the unit costs of support financed by payment schemes

The personal interview survey has collected data on the actual amount each individual spends on his or her support arrangements. The main item of expenditure is obviously the wages paid to support workers. This has been calculated by multiplying the total weekly hours provided by the hourly pay rate for each individual's support worker or workers. The amounts paid for regular and occasional workers have been calculated separately as these are often based on different hourly rates (eg. if people use more expensive agency workers to cover for their regular workers).

The amounts spent on wages are based on what support workers are actually paid rather than the payments people receive from a local authority or the ILF. This is particularly important as such payments often do not cover the full costs of support arrangements. For example, some local payment schemes include an allowance for support workers' holiday pay, while payments from the ILF do not. Similarly, while assessment for payments is typically based on a regular number of hours at a single rate of pay, additional hours (eg. for emergency cover) will often need to be purchased at a different rate. Consequently, basing the calculations on what people actually spend on their support gives a much more accurate guide to the full costs involved.

#### Revenue from charges to service users

As noted above, revenue from charges has been treated as a form of cost subsidy on local authority expenditure. Similarly, where service users are supplementing direct service provision with support purchased from independent sector agencies, any fees paid are also a form of subsidy on the cost of their support.

Consequently, where applicable, we have adjusted the gross costs of individual support packages on a case by case basis to reflect these charges. For example, if the direct weekly cost of an individual's support is £200 and that individual also pays £4 a week in charges, the net cost is calculated at £204. Similarly, where local authorities supplying cost data have included revenue from charges in their service budgets, this revenue has been added back onto their direct expenditure before calculating the unit costs for particular services. However, in cases where revenue from charges has already been counted in the calculation of unit costs for particular services, charges paid by individuals using these services have been ignored in order to avoid the charges being double counted.

#### Personal contributions to support financed by payment schemes

Support packages financed through the various payment schemes (including the ILF) also involve expenditure by both the funding authority and the disabled people receiving payments. Both services and payment schemes are, in effect, 'subsidised' by disabled people themselves. In the case of services, this subsidy is in the form of charges which are offset against local authority expenditure. As payment schemes very rarely cover the full cost of individual support arrangements, all or part of the shortfall has to be met by disabled people; consequently, such expenditure is also a form of subsidy towards the full costs involved.

However, there are important differences between these forms of subsidy which means they cannot be treated as directly comparable. First, charges are usually compulsory whereas a disabled person has some degree of choice about whether to subsidise a payment scheme, and by how much. (Although this only goes so far as exercising this choice may involve having to make do with less support). Second, charges are based on regular and fixed amounts but personal expenditure on support financed by payments schemes can vary from week to week. Third, some of the categories of additional expenditure relate to one off costs (eg. recruitment costs and payments towards personal assistants/helpers holiday expenses), or costs for which there may be no equivalent categories within service budgets (eg. expenses for personal assistants accompanying someone to a social or leisure event).

Consequently, additional costs involved in support financed by a payments scheme have only been counted if:

- a) such costs are incurred on a regular basis; and,
- b) there are broadly equivalent and quantifiable costs involved in direct service provision.

Provided these conditions are met, the costs involved have been averaged out to estimate 'typical' weekly costs for each category of expenditure. As with charges to service users, these have then been added in to the overall weekly costs of support arrangements on a case by case basis.

### Estimating the costs of informal unpaid support

As noted earlier, informal support forms a significant component of many people's support packages. This also has some important implications for the issue of costs. First, there are a range of both hidden and visible costs associated with informal support. The reduction in replaceable income for people providing such support on regular basis is clearly one of the most obvious costs involved. However, this also has less visible consequences in terms of reduced entitlement to contributions based social security benefits (particularly for women) and diminished savings capacity. Added to this, there are a wide range of both recurrent and one off costs which have a significant impact on the long-term standard of living of households containing unpaid helpers (Glendinning, 1992).

The complexities involved in trying to accurately measure all of the costs associated with informal support make it difficult to attach a definitive monetary value to the elements of unpaid support within the various support arrangements examined in this study. Nevertheless, it is important to make some form of adjustment to the unit costs in order to ensure that comparisons between the costs of the different arrangements are made on an equitable basis. This is particularly important where one type of support option routinely includes a greater proportion of unpaid support than another. In these circumstances, any cost comparisons between the options involved will be distorted by the fact that some support hours are valued at cost price while others are treated as having no cost value at all. This certainly applies to the comparison between payment schemes and direct service provision in this study as people using services rely on unpaid support to a much greater extent than those whose support is funded by direct or indirect payments.

This effectively means that service provision involves a higher level of 'subsidy' from unpaid support. This, in turn, introduces a systematic bias into the cost comparisons between the two options as service provision will almost invariably appear cheaper.

The main implication of this situation is that simple comparisons between payments and services will not be a particularly helpful guide to the real costs involved. Further, although the distorting effect of unpaid support particularly applies to the cost of service based support, support financed through payment schemes is also subsidised in the same way (albeit to a lesser extent). Consequently, a more useful approach is to consider the quantity and quality of support which can be purchased or financed for any given level of expenditure regardless of the availability of informal support.

For example, the cost of providing 20 hours personal assistance through a payments scheme can be compared to the cost of providing the same level of support by service provision. Alternatively, unpaid support hours can be costed at a notional rate and included with the paid elements of different support arrangements. Although this would still not necessarily reflect the true costs involved, it would help to illustrate what impact replacing this help with paid support might have on the overall costs of different support options.

For illustrative purposes, the unit cost comparisons presented in this report include both of these alternative adjustments for unpaid support. In the first set of costs unpaid support has been disregarded completely so that the relative costs of paid support can be compared directly. In the second set of costs, unpaid support hours have been included in the denominator for calculating hourly unit costs but have themselves been costed at a notional rate of £4.48 per hour. This figure is based on the value of an hours paid work by a care assistant in the formal labour market reported in the 1993 New Earnings Survey.

### Gross costs of support packages

The average gross cost of peoples' support is just over £300 per week. The costs of support packages for people using payments schemes and direct service provision for the bulk of their support are very similar at £303 and £293 respectively. The support arrangements for people using a combination of services and payments are noticeably more expensive, at an average of £531 per week (Table 7.1). These differences in the gross costs of support packages are statistically significant.

Over 60 percent of the payments group have support packages costing up to £300 per week, compared to 75 percent of service users and 40 percent of

those using a combination of services and payments. At the same time, there is considerably less variation in costs amongst the payments groups compared to service users or people who use a combination of payments and services. This is shown by the standard deviations (which indicates how much individual cases vary around the average) for the costs of support packages used by the different groups. While the standard deviation amongst the payments group is under £200, it is more than twice as large for the other two groups.

The higher costs for people who use mixed packages of support are due to a combination of factors. First, they use more hours each week than either the payments group or service users. Second, as they are more likely to be living alone they also have a lower proportion of their support provided by unpaid informal helpers. Third, as a consequence of these two factors, a higher proportion of their support is provided by either paid support workers or services. In addition, a higher proportion of people in this group use the district nursing service - which has a significantly higher unit costs than other services.

People who use a combination of services and payments also tend to have greater difficulty arranging cover and back-up for their usual support arrangements. Consequently, they are more likely to turn to agency care to meet this need which, again, tends to be more expensive than other forms of support. Again, this is obviously related to, the fact that they have less access to informal support. At the same time, these findings also suggest that spreading the provision of assistance between paid support workers and services is not particularly cost-efficient as it costs significantly more than packages based on payments or services on their own.

As noted in Chapter 5, although older and younger people in the sample use almost exactly the same number of hours support, the older group have a higher level of service use. This is also reflected in the gross cost of their support packages which is, on average, over £50 higher than the under 55 age group (Table 7.2).

The gross costs of weekly support packages are also around 30 percent higher amongst people who are living alone compared to those who live with others (Table 7.2). As with people who use a combination of payments and services, this is associated with people living alone having a much lower proportion of support met by informal sources. Consequently, their greater reliance on formal support (from either paid support workers or services) obviously has the effect of pushing up the gross costs of their support.

Comparison between people who receive payments from the ILF and local authority payments schemes shows that the former groups' support packages cost just over twice as much as the latter. This is mainly due to the fact that they simply use more support hours each week, although people using local schemes also have a higher proportion of their assistance provided by informal helpers.

The findings on the gross cost of support packages are also of interest in the context of the qualifying limits for the new Independent Living (1993) Fund. Amongst the sample as a whole, just over 1 in 5 people have support packages costing over £500 per week - which is the upper limit for payments from the fund. This proportion is lowest amongst service users and highest amongst the mixed group, more than twice as many of whom have support packages costing over £500.

The new Fund also requires people to be in receipt of services worth £200 in order to qualify for top-up payments. Amongst those using services or a combination of service and payments schemes, 56 and 20 percent respectively have support packages costing £200 or less and would not, therefore, be eligible to apply for any payments. Taken together with the findings on people with packages costing in excess of the £500 ceiling, this suggests that a large proportion of people in our sample would fail to meet the qualifying criteria for payments from the new Fund.



Table 7.1 Gross weekly costs of support packages

(Percent)	Payments group	Service users	Mixed group
Up to £100	19	37	0
£101 - £200	15	19	20
£201 - £300	27	19	20
£301 -£400	8	7	20
£401 -£500	8	4	7
Over £500	23	15	33
Totals	100	100	100
(Base)	(26)	(27)	(15)

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Mean	£303	£293	£531
Std. deviation	£198	£408	£476

Level of significance = 0.001

Missing cases = 2

Table 7.2 Gross weekly costs of support packages by age and living arrangements

	Mean weekly cost	Standard deviation	(Base)
Under 55	£347	£373	(58)
Over 55	£404	£365	(10)
Living alone	£399	£371	(31)
Living with others	£313	£371	(37)

Table 7.3 Gross weekly costs of support packages by source of funding (payments group only)

	Mean weekly cost	Std. deviation	(Base)
ILF	£399	£182	(26)
LA payments	£193	£158	(17)

### Comparison of unit costs

While it is important to quantify the actual weekly cost of various types of support options, gross costs are of limited use for comparing their relative cost-effectiveness. Given the variation in both the overall level of assistance involved in individual support arrangements and the proportion of assistance provided from paid and unpaid informal sources, it is impossible to make direct cost comparisons without some form of standardisation.

Consequently, we have also calculated standardised hourly unit costs which, basically, represent gross costs divided by the number of hours provided from each source. This calculation has been carried out on a case by case basis for each service used and the resulting totals aggregated to produce average unit costs for the various comparison groups. (See Appendix C for full details of the sources and calculations used).

Further, as explained in the first part of this chapter, the unit costs for support provided by formal paid sources (ie. services or directly employed support workers only) have been calculated separately from unit costs which include support provided by informal helpers. Excluding unpaid informal support from the denominator is important as this allows direct comparison between the costs of providing equivalent amounts of assistance through payments schemes and services. In other words, between what it would cost to provide one hour of assistance paid for through a payments scheme and the cost of providing the same hour of assistance by direct service provision.

However, as informal support clearly forms a significant component of many disabled peoples' support arrangements, it is also useful to look at alternative unit costs which include unpaid support in the denominator. This serves two functions. First, it allows us to examine the influence which unpaid support has on variations in the costs of different types of support arrangements. Second, by substituting a nominal cost for unpaid support, we can also illustrate the extent to which these different arrangements are 'subsidised' by informal helpers. This,

in turn, allows us to examine the potential cost implications of replacing assistance provided by informal helpers with support provided by, payments schemes or direct service provision.

Table 7.4 Hourly unit costs of paid support (including all overheads)

	Mean	Std. deviation
Payments group	£5.18	£1.31
Service users	£8.52	£4.21
Mixed group	£6.28	£1 .66

Level of significance = <0.001

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ILF payments	£4.53	£0.76
LA payments	£5.95	£1.42

Level of significance = 0.002

The findings indicate that there is a statistically significant difference in the unit costs of payments schemes and services. Support arrangements financed by direct/indirect payments are, on average, between 30 and 40 percent cheaper than equivalent service based support. The average hourly unit cost of support for people receiving payments is £5.18 compared to £8.52 for service users. As we would expect, the average unit cost for support arrangements based on a combination of payments and services falls in the middle of this range at £6.28 (Table 7.4).

It is also noticeable that there is a greater degree of variation in the unit cost of direct service provision compared to the cost of support financed through payments schemes. The standard deviation for the unit cost of service based support is over three times larger than that for payments group. This is partly due to the fact that some services are simply more costly than others wherever, and by whoever they are provided. At the same time, there is also a considerable degree of local variation in the costs of the same services in different local authorities. The unit cost of the home help service, for example ranges from £7.50 in Authority D3 to £9.58 in Authority D1 (which are both in outer-London), while the national average is £6.79 (see Table C1 in Appendix C).

This variation in the costs of different services is one of the factors influencing the relative unit costs of support provided through payments schemes and direct service provision. Some of the difference in the cost of these two options can also be accounted for by the relative costs associated with payments schemes operated by local authorities and the ILF. The average unit cost for support financed by local authority payments is £5.95, compared to £4.53 for support financed by the ILF. This difference is also statistically significant (Table 7.4). Despite these higher costs, local payment schemes are still 30 percent cheaper than direct service provision.

There is also a lot less variation in the unit cost of support financed by payments schemes. As we would expect, this is particularly true of support financed by the ILF as payments are based on fixed hourly rates. Rates for local schemes, on the other hand, are subject to the discretion of individual authorities. This is reflected in the standard deviations for the unit costs: £1.42 for local authority payments, compared to only £0.76 for ILF payments.

However, the main factor accounting for the difference between the unit costs of payments schemes and service provision is the administration costs and other overheads involved. Administration of local payment schemes adds, on average, between 9 and 15 percent to the total costs (Table 7.5). In contrast to this, with the exception of the home help service, administrative overheads for most local authority services add between 20 and 30 percent to the total costs (Table 7.6).

The lower overheads for the home help service raises some important issues about economies of scale. While local budgets for other services are typically around £500,000 or less, home help budgets generally run into millions of pounds. In Authority A, for example, the budget for this service is almost £11 million compared to only just over £500,000 for care attendant services; the overheads for these two services are 15 and 27 percent respectively.

Consequently, providing a service on a larger scale is likely to be associated with a significant reduction in the relative cost of administrative overheads.

The findings also suggest that similar considerations might apply to the administration of payment schemes as the local schemes with the fewest number of users also have the highest administration costs. For example, at the time our data was collected, the scheme run by Authority A had 70 users and overheads of 10 percent (including a grant towards the cost of guidance for users provided by the local CIL); in contrast to this, the schemes run by Authorities D2 and D3 had 7 and 14 users respectively and overheads of 15 percent. Further, the cost of administering payments by from the ILF - which had 22,000 clients - has been estimated at only 2.5 percent (Phillips, 1993).

It is also important to consider these findings on administration costs in the context of the current legal constraints on local authorities making direct payments. Where payments are made direct, people who receive these payments normally have responsibility for processing support workers' wages. However, some of the indirect payment schemes currently in operation involve local authorities taking responsibility for employment (including payroll) as a means of getting around the prohibition on paying cash direct to disabled people. Other schemes involve this task being contracted out to a third party agency. In either case, the costs of this additional responsibility inevitably contribute to an increase in administrative overheads.

The experiences reported by authorities participating in this study have also highlighted that the financial monitoring procedures involved with indirect thirdparty arrangements are often more complicated than the procedures involved in monitoring direct payments. (See comments from the descriptions of local schemes in Appendix B). Consequently, this requires a greater input of local authority staff time which, again, contributes to increased overheads.

Table 7.5 Administration costs for payments schemes

Proportion of total budget spent on administration/overheads

Authority A	10%
Authority B	9%
Authority C1	0%
Authority C2	nk
Authority C3	nk
Authority C4	nk
Authority D1	0%
Authority D2	15
Authority D3	15
ILF	2.5%

Notes:

- i) nk = administration costs missing or incomplete
- ii) See Tables C13 and C14 in Appendix C for full breakdown of local budgets

Table 7.6 Administration costs for local authority services

Average proportion of total budget spent on administration/overheads

Care attendants	31%
Day Care	31%
Home care/home help	15%
Independent Living Schemes/CSVs	22%
Meals on Wheels	17%

Note: i) See Tables C2 to C12 in Appendix C for full breakdown of service budgets

Costs met from personal income

As noted in Chapter 4, people receiving direct or indirect payments contribute between 15 and 18 percent of the total costs of their support packages from personal income. Some of this money represents social security benefits (eg. Attendance Allowance) which people are required to contribute to the cost of their assistance either by the ILF, or as a result of the charging policies of particular local authorities. The remainder represents the amounts which people contribute 'voluntarily' in order to make up any shortfall in hours, or to meet any running costs which are not covered by their payments.

The amounts people spend on direct costs (ie. support worker's and agency fees) have already been examined in Chapter 4. Data has also been collected on additional running costs and how these are distributed between different types of expenditure. The findings are summarised in Table 7.7 below.

The most significant costs are support workers' tax and National Insurance contributions (with almost 40 percent of people paying an average of £16 per week), and support workers' meals and refreshments (with almost 60 percent paying an average of £12 per week). Other notable costs include the cost of telephone calls involved in organising assistance, and workers' accommodation (although only a small proportion of people need to meet this cost).

There are also various types of occasional costs which some people might incur in addition to the regular costs described above. These include additional car insurance to cover use of peoples' cars by their support workers; workers' travel expenses; expenses for workers' accompanying people on social and leisure activities, or on holiday; and the costs of accidental damage to property (eg. spilling wheelchair battery fluid on carpets), although this may sometimes be covered by insurance. Some people also have expenses involved in using their personal assistants at work which may or not be covered by other sources such a grant from the Department of Employment.

As both the amounts spent and their occurrence are extremely variable we have not attempted to quantify these costs in average terms (although some respondents did give details of illustrative amounts). Further, it would in any case be difficult to arrive at a universally acceptable definition of which of these represent 'essential' costs, and which are 'optional'. For example, while no-one would disagree that tax and national contributions are an essential running cost, it is less clear whether the same would apply to entertainment expenses for a personal assistant accompanying someone to the cinema. One argument would be that restrictions on physical access make this an essential cost as disabled people do not have any choice about taking a personal assistant (other than staying at home). An alternative view might be that this is still a private leisure activity and should not, therefore, be counted alongside the costs of personal and domestic assistance.

This issue is part of the wider debate about the definitions of personal assistance and independent living proposed by the disability movement, and how these might differ from statutory definitions of community care. These wider questions cannot be addressed here. However, the most important practical issue in the context of a comparative cost analysis is that we try and ensure that we are comparing like with like. Consequently, as noted earlier in this chapter, any additional costs associated with payments schemes have only been counted if:

- a) such costs are incurred on a regular basis; and,
- b) there are broadly equivalent and quantifiable costs involved in direct service provision.

On this basis, costs such as telephone costs, third-party liability insurance, and employer's tax and NI contributions are counted as they all have quantifiable equivalents in service budgets. Entertainment and holiday expenses have been excluded as there are not any readily identifiable equivalents in service budgets. Workers' holiday pay, on the other hand, has been included (where applicable), as this would also be included as a direct staff cost in service budgets. (Holiday

pay is not listed as a separate item in Table 7.7, however, as it is already included in the calculation of expenditure on support worker's wages).

Recruitment costs are another item of essential expenditure for people employing their own support workers. These costs have been estimated on the basis of the amounts people spent on recruiting their current workers. In some cases, this only involved one lot of expenditure. However, some people have had to recruit more than once because their original choice left, or did not work out to their satisfaction. Most of this expenditure relates to the costs of advertising for workers, although incidental costs (eg. telephone, stationery, and postage) have also been taken into account.

Reported recruitment costs average £78, although people on local authority payments schemes tend to spend more than people receiving payments from the ILF - £81 compared to £66 (Table 7.8). This is mainly due to the fact that people using ILF payments are more likely to recruit from within existing informal support networks and, consequently, may not have advertised directly.



Table 7.7 Additional incidental and running costs associated with payment schemes

	Proportion incurring each type of costs	Average cost per week
Meals	58%	£12.00
Employer's tax and NI contributions	39%	£16.20
Telephone costs	34%	£5.90
Third-party liability/accident insurance	26%	£1.70
Entertainment expenses	26%	variable
Travel expenses	16%	variable
Refreshments	11 %	£0.70
Accidental damage to property	11 %	variable
Holiday expenses	11.1%	variable
Accommodation costs	8%	£22.50
Car insurance	8%	variable
Laundry	5 %	£2.00
(Base)	(38)	

Table 7.8 Average recruitment costs

ILF	£66
LA payment schemes	£81
All	£78

### Service charges

Service users and people who use a combination of payments and services also contribute towards the costs of their support through the payment of service charges.

Altogether, 69 percent of people in these groups are paying charges towards the cost of the services they receive. These mostly relate to the home help/home care service and services provided by independent sector care agencies. Charges for the home help/home care service range from £1 to £4.15 per hour, with the average being £2; people using this service are paying an average of £9.40 per week in total. Charges for services provided by independent agencies range from £1.80 to £9.50 per hour, with an average of £4.30; total charges for agency services average £16 per week (Table 7.9). Other charges mostly relate to meals provided at day centres or provided by the meals on wheels service.

Table 7.9 Service charges

	Proportion paying charges	Average cost per week
Home care/home help	31%	£9.40
Private care agencies	23%	£16.00
Day care	5 %	£5.40
Meals on wheels	5%	£1.10
Other services	5%	£2.90
(Base)	(39)	

Missing cases = 3

### The costs of informal support

Analysis of the gross weekly costs of support packages indicates that variations in these costs are sensitive to the relative amounts of assistance people receive from informal helpers. As different types of support options involve varying degrees of assistance from informal and formal sources, this will also have an effect on their comparative costs.

Using the value of personal assistance in the formal labour market as a guide, suggests that informal support represents a cost subsidy of approximately 4 percent on support arrangements for people receiving direct/indirect payments. Costing informal support at a nominal rate of £4.48 per hour would add £168 to the average weekly cost of support packages for people in the payments group, and £128 to the cost of support packages based on a combination of payments and services (Table 7.10).

The impact of informal support on the costs of service based support arrangements is considerably larger. Costing informal support hours at the same nominal rate adds as much as £281 to the average costs of service users support packages - an increase of 29%.

Another way of representing this form of cost subsidy is to look at the effect of including informal support hours (costed at the nominal rate of £4.48) in the denominator used to calculate standardised unit costs. While this would reduce the unit cost of support arrangements for the payments and mixed groups by around only 20 pence, the unit cost for service users would be reduced by almost £2 per hour (Table 7.11).

As shown in Table 7.10, these changes in the relative costs of the different types of support arrangements are almost directly proportional to the amounts of informal support used by each of the main comparison groups. A similar trend can be seen in the comparison between the costs of support arrangements for older and younger groups and between people who live on their own and with others.

First, the over and under 55 age groups have an almost identical proportion of their assistance provided by informal helpers. Consequently, costing this informal support at a nominal rate also increases the gross costs of their support arrangements by almost exactly the same amount (Table 7.12).

Second, people who live on their own have a far smaller proportion of their assistance provided by informal helpers compared to those living with others; costing this informal support at a nominal rate would increase the gross costs of their support by less than £80, whereas the increase for people living with others would be over £300 (Table 7.12). Further, as people who live on their own use so little informal assistance, the impact of including informal support in the denominator for calculating unit costs is negligible as this only reduces the cost by less than one percent (Table 7.13).

The same pattern emerges if we compare the costs of support arrangements financed by local payments schemes and the ILF. As people using local payment schemes have a larger proportion of their assistance provided by informal helpers, the effect of costing this assistance at the nominal rate would be to increase the unit costs by around 6 percent, compared to 2 percent for the ILF group. The increase in gross costs would be lower, however, as people on local schemes use fewer hours overall (Tables 7.14 and 7.15).

The main qualification to this trend is that the change in unit costs for the payments and mixed groups is almost identical, despite the fact that the latter use fewer hours of assistance from informal helpers. As noted earlier, this can be accounted for by the fact that they are more likely to use agency care. As agency care tends to be more expensive than using directly employed support workers, this effectively offsets some of the cost subsidy represented by informal support.

Table 7.10 Estimated costs of informal support

(Mean)	Payments group	Service users	Mixed group
Proportion of hours provided by unpaid helpers	39%	57%	26%
Weekly cost of informal support <sup>1)</sup>	£168	£281	£128
Gross total weekly costs (adjusted)	£472	£575	£659

Costed at £4.48 per hour

Table 7.11 Effect of informal support on unit costs

(Mean)	Payments group	Service users	Mixed group
Unit cost including informal support	£4.96	£6.61	£6.05
Unit cost excluding informal support	£5.18	£8.52	£6.28
Percentage change in unit cost	+ 4.4%	+ 28.9%	+ 3.8%

Table 7.12 Estimated costs of informal support by age and living arrangements

(Mean)	Under 55	Over 55	Living alone	Living with others
Proportion of hours provided by unpaid helpers	43%	41%	13%	58%
Weekly cost of informal support"	£212	£205	£79	£303
Gross total weekly costs (adjusted)	£559	£609	£478	£616
Costed at £4.48 per hour				

Table 7.13 Effect of informal support on unit costs by age and living

arrangements (Mean)	Under 55	Over 55	Living alone	Living with others
Unit cost including informal support	£5.81	£5.81	£6.23	£5.55
Unit cost excluding informal support	£6.77	£6.47	£6.28	£6.68
Percentage change in unit cost	+ 16.5%	+ 11.4%	+ 0.8%	+ 20.4%

Table 7.14 Estimated costs of informal support by source of funding

(payments group only) (Mean)	ILF	LA payments
Proportion of hours provided by unpaid helpers	35%	52%
Weekly cost of informal support"	£205	£126
Gross total weekly costs (adjusted)	£603	£319
Costed at £4.48 per hour		

Table 7.15 Effect of informal support on unit costs by source of funding (payments group only)

(Mean)	ILF	LA payments
Unit cost including informal support	£4.43	£5.59
Unit cost excluding informal support	£4.53	£5.95
Percentage change in unit cost	+ 2.3%	+ 6.4%

Do payments schemes represent value for money?

The cost-effectiveness of any particular support options relates to both quality and cost. A cost-efficient intervention or mode of support can be defined as one which maximises the outputs or benefits achieved from a given level of resources or, alternatively, one which minimises the resources required to achieve a specified level of outputs or benefits.

In the context of this particular study, the 'resources' we have measured are the costs required to deliver a given level of assistance through direct/indirect payments or service provision (or a combination of the two). The principal 'benefits' which we are concerned with are those relating to:

- a) how well particular support options satisfy people's needs (as measured by factors such as reliability, flexibility, and the degree of choice and control they offer); and,
- b) the wider benefits which follow from the degree of efficiency with which these needs are met (eg. enabling people to take up employment, the impact on family and members and so on).

The production of these benefits (ie. the meeting of needs) is the principal output which we are interested in. There is also an important distinction to be made between intermediate and final objectives or, simplifying slightly, between means and ends. For example, by itself, providing a home help or a personal assistant is only an intermediate objective (or means); improving the quality of people's lives, giving them security and control, or addressing their requirements for physical assistance are all final objectives (ie. ends). It follows that these kind of final objectives could potentially be met by a variety of alternative means. The main question we need to ask; therefore, is which of

these intermediate objectives (ie. direct/indirect payments or services) represent the most cost-effective means of producing such benefits for disabled people.

However, it is important to emphasise that the analysis produced by this research does not necessarily allow us to make definitive statements about cost-effectiveness as, clearly, we have not measured all of the outputs and benefits which might be involved. Rather, the main aim has been to examine the relative merits of payments and services by weighing up the quality of a limited (albeit important) range of benefits against the costs involved in producing them.

Further, it is also important to bear in mind that most of the people in our sample use informal support (ie. from family, friends or volunteers) in addition to either paid workers or services. It is difficult to assign specific benefits to particular components of these overall support arrangements on a definitive basis as - to a greater or lesser degree - they are all interdependent.

This particularly applies to support arrangements based on a combination of payments and services. In these cases, a definitive analysis of cost-effectiveness would also need to measure the interdependence between benefits associated with the payments component and those associated with the service component. While it would be quite feasible to carry out this kind of multivariate analysis, this has not been possible within the scale of this particular research.

However, even with these qualifications in mind, the combination of findings on the quality of different support arrangements and their relative costs clearly indicate that direct/indirect payments are a cost-effective option for meeting disabled peoples' support needs.

First, we have seen that payments schemes meet a wider range of assistance needs than service based support, and people receiving payments have fewer unmet needs than service users.

Second, the findings also indicate that people using payments schemes have more reliable support arrangements and experience fewer problems with organising suitable support than service users.

Third, people receiving payments have higher levels of satisfaction than service users on a variety of measures. We have also seen that payments schemes offer a greater degree of choice, control and flexibility than direct service provision - all of which are not only highly valued by disabled , people themselves, but are also central policy objectives for community care.

Further, although service users are generally satisfied with the qualities of individual support staff, they often remain critical about the lack of choice and control they have over the way in which services are organised. For people using payment schemes, on the other hand, being able to direct how, when, and by whom their assistance is provided is typically the most valued feature of their support arrangements. There are also some relative disadvantages associated with the level of responsibility which this degree of control entails. However, most people feel that these are far outweighed by the advantages.

Finally, the comparison of unit costs presented in this chapter indicates that support arrangements funded through payments schemes are between 30 and 40 percent cheaper than direct service provision.

Taken together with the findings on the relative quality of these two options, this clearly indicates that direct/indirect payments maximise the benefits for disabled people at cheaper cost. Further, although well run services can offer some of the same benefits as payments schemes, this is generally at a higher cost.

In other words, every pound spent through a payments scheme not only goes further than a pound spent on services, but also purchases assistance of a higher quality. According to the definition of cost-effectiveness outlined above, therefore, direct/indirect payments clearly represent better value for money than direct service provision.



## 7. THE COSTS OF PAYMENT SCHEMES AND SERVICES

### **Overview of how the cost comparisons have been made**

The overall aim of the cost analysis has been to compare the costs of support financed by payments with the costs of direct service provision. Data on the weekly support hours provided by different sources has been combined with expenditure data to estimate the unit costs of personal assistance and service based support arrangements at both individual and aggregate levels. The calculations have been done in three stages.

First, details on all expenditure (direct costs and overheads) associated with services used by people in the study have been compiled from local authorities, independent sector providers and, where local cost data has not been available, using proxy data from secondary sources. Data has also been collected on the direct costs and overheads associated with administration of local payment schemes.

Second, the interview survey has collected details on all expenditure associated with each individual's support arrangements. These include the amounts paid to personal assistants (both regular and occasional workers) and/or private agencies; any charges paid for statutory services; recruitment and management costs (eg. employers national insurance contributions); and, where applicable, any incidental costs related to their support arrangements such as support workers' travel expenses.

This expenditure data has been used to estimate the gross weekly costs of individual support packages on a case by case basis. However, given the variation in the total number of hours involved in individual support arrangements and in the proportion of the total amount of assistance provided from paid and unpaid informal sources, the gross weekly costs have also been converted into two sets of standardised hourly unit costs.

The first set of standardised hourly unit costs have been calculated by dividing the gross weekly costs of individual support packages by the total number of hours provided from formal paid sources only (ie. services or directly employed support workers). This is the most meaningful cost unit for our purposes as it allows direct comparison between the costs of providing equivalent amounts of assistance through payments and direct service provision. However, as informal support clearly forms a significant component of many disabled peoples' support arrangements, the second set of standardised unit costs include unpaid support. This allows us to examine the influence which unpaid support has on variations in the costs of different types of support arrangements.

Third, the costs of individual support arrangements have then been aggregated to produce average weekly and hourly costs for the various sub-groups in our sample. We have also compared the average costs of support arrangements financed through local authority schemes and the ILF.

Full details of the sources and calculations used to compile the unit costs are contained in Appendix C. There are also a number of important issues concerning the definition of costs and the way in which the cost data has been compiled which need to be taken into account when interpreting the cost comparisons. These are discussed below.

### Estimating the unit costs of direct service provision

Local authorities were asked to supply a breakdown of the budgets for the particular services used by people in the study. In addition they were also asked to supply details of the overall number of users and annual service hours delivered by each service. These figures were used as the denominator required to calculate the hourly unit cost of each of the services used.

**Standardisation:** The data on service budgets was collected according to a standard format to try and ensure that all of the unit costs were calculated in the same way. The format for data collection was also designed to take account of the guidelines produced by the Chartered Institute of Public Finance and Accountancy (CIPFA) which local authorities are now required to follow in costing community care budgets. According to the CIPFA guidelines, net expenditure is defined as staff and running costs less any income from sales and fees (eg. charges to clients, payments from other local authorities, and joint finance from District Health Authorities). This is essentially the basic definition we have used in this study with one important difference regarding the treatment of charges to clients which is outlined below.

**Cost subsidies:** While deducting revenue from charges from net expenditure is entirely appropriate for the purposes of estimating local community care budgets, it does present difficulties for comparing the costs of direct service provision and support financed by direct or indirect payments.

This difficulty arises because income from charges is effectively a form of 'subsidy' on local authority expenditure. Although this is not a problem in itself, other types of support arrangements also include other forms of subsidy which may be costed in completely different ways. For example, if a payments scheme does not allow for the purchase of additional cover for emergencies disabled people might have to pay for this out of their own pockets. In this case, the amount they spend is also effectively a form of

subsidy on the cost of their support even though such expenditure would not appear in the budget for their particular payment scheme. Similarly, some service users pay charges direct to independent sector agencies.

One way of dealing with these potential anomalies would be to simply ignore all forms of cost subsidy and base cost comparisons between different support options on net expenditure only. However, this approach would significantly distort any comparisons between the various support options as it would not reflect the actual costs involved. For example, payments schemes are often based on hourly pay rates which are lower than the rates paid to personal assistants/helpers. Therefore, taking net expenditure as representing the cost of the payments option inevitably increases the relative costs of services. By the same token, ignoring the subsidy from charges for services systematically increases the relative costs of payments schemes. Consequently, wherever it has been possible to identify quantifiable subsidies (including charges) these have been counted as expenditure for the purposes of calculating actual unit costs.

Capital expenditure and administrative overheads: Variations in the way different local authorities treat capital expenditure and administrative overheads in their budgets have also presented problems for compiling cost data for this study. For example, although local authorities were asked to include central establishment costs (eg. the cost of legal services or personnel) in the breakdown of their budgets, most were unable to identify what proportion of these centralised costs should be applied to particular departments. Similar problems were encountered with capital expenditure (eg. on buildings and equipment). Some authorities included capital expenditure in their budgets; others provided a 'guesstimate'; and some simply left this item out.

Where this data has been omitted we have re-contacted the local authorities concerned to establish whether this is because there is no capital expenditure involved with a particular service, or simply because the costs are unknown. If it is because the costs are unknown we have estimated the capital element of particular service budgets on the basis of average proportion allocated to capital expenditure in other local authority budgets.

Missing/incomplete data: A further complication with calculating unit costs is that most local authorities have not been able to supply complete budget data for all of the services used by people in our sample.

In most cases, the main problem has been that, although we may have been able to obtain details of the overall budget for particular services, the local

authorities concerned have not been able to supply sufficient detail on levels of service use which would be necessary to calculate accurate unit costs. In some cases, there were also gaps in the data provided which meant that costs could be calculated for some services, but not for others. Overall, it has only been possible to calculate accurate local unit costs for 16 out of the 35 different services provided by the local authorities in the study (ie. 46 percent). Collecting budget data on the administrative costs involved with running local payment schemes has proved easier however, as 6 out of the 9 local authorities were able to supply this information.

In view of these difficulties, gaps in the expenditure budgets for particular local services have been filled by using proxy data from other sources. In some cases (eg. with capital expenditure) we have estimated the missing costs based on the average expenditure under the relevant budget heads reported by other local authorities in the study. Where the data on particular services is missing altogether, we have substituted unit costs based on the estimates of national costs compiled annually by the Personal Social Services Research Unit (PSSRU) at the University of Kent on behalf of the Department of Health (Netten and Smart, 1993).

#### Estimating the unit costs of support financed by payment schemes

The personal interview survey has collected data on the actual amount each individual spends on his or her support arrangements. The main item of expenditure is obviously the wages paid to support workers. This has been calculated by multiplying the total weekly hours provided by the hourly pay rate for each individual's support worker or workers. The amounts paid for regular and occasional workers have been calculated separately as these are often based on different hourly rates (eg. if people use more expensive agency workers to cover for their regular workers).

The amounts spent on wages are based on what support workers are actually paid rather than the payments people receive from a local authority or the ILF. This is particularly important as such payments often do not cover the full costs of support arrangements. For example, some local payment schemes include an allowance for support workers' holiday pay, while payments from the ILF do not. Similarly, while assessment for payments is typically based on a regular number of hours at a single rate of pay, additional hours (eg. for emergency cover) will often need to be purchased at a different rate. Consequently, basing the calculations on what people actually spend on their support gives a much more accurate guide to the full costs involved.

#### Revenue from charges to service users

As noted above, revenue from charges has been treated as a form of cost subsidy on local authority expenditure. Similarly, where service users are supplementing direct service provision with support purchased from independent sector agencies, any fees paid are also a form of subsidy on the cost of their support.

Consequently, where applicable, we have adjusted the gross costs of individual support packages on a case by case basis to reflect these charges. For example, if the direct weekly cost of an individual's support is £200 and that individual also pays £4 a week in charges, the net cost is calculated at £204. Similarly, where local authorities supplying cost data have included revenue from charges in their service budgets, this revenue has been added back onto their direct expenditure before calculating the unit costs for particular services. However, in cases where revenue from charges has already been counted in the calculation of unit costs for particular services, charges paid by individuals using these services have been ignored in order to avoid the charges being double counted.

#### Personal contributions to support financed by payment schemes

Support packages financed through the various payment schemes (including the ILF) also involve expenditure by both the funding authority and the disabled people receiving payments. Both services and payment schemes are, in effect, 'subsidised' by disabled people themselves. In the case of services, this subsidy is in the form of charges which are offset against local authority expenditure. As payment schemes very rarely cover the full cost of individual support arrangements, all or part of the shortfall has to be met by disabled people; consequently, such expenditure is also a form of subsidy towards the full costs involved.

However, there are important differences between these forms of subsidy which means they cannot be treated as directly comparable. First, charges are usually compulsory whereas a disabled person has some degree of choice about whether to subsidise a payment scheme, and by how much. (Although this only goes so far as exercising this choice may involve having to make do with less support). Second, charges are based on regular and fixed amounts but personal expenditure on support financed by payments schemes can vary from week to week. Third, some of the categories of additional expenditure relate to one off costs (eg. recruitment costs and payments towards personal assistants/helpers holiday expenses), or costs for which there may be no equivalent categories within service budgets (eg. expenses for personal assistants accompanying someone to a social or leisure event).

Consequently, additional costs involved in support financed by a payments scheme have only been counted if:

- a) such costs are incurred on a regular basis; and,
- b) there are broadly equivalent and quantifiable costs involved in direct service provision.

Provided these conditions are met, the costs involved have been averaged out to estimate 'typical' weekly costs for each category of expenditure. As with charges to service users, these have then been added in to the overall weekly costs of support arrangements on a case by case basis.

### Estimating the costs of informal unpaid support

As noted earlier, informal support forms a significant component of many people's support packages. This also has some important implications for the issue of costs. First, there are a range of both hidden and visible costs associated with informal support. The reduction in replaceable income for people providing such support on regular basis is clearly one of the most obvious costs involved. However, this also has less visible consequences in terms of reduced entitlement to contributions based social security benefits (particularly for women) and diminished savings capacity. Added to this, there are a wide range of both recurrent and one off costs which have a significant impact on the long-term standard of living of households containing unpaid helpers (Glendinning, 1992).

The complexities involved in trying to accurately measure all of the costs associated with informal support make it difficult to attach a definitive monetary value to the elements of unpaid support within the various support arrangements examined in this study. Nevertheless, it is important to make some form of adjustment to the unit costs in order to ensure that comparisons between the costs of the different arrangements are made on an equitable basis. This is particularly important where one type of support option routinely includes a greater proportion of unpaid support than another. In these circumstances, any cost comparisons between the options involved will be distorted by the fact that some support hours are valued at cost price while others are treated as having no cost value at all. This certainly applies to the comparison between payment schemes and direct service provision in this study as people using services rely on unpaid support to a much greater extent than those whose support is funded by direct or indirect payments.

This effectively means that service provision involves a higher level of 'subsidy' from unpaid support. This, in turn, introduces a systematic bias into the cost comparisons between the two options as service provision will almost invariably appear cheaper.

The main implication of this situation is that simple comparisons between payments and services will not be a particularly helpful guide to the real costs involved. Further, although the distorting effect of unpaid support particularly applies to the cost of service based support, support financed through payment schemes is also subsidised in the same way (albeit to a lesser extent). Consequently, a more useful approach is to consider the quantity and quality of support which can be purchased or financed for any given level of expenditure regardless of the availability of informal support.

For example, the cost of providing 20 hours personal assistance through a payments scheme can be compared to the cost of providing the same level of support by service provision. Alternatively, unpaid support hours can be costed at a notional rate and included with the paid elements of different support arrangements. Although this would still not necessarily reflect the true costs involved, it would help to illustrate what impact replacing this help with paid support might have on the overall costs of different support options.

For illustrative purposes, the unit cost comparisons presented in this report include both of these alternative adjustments for unpaid support. In the first set of costs unpaid support has been disregarded completely so that the relative costs of paid support can be compared directly. In the second set of costs, unpaid support hours have been included in the denominator for calculating hourly unit costs but have themselves been costed at a notional rate of £4.48 per hour. This figure is based on the value of an hours paid work by a care assistant in the formal labour market reported in the 1993 New Earnings Survey.

### Gross costs of support packages

The average gross cost of peoples' support is just over £300 per week. The costs of support packages for people using payments schemes and direct service provision for the bulk of their support are very similar at £303 and £293 respectively. The support arrangements for people using a combination of services and payments are noticeably more expensive, at an average of £531 per week (Table 7.1). These differences in the gross costs of support packages are statistically significant.

Over 60 percent of the payments group have support packages costing up to £300 per week, compared to 75 percent of service users and 40 percent of

those using a combination of services and payments. At the same time, there is considerably less variation in costs amongst the payments groups compared to service users or people who use a combination of payments and services. This is shown by the standard deviations (which indicates how much individual cases vary around the average) for the costs of support packages used by the different groups. While the standard deviation amongst the payments group is under £200, it is more than twice as large for the other two groups.

The higher costs for people who use mixed packages of support are due to a combination of factors. First, they use more hours each week than either the payments group or service users. Second, as they are more likely to be living alone they also have a lower proportion of their support provided by unpaid informal helpers. Third, as a consequence of these two factors, a higher proportion of their support is provided by either paid support workers or services. In addition, a higher proportion of people in this group use the district nursing service - which has a significantly higher unit costs than other services.

People who use a combination of services and payments also tend to have greater difficulty arranging cover and back-up for their usual support arrangements. Consequently, they are more likely to turn to agency care to meet this need which, again, tends to be more expensive than other forms of support. Again, this is obviously related to, the fact that they have less access to informal support. At the same time, these findings also suggest that spreading the provision of assistance between paid support workers and services is not particularly cost-efficient as it costs significantly more than packages based on payments or services on their own.

As noted in Chapter 5, although older and younger people in the sample use almost exactly the same number of hours support, the older group have a higher level of service use. This is also reflected in the gross cost of their support packages which is, on average, over £50 higher than the under 55 age group (Table 7.2).

The gross costs of weekly support packages are also around 30 percent higher amongst people who are living alone compared to those who live with others (Table 7.2). As with people who use a combination of payments and services, this is associated with people living alone having a much lower proportion of support met by informal sources. Consequently, their greater reliance on formal support (from either paid support workers or services) obviously has the effect of pushing up the gross costs of their support.



Comparison between people who receive payments from the ILF and local authority payments schemes shows that the former groups' support packages cost just over twice as much as the latter. This is mainly due to the fact that they simply use more support hours each week, although people using local schemes also have a higher proportion of their assistance provided by informal helpers.

The findings on the gross cost of support packages are also of interest in the context of the qualifying limits for the new Independent Living (1993) Fund. Amongst the sample as a whole, just over 1 in 5 people have support packages costing over £500 per week - which is the upper limit for payments from the fund. This proportion is lowest amongst service users and highest amongst the mixed group, more than twice as many of whom have support packages costing over £500.

The new Fund also requires people to be in receipt of services worth £200 in order to qualify for top-up payments. Amongst those using services or a combination of service and payments schemes, 56 and 20 percent respectively have support packages costing £200 or less and would not, therefore, be eligible to apply for any payments. Taken together with the findings on people with packages costing in excess of the £500 ceiling, this suggests that a large proportion of people in our sample would fail to meet the qualifying criteria for payments from the new Fund.

Table 7.1 Gross weekly costs of support packages

(Percent)	Payments group	Service users	Mixed group
Up to £100	19	37	0
£101 - £200	15	19	20
£201 - £300	27	19	20
£301 -£400	8	7	20
£401 -£500	8	4	7
Over £500	23	15	33
Totals	100	100	100
(Base)	(26)	(27)	(15)

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Mean	£303	£293	£531
Std. deviation	£198	£408	£476

Level of significance = 0.001

Missing cases = 2

Table 7.2 Gross weekly costs of support packages by age and living arrangements

	Mean weekly cost	Standard deviation	(Base)
Under 55	£347	£373	(58)
Over 55	£404	£365	(10)
Living alone	£399	£371	(31)
Living with others	£313	£371	(37)

Table 7.3 Gross weekly costs of support packages by source of funding (payments group only)

	Mean weekly cost	Std. deviation	(Base)
ILF	£399	£182	(26)
LA payments	£193	£158	(17)

### Comparison of unit costs

While it is important to quantify the actual weekly cost of various types of support options, gross costs are of limited use for comparing their relative cost-effectiveness. Given the variation in both the overall level of assistance involved in individual support arrangements and the proportion of assistance provided from paid and unpaid informal sources, it is impossible to make direct cost comparisons without some form of standardisation.

Consequently, we have also calculated standardised hourly unit costs which, basically, represent gross costs divided by the number of hours provided from each source. This calculation has been carried out on a case by case basis for each service used and the resulting totals aggregated to produce average unit costs for the various comparison groups. (See Appendix C for full details of the sources and calculations used).

Further, as explained in the first part of this chapter, the unit costs for support provided by formal paid sources (ie. services or directly employed support workers only) have been calculated separately from unit costs which include support provided by informal helpers. Excluding unpaid informal support from the denominator is important as this allows direct comparison between the costs of providing equivalent amounts of assistance through payments schemes and services. In other words, between what it would cost to provide one hour of assistance paid for through a payments scheme and the cost of providing the same hour of assistance by direct service provision.

However, as informal support clearly forms a significant component of many disabled peoples' support arrangements, it is also useful to look at alternative unit costs which include unpaid support in the denominator. This serves two functions. First, it allows us to examine the influence which unpaid support has on variations in the costs of different types of support arrangements. Second, by substituting a nominal cost for unpaid support, we can also illustrate the extent to which these different arrangements are 'subsidised' by informal helpers. This,

in turn, allows us to examine the potential cost implications of replacing assistance provided by informal helpers with support provided by, payments schemes or direct service provision.

Table 7.4 Hourly unit costs of paid support (including all overheads)

	Mean	Std. deviation
Payments group	£5.18	£1.31
Service users	£8.52	£4.21
Mixed group	£6.28	£1 .66

Level of significance = <0.001

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ILF payments	£4.53	£0.76
LA payments	£5.95	£1.42

Level of significance = 0.002

The findings indicate that there is a statistically significant difference in the unit costs of payments schemes and services. Support arrangements financed by direct/indirect payments are, on average, between 30 and 40 percent cheaper than equivalent service based support. The average hourly unit cost of support for people receiving payments is £5.18 compared to £8.52 for service users. As we would expect, the average unit cost for support arrangements based on a combination of payments and services falls in the middle of this range at £6.28 (Table 7.4).

It is also noticeable that there is a greater degree of variation in the unit cost of direct service provision compared to the cost of support financed through payments schemes. The standard deviation for the unit cost of service based support is over three times larger than that for payments group. This is partly due to the fact that some services are simply more costly than others wherever, and by whoever they are provided. At the same time, there is also a considerable degree of local variation in the costs of the same services in different local authorities. The unit cost of the home help service, for example ranges from £7.50 in Authority D3 to £9.58 in Authority D1 (which are both in outer-London), while the national average is £6.79 (see Table C1 in Appendix C).

This variation in the costs of different services is one of the factors influencing the relative unit costs of support provided through payments schemes and direct service provision. Some of the difference in the cost of these two options can also be accounted for by the relative costs associated with payments schemes operated by local authorities and the ILF. The average unit cost for support financed by local authority payments is £5.95, compared to £4.53 for support financed by the ILF. This difference is also statistically significant (Table 7.4). Despite these higher costs, local payment schemes are still 30 percent cheaper than direct service provision.

There is also a lot less variation in the unit cost of support financed by payments schemes. As we would expect, this is particularly true of support financed by the ILF as payments are based on fixed hourly rates. Rates for local schemes, on the other hand, are subject to the discretion of individual authorities. This is reflected in the standard deviations for the unit costs: £1.42 for local authority payments, compared to only £0.76 for ILF payments.

However, the main factor accounting for the difference between the unit costs of payments schemes and service provision is the administration costs and other overheads involved. Administration of local payment schemes adds, on average, between 9 and 15 percent to the total costs (Table 7.5). In contrast to this, with the exception of the home help service, administrative overheads for most local authority services add between 20 and 30 percent to the total costs (Table 7.6).

The lower overheads for the home help service raises some important issues about economies of scale. While local budgets for other services are typically around £500,000 or less, home help budgets generally run into millions of pounds. In Authority A, for example, the budget for this service is almost £11 million compared to only just over £500,000 for care attendant services; the overheads for these two services are 15 and 27 percent respectively.

Consequently, providing a service on a larger scale is likely to be associated with a significant reduction in the relative cost of administrative overheads.

The findings also suggest that similar considerations might apply to the administration of payment schemes as the local schemes with the fewest number of users also have the highest administration costs. For example, at the time our data was collected, the scheme run by Authority A had 70 users and overheads of 10 percent (including a grant towards the cost of guidance for users provided by the local CIL); in contrast to this, the schemes run by Authorities D2 and D3 had 7 and 14 users respectively and overheads of 15 percent. Further, the cost of administering payments by from the ILF - which had 22,000 clients - has been estimated at only 2.5 percent (Phillips, 1993).

It is also important to consider these findings on administration costs in the context of the current legal constraints on local authorities making direct payments. Where payments are made direct, people who receive these payments normally have responsibility for processing support workers' wages. However, some of the indirect payment schemes currently in operation involve local authorities taking responsibility for employment (including payroll) as a means of getting around the prohibition on paying cash direct to disabled people. Other schemes involve this task being contracted out to a third party agency. In either case, the costs of this additional responsibility inevitably contribute to an increase in administrative overheads.

The experiences reported by authorities participating in this study have also highlighted that the financial monitoring procedures involved with indirect thirdparty arrangements are often more complicated than the procedures involved in monitoring direct payments. (See comments from the descriptions of local schemes in Appendix B). Consequently, this requires a greater input of local authority staff time which, again, contributes to increased overheads.

Table 7.5 Administration costs for payments schemes

Proportion of total budget spent on administration/overheads

Authority A	10%
Authority B	9%
Authority C1	0%
Authority C2	nk
Authority C3	nk
Authority C4	nk
Authority D1	0%
Authority D2	15
Authority D3	15
ILF	2.5%

Notes:

- i) nk = administration costs missing or incomplete
- iii) See Tables C13 and C14 in Appendix C for full breakdown of local budgets

Table 7.6 Administration costs for local authority services

Average proportion of total budget spent on administration/overheads

Care attendants	31%
Day Care	31%
Home care/home help	15%
Independent Living Schemes/CSVs	22%
Meals on Wheels	17%

Note: i) See Tables C2 to C12 in Appendix C for full breakdown of service budgets

#### Costs met from personal income

As noted in Chapter 4, people receiving direct or indirect payments contribute between 15 and 18 percent of the total costs of their support packages from personal income. Some of this money represents social security benefits (eg. Attendance Allowance) which people are required to contribute to the cost of their assistance either by the ILF, or as a result of the charging policies of particular local authorities. The remainder represents the amounts which people contribute 'voluntarily' in order to make up any shortfall in hours, or to meet any running costs which are not covered by their payments.

The amounts people spend on direct costs (ie. support worker's and agency fees) have already been examined in Chapter 4. Data has also been collected on additional running costs and how these are distributed between different types of expenditure. The findings are summarised in Table 7.7 below.

The most significant costs are support workers' tax and National Insurance contributions (with almost 40 percent of people paying an average of £16 per week), and support workers' meals and refreshments (with almost 60 percent paying an average of £12 per week). Other notable costs include the cost of telephone calls involved in organising assistance, and workers' accommodation (although only a small proportion of people need to meet this cost).

There are also various types of occasional costs which some people might incur in addition to the regular costs described above. These include additional car insurance to cover use of peoples' cars by their support workers; workers' travel expenses; expenses for workers' accompanying people on social and leisure activities, or on holiday; and the costs of accidental damage to property (eg. spilling wheelchair battery fluid on carpets), although this may sometimes be covered by insurance. Some people also have expenses involved in using their personal assistants at work which may or not be covered by other sources such a grant from the Department of Employment.

As both the amounts spent and their occurrence are extremely variable we have not attempted to quantify these costs in average terms (although some respondents did give details of illustrative amounts). Further, it would in any case be difficult to arrive at a universally acceptable definition of which of these represent 'essential' costs, and which are 'optional'. For example, while no-one would disagree that tax and national contributions are an essential running cost, it is less clear whether the same would apply to entertainment expenses for a personal assistant accompanying someone to the cinema. One argument would be that restrictions on physical access make this an essential cost as disabled people do not have any choice about taking a personal assistant (other than staying at home). An alternative view might be that this is still a private leisure activity and should not, therefore, be counted alongside the costs of personal and domestic assistance.

This issue is part of the wider debate about the definitions of personal assistance and independent living proposed by the disability movement, and how these might differ from statutory definitions of community care. These wider questions cannot be addressed here. However, the most important practical issue in the context of a comparative cost analysis is that we try and ensure that we are comparing like with like. Consequently, as noted earlier in this chapter, any additional costs associated with payments schemes have only been counted if:

- a) such costs are incurred on a regular basis; and,
- b) there are broadly equivalent and quantifiable costs involved in direct service provision.

On this basis, costs such as telephone costs, third-party liability insurance, and employer's tax and NI contributions are counted as they all have quantifiable equivalents in service budgets. Entertainment and holiday expenses have been excluded as there are not any readily identifiable equivalents in service budgets. Workers' holiday pay, on the other hand, has been included (where applicable), as this would also be included as a direct staff cost in service budgets. (Holiday



pay is not listed as a separate item in Table 7.7, however, as it is already included in the calculation of expenditure on support worker's wages).

Recruitment costs are another item of essential expenditure for people employing their own support workers. These costs have been estimated on the basis of the amounts people spent on recruiting their current workers. In some cases, this only involved one lot of expenditure. However, some people have had to recruit more than once because their original choice left, or did not work out to their satisfaction. Most of this expenditure relates to the costs of advertising for workers, although incidental costs (eg. telephone, stationery, and postage) have also been taken into account.

Reported recruitment costs average £78, although people on local authority payments schemes tend to spend more than people receiving payments from the ILF - £81 compared to £66 (Table 7.8). This is mainly due to the fact that people using ILF payments are more likely to recruit from within existing informal support networks and, consequently, may not have advertised directly.

Table 7.7 Additional incidental and running costs associated with payment schemes

	Proportion incurring each type of costs	Average cost per week
Meals	58%	£12.00
Employer's tax and NI contributions	39%	£16.20
Telephone costs	34%	£5.90
Third-party liability/accident insurance	26%	£1.70
Entertainment expenses	26%	variable
Travel expenses	16%	variable
Refreshments	11 %	£0.70
Accidental damage to property	11 %	variable
Holiday expenses	11.1%	variable
Accommodation costs	8%	£22.50
Car insurance	8%	variable
Laundry	5 %	£2.00
(Base)	(38)	

Table 7.8 Average recruitment costs

ILF	£66
LA payment schemes	£81
All	£78

### Service charges

Service users and people who use a combination of payments and services also contribute towards the costs of their support through the payment of service charges.

Altogether, 69 percent of people in these groups are paying charges towards the cost of the services they receive. These mostly relate to the home help/home care service and services provided by independent sector care agencies. Charges for the home help/home care service range from £1 to £4.15 per hour, with the average being £2; people using this service are paying an average of £9.40 per week in total. Charges for services provided by independent agencies range from £1.80 to £9.50 per hour, with an average of £4.30; total charges for agency services average £16 per week (Table 7.9). Other charges mostly relate to meals provided at day centres or provided by the meals on wheels service.

Table 7.9 Service charges

	Proportion paying charges	Average cost per week
Home care/home help	31%	£9.40
Private care agencies	23%	£16.00
Day care	5 %	£5.40
Meals on wheels	5%	£1.10
Other services	5%	£2.90
(Base)	(39)	

Missing cases = 3

### The costs of informal support

Analysis of the gross weekly costs of support packages indicates that variations in these costs are sensitive to the relative amounts of assistance people receive from informal helpers. As different types of support options involve varying degrees of assistance from informal and formal sources, this will also have an effect on their comparative costs.

Using the value of personal assistance in the formal labour market as a guide, suggests that informal support represents a cost subsidy of approximately 4 percent on support arrangements for people receiving direct/indirect payments. Costing informal support at a nominal rate of £4.48 per hour would add £168 to the average weekly cost of support packages for people in the payments group, and £128 to the cost of support packages based on a combination of payments and services (Table 7.10).

The impact of informal support on the costs of service based support arrangements is considerably larger. Costing informal support hours at the same nominal rate adds as much as £281 to the average costs of service users support packages - an increase of 29%.

Another way of representing this form of cost subsidy is to look at the effect of including informal support hours (costed at the nominal rate of £4.48) in the denominator used to calculate standardised unit costs. While this would reduce the unit cost of support arrangements for the payments and mixed groups by around only 20 pence, the unit cost for service users would be reduced by almost £2 per hour (Table 7.11).

As shown in Table 7.10, these changes in the relative costs of the different types of support arrangements are almost directly proportional to the amounts of informal support used by each of the main comparison groups. A similar trend can be seen in the comparison between the costs of support arrangements for older and younger groups and between people who live on their own and with others.

First, the over and under 55 age groups have an almost identical proportion of their assistance provided by informal helpers. Consequently, costing this informal support at a nominal rate also increases the gross costs of their support arrangements by almost exactly the same amount (Table 7.12).

Second, people who live on their own have a far smaller proportion of their assistance provided by informal helpers compared to those living with others; costing this informal support at a nominal rate would increase the gross costs of their support by less than £80, whereas the increase for people living with others would be over £300 (Table 7.12). Further, as people who live on their own use so little informal assistance, the impact of including informal support in the denominator for calculating unit costs is negligible as this only reduces the cost by less than one percent (Table 7.13).

The same pattern emerges if we compare the costs of support arrangements financed by local payments schemes and the ILF. As people using local payment schemes have a larger proportion of their assistance provided by informal helpers, the effect of costing this assistance at the nominal rate would be to increase the unit costs by around 6 percent, compared to 2 percent for the ILF group. The increase in gross costs would be lower, however, as people on local schemes use fewer hours overall (Tables 7.14 and 7.15).

The main qualification to this trend is that the change in unit costs for the payments and mixed groups is almost identical, despite the fact that the latter use fewer hours of assistance from informal helpers. As noted earlier, this can be accounted for by the fact that they are more likely to use agency care. As agency care tends to be more expensive than using directly employed support workers, this effectively offsets some of the cost subsidy represented by informal support.

Table 7.10 Estimated costs of informal support

(Mean)	Payments group	Service users	Mixed group
Proportion of hours provided by unpaid helpers	39%	57%	26%
Weekly cost of informal support <sup>1)</sup>	£168	£281	£128
Gross total weekly costs (adjusted)	£472	£575	£659

Costed at £4.48 per hour

Table 7.11 Effect of informal support on unit costs

(Mean)	Payments group	Service users	Mixed group
Unit cost including informal support	£4.96	£6.61	£6.05
Unit cost excluding informal support	£5.18	£8.52	£6.28
Percentage change in unit cost	+ 4.4%	+ 28.9%	+ 3.8%

Table 7.12 Estimated costs of informal support by age and living arrangements

(Mean)	Under 55	Over 55	Living alone	Living with others
Proportion of hours provided by unpaid helpers	43%	41%	13%	58%
Weekly cost of informal support"	£212	£205	£79	£303
Gross total weekly costs (adjusted)	£559	£609	£478	£616
Costed at £4.48 per hour				

Table 7.13 Effect of informal support on unit costs by age and living

arrangements (Mean)	Under 55	Over 55	Living alone	Living with others
Unit cost including informal support	£5.81	£5.81	£6.23	£5.55
Unit cost excluding informal support	£6.77	£6.47	£6.28	£6.68
Percentage change in unit cost	+ 16.5%	+ 11.4%	+ 0.8%	+ 20.4%

Table 7.14 Estimated costs of informal support by source of funding

(payments group only) (Mean)	ILF	LA payments
Proportion of hours provided by unpaid helpers	35%	52%
Weekly cost of informal support"	£205	£126
Gross total weekly costs (adjusted)	£603	£319
Costed at £4.48 per hour		

Table 7.15 Effect of informal support on unit costs by source of funding (payments group only)

(Mean)	ILF	LA payments
Unit cost including informal support	£4.43	£5.59
Unit cost excluding informal support	£4.53	£5.95
Percentage change in unit cost	+ 2.3%	+ 6.4%

Do payments schemes represent value for money?

The cost-effectiveness of any particular support options relates to both quality and cost. A cost-efficient intervention or mode of support can be defined as one which maximises the outputs or benefits achieved from a given level of resources or, alternatively, one which minimises the resources required to achieve a specified level of outputs or benefits.

In the context of this particular study, the 'resources' we have measured are the costs required to deliver a given level of assistance through direct/indirect payments or service provision (or a combination of the two). The principal 'benefits' which we are concerned with are those relating to:

- a) how well particular support options satisfy people's needs (as measured by factors such as reliability, flexibility, and the degree of choice and control they offer); and,
- b) the wider benefits which follow from the degree of efficiency with which these needs are met (eg. enabling people to take up employment, the impact on family and members and so on).

The production of these benefits (ie. the meeting of needs) is the principal output which we are interested in. There is also an important distinction to be made between intermediate and final objectives or, simplifying slightly, between means and ends. For example, by itself, providing a home help or a personal assistant is only an intermediate objective (or means); improving the quality of people's lives, giving them security and control, or addressing their requirements for physical assistance are all final objectives (ie. ends). It follows that these kind of final objectives could potentially be met by a variety of alternative means. The main question we need to ask; therefore, is which of

these intermediate objectives (ie. direct/indirect payments or services) represent the most cost-effective means of producing such benefits for disabled people.

However, it is important to emphasise that the analysis produced by this research does not necessarily allow us to make definitive statements about cost-effectiveness as, clearly, we have not measured all of the outputs and benefits which might be involved. Rather, the main aim has been to examine the relative merits of payments and services by weighing up the quality of a limited (albeit important) range of benefits against the costs involved in producing them.

Further, it is also important to bear in mind that most of the people in our sample use informal support (ie. from family, friends or volunteers) in addition to either paid workers or services. It is difficult to assign specific benefits to particular components of these overall support arrangements on a definitive basis as - to a greater or lesser degree - they are all interdependent.

This particularly applies to support arrangements based on a combination of payments and services. In these cases, a definitive analysis of cost-effectiveness would also need to measure the interdependence between benefits associated with the payments component and those associated with the service component. While it would be quite feasible to carry out this kind of multivariate analysis, this has not been possible within the scale of this particular research.

However, even with these qualifications in mind, the combination of findings on the quality of different support arrangements and their relative costs clearly indicate that direct/indirect payments are a cost-effective option for meeting disabled peoples' support needs.

First, we have seen that payments schemes meet a wider range of assistance needs than service based support, and people receiving payments have fewer unmet needs than service users.

Second, the findings also indicate that people using payments schemes have more reliable support arrangements and experience fewer problems with organising suitable support than service users.

Third, people receiving payments have higher levels of satisfaction than service users on a variety of measures. We have also seen that payments schemes offer a greater degree of choice, control and flexibility than direct service provision - all of which are not only highly valued by disabled , people themselves, but are also central policy objectives for community care.



Further, although service users are generally satisfied with the qualities of individual support staff, they often remain critical about the lack of choice and control they have over the way in which services are organised. For people using payment schemes, on the other hand, being able to direct how, when, and by whom their assistance is provided is typically the most valued feature of their support arrangements. There are also some relative disadvantages associated with the level of responsibility which this degree of control entails. However, most people feel that these are far outweighed by the advantages.

Finally, the comparison of unit costs presented in this chapter indicates that support arrangements funded through payments schemes are between 30 and 40 percent cheaper than direct service provision.

Taken together with the findings on the relative quality of these two options, this clearly indicates that direct/indirect payments maximise the benefits for disabled people at cheaper cost. Further, although well run services can offer some of the same benefits as payments schemes, this is generally at a higher cost.

In other words, every pound spent through a payments scheme not only goes further than a pound spent on services, but also purchases assistance of a higher quality. According to the definition of cost-effectiveness outlined above, therefore, direct/indirect payments clearly represent better value for money than direct service provision.

## 8. CONCLUSIONS AND POLICY IMPLICATIONS

The last three chapters have demonstrated that payment schemes are associated with higher quality support than services. In particular, the findings on the comparative costs have also shown that payment schemes are not only a cost-effective means of meeting disabled peoples' practical support needs, but often represent considerably better value for money than direct service provision.

However, there are a number of practical, administrative and legal issues which would need to be addressed if direct payments are to become more widely available in the future. Although this research was never intended to include a detailed examination of the feasibility of providing direct payments, it has nevertheless highlighted some important issues about how payments schemes currently operate in practice. This final chapter discusses the implications of the findings for the policy issues outlined at the start of the report and considers the lessons which might be drawn for the further development of payments schemes in the future.

First, we consider how payments schemes fit in with current community care arrangements and their potential as a means of enabling local authorities to deliver the key objectives of this policy.

Second, we examine the issue of how payment schemes are administered by local authorities and the relative advantages and disadvantages of local schemes compared to a universal system of payments like the ILF.

Third, we discuss the related issue of how eligibility for direct payments might be defined. In particular, the issue of whether or not it is possible to meet the demand for universal eligibility while still retaining the advantages of locally run payment schemes.

Fourth, we look at the implications of the findings for a variety of employment related issues such as meeting PAYE requirements; employer's liability; ensuring reasonable terms and conditions for support workers; and advice and support for disabled people employing their own support workers.

Fifth, we consider the issue of the potential demand for direct payments and, in particular, the demand for 'high cost' payments for people who might otherwise face the possibility of residential care.

Finally, drawing on the key findings from the study, the chapter ends with some general conclusions about the advantages and disadvantages of payments schemes as a means of meeting disabled peoples' support needs.

Payments schemes and community care

As noted in Chapter 2, one of the government's objections to direct payments is that the new community care arrangements already offer the means of delivering a high degree of choice, control and flexibility in disabled peoples' support arrangements. Consequently direct payment are considered to be unnecessary. Further, there are also concerns that adding to local authorities responsibilities may even be counter-productive as this could divert effort and resources away from other groups and service areas.

Local Authorities, on the other hand, have argued that enabling them to make direct payments would make it easier rather than harder to offer disabled people greater control over their support arrangements. Also, that, by enabling disabled people to exercise their own choices, direct payments would encourage the development of innovative forms of support provision. Although, in some cases this might involve a combination of directly delivered services and self-recruited support workers.

The findings from this research certainly tend to support this view. Although some genuinely user-orientated services are able to offer a high degree of choice and flexibility, they are rarely able to offer the same degree of direct control as payments schemes. As a consequence of this, the degree of choice offered to service users also tends to be dependent on the discretion of particular providers. Support arrangements controlled by disabled people, on the other hand, are not subject to this qualification as workers are directly answerable to the person for whom they are providing assistance.

Another of the wider benefits of payment schemes is that they often enable people to secure support for times when the availability of services is generally extremely restricted. A recent survey of Directors of Social Services, for example, highlighted that more than half of local authorities had only restricted availability for weekend and nighttime support, and a quarter could not provide any nighttime cover at all (Thompson, 1993). This is also borne out by the experiences reported by service users in this study. People using payment schemes, on the other hand, generally have considerably less difficulty in arranging cover at these times. So, by allowing disabled people to secure reliable support the payments option also provides local authorities with a means of meeting needs which they might not be able to otherwise.

The question of whether or not direct payments would divert resources away from other clients and service areas is more complex. Part of the answer is dependent on assumptions about the potential demand for direct payments (which is discussed further below). In addition, we also need to consider the range of needs which payments and services are able to meet, as well as the costs involved in providing comparable amounts of support.

Supporters of the direct payments option suggest that all they are proposing is for people who qualify for services to be offered the choice of having a cash equivalent to enable them to purchase their own support; consequently there would be no change in the net expenditure involved. However, the findings on the ways in which people use payments suggest that this proposition is a slight oversimplification. As we have seen, while all of the people in this study report a similar range of needs, payments schemes tend to leave fewer gaps in basic assistance needs compared to direct service provision. As a result, once people's basic needs have been met, there is also a tendency to look for ways of using personal assistance to meet a broader range of needs.

Although this is clearly a very positive aspect of enabling people to control their own support arrangements, people using services are unlikely to be offered the same range of benefits. Consequently, investing the same resources in direct payments or services would not necessarily produce the same outputs as

payments might be used in different ways. This, in turn, points to the crucial issue of how needs are defined, and by whom.

In the specific context of debates about direct payments the issue revolves around the difference between the definitions of independent living and community care. The essence of independent living, as defined by the disability movement, is that people should be enabled to define their own needs and how these should be met. The concept of community care also includes maximising choice and flexibility as one of its central objectives. Under community care, however, needs are still essentially defined by enabling authorities. Further, as any form of community care provision is subject to the availability of resources, the process of assessing and defining also inevitably involves a process of rationing these resources between competing claims.

In one sense, allowing disabled people to have complete discretion over how to use direct payments would be counter to this function of community care (although it would, of course, be entirely consistent with the goal of independent living). Further, even though many existing payment schemes do include certain constraints on how the money can be used (eg. some restrict the use of payments to personal assistance only), these are not applied consistently and are, in any case, difficult to enforce definitively.

On the other hand, the fact that people who use payment schemes often depend on the assistance purchased for their survival means that there is an inherent (and powerful) incentive for them to use this money effectively. If they may sometimes choose to purchase alternative types of assistance which are not easily available through service provision, this would normally be because this is seen as more appropriate to their particular needs. So, putting the issue the other way around, it could be argued that - rather than diverting resources away from other areas of need - direct payments actually represent a more efficient way of targeting limited resources.

The other important question is whether or not providing cash in lieu of services would involve any change in net expenditure. As discussed above, people who use existing payment schemes tend to use this money to purchase a wider range of benefits than those available to service users. At the same time, we have also seen that this sometimes involves people having to supplement their payments with personal income in order to purchase additional assistance (eg. weekend cover). However, this has been taken into account in calculating the unit costs (see Chapter 7), and these are still considerably cheaper than the costs of equivalent service based support.

Consequently, there is no evidence from this study to suggest that offering cash in lieu of services would lead to resources being diverted from other priority areas as a result of an increase in expenditure. If anything, the lower costs involved suggest that people receiving payments would often be able to make the same resources go further than they would if they were using direct services.

#### Local authority management of payment schemes

The findings from this research indicate that, with the important exception of difficulties in establishing eligibility, local payment schemes have a number of advantages over a centralised payments scheme like the ILF. In particular, the localised nature of such schemes means that people using them are far more likely to have access to sources of advice and support to enable them to manage their support arrangements more efficiently. Although this additional support does add to the cost of such schemes, the benefits for people using them suggest this expenditure does represent value for money. It also appears that the higher pay rates associated with local schemes also give people greater purchasing power which, in comparison with the ILF, increases the degree of flexibility they have in organising their support.

However, the findings also suggest that the various mechanisms which local authorities use to get around the legal obstacles to making direct cash payments often appear to create sources of inefficiency and/or inequity which might otherwise be avoidable. In many cases, the greater complexity involved in monitoring procedures and processing payments also lead to an increase in administrative overheads. In the case of schemes which are linked to the new ILF (ie. the 1993 Fund), there are added complications arising from the way in which the new fund has been set up (ie. inconsistency in calculating unit costs for services, and difficulties meeting the £200 threshold).

In this sense, local authorities who wish to enable disabled people to have more control over their personal assistance arrangements, are being hampered by the present legislation. It is, perhaps, not surprising that some are unable to offer disabled people the degree of choice and control that they had intended. Nevertheless, despite these structural difficulties, the study has also identified elements of good practice and a comparatively high degree of user satisfaction at a local level. This suggests that - despite these restrictions - some local authorities at least are clearly capable of operating payment schemes in ways which are both efficient, and which give disabled people the kind of support arrangements they want.

The further development of local payment schemes will obviously depend on whether any changes to the legislative framework encourage or deter local

authorities from moving in this direction. Clearly, the vast majority of local authorities support the call for changes in the law which would enable them to make direct cash payments to people who want and could benefit from this option (see Chapter 4). At their AGM in 1992, the Association of Directors of Social Services also passed a motion calling on the government to empower local authorities to make direct payments with the Chair of the ADSS Disabilities Committee describing the case for such a move as - *'overwhelming in terms of effective financial management, best community care practice, empowerment, coal face' quality control, on-site monitoring, and sound commonsense'*.

However, although most local authorities are clearly in favour of the principle of direct payments, the enthusiasm which has been expressed by bodies like the ADSS may need to be interpreted with caution at this stage.

As noted in Chapter 2, one of the government's main concerns about sanctioning the direct payments option is that this would increase the administrative responsibilities of local authorities at a time when they are still attempting to get to grips with the new community care arrangements. There is some justification for this view as local authorities themselves expressed similar concerns when the idea of transferring the ILF caseload to local authorities was first raised in 1990 (Lunn, 1990).

Similarly, it is doubtful whether the majority of local authorities would remain as enthusiastic about direct payments without some kind of assurances about a ring-fenced budget for payment schemes. A recent survey of Directors of Social Services found that nearly half expressed doubts about the funds diverted from the ILF via the community care special transitional grant being sufficient to meet assessed needs, and seven out of ten were concerned about the possibility of budget restrictions forcing disabled people into residential care (Thompson, 1993).

This is not to say that local authorities would be unwilling to translate their good intentions regarding direct payments into practice. However, it is clear that, without a greater degree of clarity about how community care funding would be distributed between cash payments and services, it is likely that take up of this option may be much slower than their expressions of support for direct payments might suggest.

Evaluation of the operation of the ILF has also shown that the level of applications to the Fund from different local authority areas has always been very uneven. It is unclear precisely how much of this variation has been due to differences in the prevalence of disability, the adequacy of existing service

provision, or the levels of awareness of, and dissemination about, the Fund in different areas. At the same time, it is clear that the ILF's attempts to promote take-up by targeting information at SSD's and Health authorities has produced very mixed results (Kestenbaum, 1993).

The current uncertainty over the legal status of various indirect payment schemes has also had an impact on take-up. Additionally, the fluctuating commitment by local authority finance and legal departments to the schemes has mitigated against them being formally promoted within a number of authorities.

There is also a considerable degree of local variation in eligibility criteria. Some schemes are aimed at people leaving residential care; some at people with a high level of personal assistance needs; some are based on, or linked to, eligibility for ILF payments; and some are intended for people for whom services are considered inappropriate. Although these criteria overlap, they are all different and are not always applied consistently in any case. In addition, procedures for processing applications to local payment schemes are often carried out in an ad hoc and informal fashion. Again, this variation in the availability of, and access to, payments has also had a negative impact on take up.

Clearly most of these kinds of obstacles to the development of payment schemes would be removed simply by changing existing legislation to allow local authorities to make direct cash payments. However, this stills leave a number of specific administrative issues which would need to be addressed.

First, there would need to be appropriate procedures for ensuring accountability in the way in which payments are used. Second, local authority concerns about the distribution of community care budgets between payments and services would also need to be resolved so that resources could be allocated on an equitable and efficient basis. This, in turn, would require appropriate procedures for assessing peoples' needs. Third, the allocation of payments on an equitable basis would also require agreement on the adoption of suitable eligibility criteria. These three issues are discussed below.

### Ensuring accountability

Statutory authorities who have responsibility for allocating direct or indirect payments obviously need to be satisfied that such payments are used responsibly. Most importantly, they need to be satisfied that the money is not being used for purposes other than those for which it is intended.

This raises some important questions about how such accountability can be maintained without becoming unnecessarily bureaucratic or intrusive. However, as Craig (1992) points out, it is by no means clear that this dichotomy can be easily resolved as there is an inherent tension between individual control which would promote choice and autonomy, and public accountability in the interests of planning and efficiency (Craig, 1992).

Although some local payment schemes have fairly restrictive rules about the kinds of assistance which people are supposed to purchase, others adopt much looser or broader criteria which enable them to offer a high degree of flexibility. For example, in addition to personal and domestic assistance, some schemes allow people to purchase help with home maintenance or gardening, while others include assistance at work, and assistance which enables people to participate in social and leisure activities.

This kind of flexibility is precisely why payments schemes are highly valued by the people who use them. There is a danger, therefore, that overly-bureaucratic controls on the way in which the money is spent could jeopardise this flexibility by forcing people to demarcate their assistance needs into arbitrary accounting units.

Nevertheless, local authorities still have to account for this expenditure in order to meet their own responsibilities for audit. While they may have some discretion about the level of detail on how the money is spent, they must - at a minimum - be able to satisfy auditors that:

- a) the destination of the money (ie. who they have given it to) is clearly recorded; and,
- b) it has been used to purchase assistance (ie. that whoever they have given it to has not absconded with public funds).

One of the government's (and the treasury's) concerns about direct payments is that it may be difficult to establish adequate procedures for ensuring this level of accountability. Although we have not been able to examine this issue directly, the research has at least provided some evidence on the kind of procedures adopted in existing schemes.

In some of the schemes we have looked at, for example, local authorities deal with this issue by taking on the role of paymaster; people using the schemes are required to provide monthly timesheets signed by their workers before subsequent payments are released. Others adopt similar measures by asking people to provide invoices from any care agencies they have used to purchase assistance from. Some require people receiving payments to set up a dedicated



bank account - which is available for audit at any time - and provide monthly statements of withdrawals. In some areas, further checks are provided by the requirement for people to supply names and national insurance numbers of their support workers to the Inland Revenue and/or DSS. (People receiving payments from the ILF are now also required to supply this information). Some of the authorities participating in the research also gave instances of people whose payments have been stopped for failing to comply with these requirements.

Disabled people interviewed for this study did not raise any major concerns about most of these kind of measures. Although they do add to the effort involved in organising their support arrangements, they are generally seen as being a fairly reasonable requirement or, at least, a necessary evil in order for them to maintain the benefits of receiving payments. The most important exception to this is the requirement to pass on personal details about their support workers.

In addition, as some of the people using these schemes pointed out, the fact that they depend on continuing to receive payments for their survival means that they also have a very strong personal incentive to ensure that the money is used prudently, and for the purpose it is intended.

### Defining eligibility for direct payments

The lack of consensus over how eligibility to cash payments could, or should, be defined remains a significant obstacle to the introduction of a general system of direct payments.

The issue of eligibility (at least as far as the Government are concerned) cannot be considered separately from the overall level of resource allocation. In practice this means that there is always an incentive to define needs and eligibility according to the level of resources available. While this is obviously a perennial issue for the allocation of welfare resources in general, it does create particular difficulties for establishing eligibility criteria for direct payments in the context of the new community care arrangements.

The fact that local authorities have been handed responsibility for ensuring delivery of community care has effectively translated the question of resource allocation into a series of local decision making processes. In practice, this means that access to services becomes dependant on the ways in which eligibility is defined in particular local authorities, as well as the efficiency with which they manage their local community care budgets.

The main difficulty as far as direct payments are concerned is how this situation can be reconciled with the disability lobby's desire for payments to be allocated on an equitable basis, as of right. It is also largely incompatible with the preference for a single statutory source of funding as a means of ensuring that all disabled people meeting the same eligibility criteria would be guaranteed to receive the same level of payments.

As noted earlier, apart from the fact that payments for personal assistance are not universally available, there is already a considerable degree of inconsistency in the way eligibility criteria have been applied in the different local payment schemes which are currently available. Further, these schemes also vary in the extent to which they give disabled people control over how the payments can be used.

This is not to say that local administration of direct payments is inherently inequitable. However, it does clearly suggest a need for greater clarity on how eligibility should or could be defined. One option might for any future changes in legislation to include some provision for universal eligibility criteria which all local authorities would be required to apply. Although, to a certain extent, this would seem to conflict with the devolutionary principles of the community care reforms, there are clear precedents for such a system as local authorities already have responsibility for administering certain universal statutory payments. Further, the arrangements for the new ILF also require local authorities to apply a universal set of eligibility criteria in making applications for cash payments to the Fund.

At the same time, there is a potential obstacle in that universal eligibility may reduce the autonomy and flexibility which is characteristic of best practice in local payment schemes. Clearly, this is an issue which needs to be given further consideration by government, local authorities and the disability movement itself.

A further difficulty with establishing universal eligibility criteria for direct cash payments is that, inevitably, such payments would need to be quite tightly targeted in order to allay government concerns about controlling costs. Current trends in community care policy are increasingly based on targeting resources on people who are defined as being in the greatest need. In the case of the ILF, for example, this has essentially involved basing eligibility around the extent to which there is a risk of someone entering residential care unless they are provided with sufficient support to enable them to live in the community.

The means testing involved this kind of allocation system can also create a 'catch 22' situation for people who are, or wish to be, in paid employment. Some

people will require personal assistance to enable them to work; however, earnings from employment will normally reduce the amount of personal assistance funding they receive or, in some cases, may even disqualify them from payments altogether.

Whatever the precise eligibility criteria for direct payments might be in the future, it will also be necessary to devise appropriate mechanisms for establishing access to payments. The two basic options which are already available would be to link eligibility to community care assessments or, alternatively, to operate a centralised assessment similar to the arrangements for dealing with applications to the ILF.

However, there are important differences between the two options. On the one hand, local authorities are not only obliged to carry out assessments for anyone requesting them, they also have a statutory obligation to provide services to anyone assessed as needing them. In contrast, the ILF Trustees have always had the option of restricting eligibility in order to balance demand with the resources available. In other words, the essential difference between these basic options is that former is based on statutory eligibility, while the latter is based on discretionary eligibility.

This distinction obviously has a particularly important bearing on the issue of equity as statutory eligibility is clearly more consistent with the disability lobbys' desire for direct payments to be made available, as of right, according to need. However, whatever procedures might be adopted in the future, it would clearly be very difficult to have a dual system of national assessment of eligibility for payments, and local assessment of need for services. Either both would have to operate on the basis of local discretion, or both would have to be based on national and structured criteria. The important point is that an individual's total need would have to be assessed - by one or other of these methods - before any decision (either by the enabling authority or the disabled person) could be made about whether to meet this need with cash or services.

Again, this is not to say that direct payments could not be incorporated into existing community care arrangements. At the same time, it is fairly clear that there are a number of potential tensions between universal eligibility and local discretion and flexibility which would need to be addressed in future policy developments.

### Employment issues

The research has highlighted a number of important issues relating to the employment of personal assistants with funding from payment schemes. First, it

is clear that most disabled people who receive payments for personal assistance are acting as responsible employers. However, a combination of the level of funding available, restrictions on how the money can be spent, PAYE and benefit rules and, most importantly, the complications involved in indirect third party payments schemes, means that employment conditions are sometimes less than ideal.

First, there is a lack of clarity on the employment status of personal assistants recruited under the various payment schemes which are currently operating. Some are recruited by individual disabled people but remain employees of either the local authority or, in some cases, a contracted care agency. Some are employed directly by disabled people who assume responsibility for administering PAYE, while some have their PAYE administered by a third-party arranged by the local authority as part of their local payments scheme. Others are acting as self-employed even though it is doubtful that they would be recognised as such by the Inland Revenue and DSS.

The degree of variation which currently exists can lead to confusion for both disabled people and workers and is often a hindrance to recruitment. The situation also means that disabled people are not always able to offer their personal assistants the kind of stable and equitable employment conditions which are necessary for the security of both parties.

Second, the complicated employment arrangements on some indirect payment schemes can compromise the level of accountability which workers have towards disabled people they are working for. Similarly, the use of agency staff in some schemes can have an influence on the level of workers' commitment to individual disabled people.

Third, the lack of clarity over employment status also raises important questions about exactly who is liable for ensuring compliance with minimum health and safety requirements for support workers which have yet to be addressed.

Local authorities' inability to make direct payments has clearly muddied the waters as far as employment relations are concerned. Although most people have been able to resolve these potential difficulties by negotiation, they do appear to represent an unnecessary obstacle which the simpler direct payment option would avoid.

### The employer-employee relationship

The independent living movement has always stressed that by employing personal assistants directly, disabled people can be sure of retaining complete

control over the quality and form of assistance provided. Being an employer means that they can use the ultimate sanction: terminating employment.

However, not all disabled people want all the responsibilities of being an employer. In particular, even experienced personal assistance users may have reservations about having to operate support worker's PAYE as this can be both complicated and, most importantly, time consuming. Consequently, unless they have access to a payroll service, people who want to avoid some of these extra responsibilities while still retaining control over their support workers tend to follow one of three options: organising their support arrangements in such a way that workers' earnings remain below the threshold for tax and National Insurance; using self-employed workers; or, paying their workers cash in hand. Although each of these options has certain advantages, there are also a number of important disadvantages and these are outlined below.

**Limiting support workers' hours:** Ensuring that support workers' earnings stay below the tax and National Insurance threshold means that each worker can only be employed for a limited number of hours a week. While this kind of arrangement is entirely legitimate (ie. from the point of view of the Inland Revenue and DSS), it can be difficult to maintain in practice.

For example, people who require a high level of regular assistance will often need to employ several workers; therefore, the advantages of avoiding responsibility for PAYE has to be weighed against the extra workload in organising and managing this arrangement. Further, people who require less assistance on a regular basis may have occasional periods when they need their workers to work extra hours (eg. when they are unwell or on holiday). Therefore, there may be temporary periods when they either become liable for PAYE or, alternatively, have to find additional workers to spread the extra hours between.

**Using self-employed workers:** Some employers designate support workers as self-employed - and may even ask them to sign a statement to that effect. However, such a declaration has no legal force, and it is clear that the Inland Revenue are becoming increasingly intolerant of such arrangements. If a support worker is working for a particular disabled person on a regular basis, and this constitutes his or her only or main employment, it is unlikely that self-employed status would be accepted by either the Inland Revenue or the DSS.

Despite this, the practice of designating workers as self-employed is used, not only by some individual disabled people, but also by private agencies and local authorities. Some local authorities use self-employed support workers as a means of getting around the legal restrictions on paying cash direct to disabled

people. Private agencies adopt the same practice as a means of avoiding liability for VAT. However, as we have already noted, some local authority payment schemes which include this practice have run into trouble with the Inland Revenue who have ruled that the workers are employees of either the authority themselves, or the disabled people with whom they are working.

Another potential problem with this option is that self-employed workers (even if their status is accepted as legitimate) may have very limited terms of employment. For example, they do not have any formal entitlement to holiday or sick pay - although there may often be an informal arrangement with the disabled person they are working for. Similarly, they are not formally entitled to any form of written contract of employment and, even though they may have an agreement with the people they are working for, this is unlikely to have very much force in law.

Paying 'cash in hand': The most obvious disadvantage of paying support workers cash in hand (ie. without operating PAYE) is that it is illegal. Both the Department of Social Security and the Inland Revenue are becoming much more vigilant and, increasingly, taking action to deter people from operating in this way. For example, the Independent Living (Extension) Fund are now required to collect details of names, addresses and national insurance numbers for all workers used by people receiving ILF grants and, if requested, to pass this information on to the DSS.

Apart from the risk of being fined (or worse), the fact that payment arrangements are being scrutinised can also affect peoples' ability to recruit and/or keep their support workers. This is because, as with any low-pay occupation, the labour market for personal assistance workers often tends to be semi-informal in nature (Lakey, 1994). Some workers rely on receiving cash in hand as the only way of making the work economically viable. Consequently, wage levels may not be sufficiently attractive after the deduction of tax and national insurance contributions.

At the same time, this situation is also a reflection on the funding levels for payments schemes and the pressure this creates for personal assistance users to keep wages low or face a reduction in their hours. Similarly, if they have been assessed for less hours than they require, some people may attempt to get more hours out of their allocation either by reducing their worker's hourly pay rate, or by not paying tax and NI contributions. This is particularly the case with the ILF, as payments from the fund do not include any allowance for tax and national insurance contributions or holiday pay. Local authority schemes also vary in the extent to which payments reflect these costs although, on average, hourly rates are still noticeably higher than those set by the ILF.

Consequently, although a small number of individuals appear to be acting illegally in the way they handle workers' pay, this would appear to be mostly out of necessity rather than any deliberate attempt to defraud. As we have already seen, the majority of the people receiving payments in this study want to be able to pay support workers higher wages and/or increase their hours. Further, over half of those who are not paying their workers tax and national insurance contributions would prefer to do so.

### Enabling responsible employment practice

The extent to which personal assistance users are able to negotiate their way through the potential difficulties associated with employing their own workers is very much dependent on the quality of advice and support they receive when organising their support arrangements. This, in turn, leads on to the wider issue of the kind of mechanisms for enabling responsible employment practice which can be built in to payment schemes.

Both the ILF as well as some of the local schemes we have examined appear to treat this as essentially a matter for individual disabled people; consequently, disabled people are offered virtually nothing in the way of advice or information on employing support workers. Some schemes involve guiding people receiving payments towards sources of advice such as a local disability organisation or a Centre for Independent Living, but do not provide any other back-up.

Further, although there are mechanisms in place to assist people with handling support workers' wages (eg. simplified deductions schemes), we have not found any evidence that these are being widely promoted, either by the ILF or by local authorities.

However, some local authorities have gone much further than others in helping to enable disabled people to act as responsible and effective employers. Some (eg. Authority A) have access to the expertise of a Centre for Independent Living built in to their payment schemes, with additional funding to ensure that this is available to all who need it. Similarly, one or two (eg. Authority D3) pay for people on their payment schemes to go on independent living skills training courses covering all aspects of managing their own support - including dealing with tax and NI. Others also offer practical assistance by establishing local payroll services to relieve people of the need to manage PAYE for themselves.

As we have seen, the availability of this kind of advice and support is reflected in the extremely high levels of satisfaction amongst people using these schemes. Further, although this does add slightly to the overhead costs of these schemes,

the added benefits in terms of enabling people to manage their support more efficiently indicates that this is a cost-effective use of resources.

### Potential demand for direct payments

Although this study has not attempted to provide any objective measure of demand for payments for personal assistance, some indication can be provided by the experience of local authorities which have actively encouraged take-up. This suggests that take-up has, so far at least, been very low.

However, it is also clear that demand in most local authorities is restrained by a combination of lack of awareness, availability of funds, and uncertainty about the legal status of payment schemes (which prevents some authorities from promoting their schemes as actively as they might). Further, the experience of the original Independent Living Fund has shown that take-up is likely to increase as more people become aware of the availability of this option for meeting their support needs.

This is also reflected in the findings from this research. Amongst the group of service users in the study, two-thirds were unaware of the existence of a local payments scheme although just over half subsequently expressed an interest in using such a scheme. Given that this was a matched sample with similar levels of personal and domestic assistance needs to those already receiving payments their preferences do represent a more realistic (albeit very approximate) indication of what the level of demand for payments for disabled people with higher levels of need might be.

Obviously, without more extensive research, it is impossible to tell if this level of demand would be replicated amongst disabled people as a whole. However, as noted in Chapter 2, the evidence from analysis of take-up of ILF payments suggests that there may still have been a significant amount of unmet demand for this option when the original Fund was closed (Lakey, 1994).

At the same time, the experience of the ILF has also shown that there are already mechanisms available to impose an overall ceiling on demand should this be required. Further, it is also important to bear in mind that previous research has suggested that demand is likely to be lower amongst older people - who constitute the largest proportion of the overall number of disabled people (Zarb and Oliver, 1993). This also appears to be borne out by the findings from this research which show that older people are less likely to employ their own support workers (see Chapter 5).



Other research has also indicated a need to take account of differences in peoples' ability to manage their own support arrangements. For example the study by Lakey (1994) on the experiences of ILF clients suggested that payments may often effectively be managed by relatives rather than the people for whom the payments are intended to support; also, that this may be particularly likely in the case of people with learning difficulties.

At the same time, it is difficult to draw any firm conclusions about demand from such findings for two main reasons. First, it is impossible to know what proportion of people would choose the payments option if they routinely had access to appropriate sources of advice and training. Second, payments schemes are not currently widely available to certain groups. This particularly applies to older people as both the ILF and most of the local schemes we have examined have an upper age limit on eligibility.

#### Demand from high cost users

Although there will clearly always be individual cases where the costs of a personal assistance package exceed even the most expensive residential care, there is little evidence that these would represent anything other than a small proportion of the overall numbers involved. Indeed, the ILF - which did not originally place any ceiling on the level of awards - made weekly payments in excess of £500 to only half a percent of clients; even when the numbers who received awards near the threshold for the new ILF (ie. between £400 and £500 per week) are added, this still only represents under 3 percent of the total client group (Kestenbaum, 1993).

It is difficult to estimate the extent to which the level of ILF awards in previous years might provide an accurate guide to future demand for direct payments in excess of the £500 threshold. One of the main difficulties is that we do not have data on any direct comparison group within the general population. However, it is possible to get a very approximate idea of the potential numbers involved based on receipt of higher rate Attendance Allowance (or the higher care component of Disabled Living Allowance).

There are just over 450,000 people aged 16 or over who receive one of these higher rate allowances (DSS, 1993). Obviously it is extremely unlikely that all of this group would either want or need payments for personal assistance. However, even if we assume that they would, this still only translates to a maximum of 12,200 people requiring payments in excess of £500 per week nationally. In reality, the actual demand for such payments is likely to be considerably lower than this for two main reasons.

First, it is extremely unlikely that all of the people falling into this category would choose to take up the payments option even if it were universally available. Second, people receiving higher rate Attendance Allowance include a much higher proportion of older people than those who receive payments from the ILF. This is partly due to the age related eligibility criteria used in the past (Lakey, 1994). However, as noted above, this may also be a reflection on the fact that older disabled people are more likely to have reservations about taking responsibility for directing their own support arrangements.

Further, even though the government has defined the cut-off point for ILF payments as £500, some residential provision for disabled people is significantly more expensive than this. For example, a recent study of the costs of local authority residential care (using data from the Department of Health) estimates the average cost of a place in a home for disabled people to be £458 a week at 1992 prices (Phillips, 1993). However, the same study also highlighted that there is a huge amount of variation around this average, with almost thirty percent of places costing more than £500 a week.

It is by no means clear, therefore, that residential care necessarily represents a cheaper option than making direct payments in excess of £500 a week to a limited number of people. At the same time, the illustrative figures on the potential demand for payments in excess of £500 per week do not take account of disabled people who are already in residential care, but who might wish to use payments for personal assistance to enable them to return to living in the community. Although the ILF did provide a route to leaving residential care for a small proportion of clients, it is quite possible that more would follow if given the choice.

However, the important question is not simply about the relative costs of these two options, but whether or not the quality of support provided (and the related personal benefits in terms of maintaining dignity, choice and control) can be seen to justify the relatively small proportion of additional expenditure which might be involved.

This study has demonstrated that payments schemes are able to deliver these benefits more efficiently than direct service provision and, on average, at considerably less cost. In the final part of this chapter we draw together the key findings from the research and offer some general conclusions on the benefits of payments schemes.

Final conclusions

The findings from this research suggest that there are clearly a range of advantages of the payments option as a means of meeting disabled peoples' support needs.

For disabled people themselves, the principal advantages would seem to be that payments schemes offer a greater degree of choice and control than direct service provision. This in turn leads to more reliable and flexible support arrangements which are closely matched to individual needs. The findings also suggest that payments schemes tend to meet a wider range of needs than services and, consequently, are less likely to leave gaps in peoples' support.

The findings also illustrate some of the wider benefits of increased reliability and flexibility such as enabling people to use their own time more productively and, most importantly, enabling them to reduce their dependency on their families and other sources of informal support. More generally, these kinds of benefits can have a significant impact on how people view the overall quality of their lives.

At the same time, the research has also pointed to some of the relative disadvantages of payments schemes. For example, the greater degree of time and effort which is often involved with managing one's own support arrangements and, for some people, the additional responsibilities of being an employer. However, it is also clear that people in the study who are using these schemes mostly feel that these potential difficulties are far outweighed by the advantages.

It is also important to bear in mind that the elements which determine high quality support arrangements can be delivered in a variety of ways. Well organised services, for example, can also provide reliability and flexibility for the people who use them. Similarly, services which incorporate mechanisms for extending the degree of choice users have over their support arrangements can also be associated with higher levels of user satisfaction. However, while the findings from the research suggest that some local services are able to deliver some of these benefits this tends to be the exception rather than the rule.

At the same time, the findings also suggest some of the ways in which direct service provision can offer certain benefits for people who, for whatever reason, do not wish to organise their own support arrangements. For example, some of the service users in the study place particular value of not having to rely on a single source of support to meet all their needs; a few people also point to having greater continuity of support as one of the principal reasons why they would choose to stay with direct service provision. Nevertheless, more than half

of the service users in the study would prefer to switch to a payments scheme. Further, most of the remainder were unable to give any firm indication of their choice because of their lack of knowledge about the payments option. It is quite possible, therefore, that more would in fact choose to take this up if they were offered the opportunity.

For local authorities, the main benefits of payments schemes are that they offer a mechanism which enables them to deliver on the key community care objectives of offering greater choice, empowering users, and encouraging diversity of support provision - particularly amongst independent providers. The findings also suggest that there are some particular advantages which local payments schemes have over a national system of payments such as the ILF. In particular, that local schemes are better placed to offer appropriate advice and back-up to people who are organising their own support arrangements; also, that they are associated with a greater degree of local autonomy and flexibility which may in turn offer greater scope for responding to local needs.

However, the findings also suggest that there is a considerable degree of variation in the extent to which local authorities are able to take full advantage of these kinds of benefits. Most importantly, it seems fairly clear that the authorities participating in this study are often hampered by the present restrictions on making direct cash payments and the various measures which they have to adopt to stay within the law. It would appear that these restrictions not only reduce the efficiency of particular local schemes but, in some cases, have also led to an increase in administrative costs. The same kinds of difficulties have led other authorities to either change their payments schemes or even suspend them altogether.

The present situation regarding the operation of local payment schemes also raises some further questions about the relative advantages of direct and indirect cash payments. Specifically, whether or not indirect schemes are able to offer the same degree of choice and flexibility as paying cash direct to disabled people.

Given that practically all local schemes are currently based on indirect payments it is not possible to test this proposition through direct comparison at a local level. (Although we have attempted to highlight comparisons between local schemes and the ILF wherever possible). At the same time, comparing the research findings against the definition of the 'pure type' of direct payments outlined in Chapter 4 does suggest that some local schemes are able to offer people something approximating to complete control over their support arrangements. However, it is also fairly clear that most schemes

involve some degree of compromise over this important issue as a result of not being able to pay cash directly. In addition, because indirect payments can lead to an increase in the use of administrative resources, gains made in the interests of extending choice and control may often be offset against losses in terms of efficiency.

The research also points to some interesting observations on the use of support packages based on a combination of payments and direct service provision. The provision of 'care packages' tailored to individual needs and circumstances is intended to be one of the principle benefits of the new community care arrangements. Unlike the old ILF, the new Independent Living (1993) Fund is also based on disabled people receiving a combination of services and cash payments for the purchase of personal and domestic assistance. In theory, such arrangements might offer people the best of both worlds; a high degree of choice and control over support workers recruited using cash from a payments scheme, with additional back-up from local services. However, the experiences reported by people in this study suggest that these kind of 'mixed' arrangements are a less efficient means of meeting peoples' needs than either the payments option or services on their own.

Further, it also appears that, where people have such arrangements, this may often be more out of necessity than choice. In some cases, the need to supplement support workers with direct services (usually agency care) results from people not having access to the same level of informal support as people who use either services or payments schemes for the bulk of their needs. For others, this appears to be the result of having to plug gaps left in their usual support (eg. because of inadequate funding from a payments scheme, or because services are unavailable at particular times). Consequently, far from leading to greater flexibility and reliability, these kinds of mixed arrangements tend to be associated with significantly lower levels of user satisfaction compared to arrangements based on services or payments schemes alone.

In addition to the potential benefits in terms of quality of support, it is also important to consider whether or not the payments option represents a cost-efficient use of resources. Clearly, any support option which increases benefits to users is of potential interest to policy makers. However, where gains in quality can only be achieved at additional cost, it is inevitable that this would be seen as negating (either partially or completely) the benefits which would otherwise be gained. It is not surprising, therefore, that policy makers would want to ask whether or not payments schemes offer value for money.

This question is likely to be particularly important in the light of the current pressures on funding for public services in general, and for community care

in particular. In this context, the specific issue of most relevance is whether or not payments schemes represent a cost-efficient alternative to services as a means of meeting disabled peoples' support needs. The illustrative findings from our analysis of costs indicate that this is in fact the case as support arrangements for people using payments schemes are, on average, between 30 and 40 percent cheaper than arrangements based on direct service provision. Further, the findings also suggest that there may be scope for reducing the administrative costs of payments schemes if local authorities were enabled to make cash payments direct to individual disabled people.

The findings on costs also give an illustration of the extent to which disabled people - both service users and people using payments schemes - contribute to the costs of their support arrangements. In some cases, this involves people topping-up cash payments with personal income or benefits, while some people also contribute through purchasing additional services privately, or through paying charges for services provided by a local authority.

In addition, the cost analysis has also given some indication of the extent to which the costs of different support arrangements are subsidised by unpaid informal support and the potential effects of replacing such support with direct provision. The findings indicate that this form of indirect cost subsidy appears to be considerably greater for services compared to direct/indirect payments. The findings on how people use payments and services also suggest that this is related to the fact that payments schemes tend to meet a wider range of needs than services, thereby reducing peoples' reliance on informal support.

Finally, added to the findings on the comparative quality of support arrangements based on the two options, the cost analysis indicates that payments schemes not only increase the benefits for disabled people, but also represent better value for money than direct service provision. At a time when there is continuing pressure to make the most effective use of public resources, payments schemes would seem to offer a cost-effective alternative to services as a means of meeting disabled peoples' support needs.

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APPENDIX A

Table A1  
 DETAILS OF THE RESEARCH SAMPLE  
 Breakdown of interview sample by age and sex

AGE (percent)	Payments group	Service users	Mixed group	All
16 to 24	7	11	7	9
25 to 34	22	22	20	22
35 to 44	37	26	13	28
45 to 54	26	26	33	28
55 to 64	7	15	20	13
65 to 74	0	0	7	1
Totals	100	100	100	100
(Base)	(27)	(27)	(15)	(69)
Average age	39.4	40.3	45.1	41.0

SEX (percent)

Male	22	41	67	39
Female	78	59	33	61
Totals	100	100	100	100
(Base)	(27)	(27)	(15)	(69)

(Missing data = 1)

Table A2 Breakdown of interview sample by ethnic group

(Percent)	Payments group	Service users	Mixed group	All
White - UK	96	90	100	95
Black - African /Caribbean	4	5	0	3
Black - Asian	0	5	0	2
Totals	100	100	100	100
(Base)	(25)	(21)	(14)	(60)
(Missing data = 10)				

Table A3 Breakdown of interview sample by household composition

(Percent)	Payments group	Service users	Mixed group	All
Living alone	33	50	60	47
Living with spouse/partner	30	8	13	18
Living with children	0	4	0	2
Living with parents	15	19	7	15
Living with other adults	11	8	7	9
Living with spouse/partner & children	11	12	13	12
Totals	100	100	100	100
(Base)	(27)	(26)	(15)	(68)
(Missing data = 2)				

Table A4 Breakdown of interview sample by employment status

(Percent)	Payments group	Service users	Mixed group
Working (f/t)	19	8	7
Working (p/t)	19	12	20
Unemployed	37	62	47
Looking after home	7	0	7
Studying	19	8	0
Retired	0	12	20
Totals	100	100	100
(Base)	(27)	(26)	(15)

(Missing data = 2)

Table A5 Main sources of household income

(Percent)	Payments group	Service users	Mixed group
Benefits/pensions	63	81	80
Employment	22	12	7
Other	11	8	13
Totals	100	100	100
(Base)	(27)	(26)	(15)

Table A6 Average weekly household income (Gross)

Payments group	£239.28
Service users	£216.23
Mixed group	£229.40
ILF	£215.56
LA payments	£366.76
All	£262.32

## APPENDIX B

### DETAILS OF LOCAL PAYMENTS SCHEMES

#### AUTHORITY A

Type of scheme: This is a straightforward indirect payments scheme. Payments are made by cheque via an independent third-party agency contracted by the local authority.

Aims and development of the scheme: This authority was one of the first to make payments for personal assistance and has continued to do so for many years. The scheme is supported on the basis that it 'enables people to have greater freedom and choice about their own lifestyles and has proved to be cost-effective as there are few infrastructure costs involved'.

Eligibility criteria: The scheme was, until recently, restricted to people 'aged 16 to 65 with a severe physical disability who chose to and were considered able to manage their own care arrangements'. This has now been extended to include other client groups (eg. older people and people with learning difficulties), provided that they actively choose this option in preference to direct services. Although qualification for ILF payments is not one of the criteria for acceptance onto the scheme, appropriate individuals are encouraged to apply. (The ILF also accept payments provided through the scheme as counting towards the £200 service component for the new 1993 Fund).

Individuals joining the scheme assess their own needs jointly with a social worker/care manager within a full community care assessment. Applicants are referred to the local CIL who assist them with putting together an individual care plan.

Level of payments: Payments are made at a standard rate of £5.50 per hour. This rate was based on the costs of local care attendant services plus 20% - the amount which the authority estimated people would require for employment overheads (eg. NI contributions, administering workers' payroll etc) and to cover the administration charges made by the third-party handling agency. The rates are updated annually in line with other local authority service budgets and pay scales.

The maximum payment is currently £200 per week for personal assistance. There is no minimum payment. However, as the budget is devolved to area offices, there is some scope for local discretion over the amounts paid. Some individuals also receive additional financial assistance with purchasing essential items of equipment from the same budget.

Number of users: At the time the data for this study was collected there were 71 people receiving payments on the scheme. However, the scheme has expanded rapidly during the last twelve months and there are now over 200 people receiving payments. In addition, around 270 people throughout the county also receive payments from the ILF.

Support for scheme users: Practical advice and guidance materials are provided by a local Centre for Independent Living (which is part-funded by the local authority). This includes providing peer support from existing personal assistance users; help with assessing care needs; advice and guidance on recruiting and managing support workers; and, advice on dealing with tax and national insurance.

There is minimal social services contact after the initial application stage, although individual care plans are meant to be reviewed at least once a year. The authority are also considering the possibility of appointing a district support worker (who would be based at the local CIL)

Charges: Clients are charged a fee of £12.50 for setting-up the payment arrangement, and £2.50 per month for administration of the payments by the third-party agency.

The authority does not have a charging policy for community services. Consequently, individual financial circumstances are not normally taken into account when people apply to the scheme; however, care managers have been instructed that they should be aware of people who have significant resources for purchasing personal assistance (eg. large industrial injury settlements).

Legal status: The legal advice received by the authority recommended that they could continue to make indirect payments, but should avoid formalising the conditions under which payments can be made and used terms in any written contracts.

Other comments: This is the largest and longest established of the payment schemes amongst the authorities included in the research. Although take-up has been encouraged throughout the authority, some social services area offices do not appear to have been promoting the scheme as actively as others as take-up has not been distributed evenly. This is currently being addressed to ensure that all care managers are aware of the scheme, and are encouraging appropriate individuals to apply.

## AUTHORITY B

Type of scheme: This authority operates an indirect payments scheme with payments being made via third party arrangements. The most notable feature of the scheme is that the majority of clients are required to use the payments to purchase assistance from local care agencies.

Aims and development of the scheme: At the time the research was started, this authority was making direct payments. However, from April 1993, this has been changed to an indirect scheme following advice received on the illegality of direct payments. (Although existing direct payments were continued for a small number of people who were on the original scheme). As this decision was made unexpectedly by the Assistant Director of Finance, this left little time to put alternative arrangements in place. Consequently, the decision was made that payments would mainly be used to purchase agency care. Local care agencies are also considered to be highly responsive to users as a result of their experience with working with local ILF clients.

Eligibility criteria: Eligibility is determined by individual social workers as part of a standard community care assessment and there is no set application procedure. However, acceptance onto the scheme is dependent on a judgement about individual's ability to direct their own support arrangements. (Under the earlier direct payment arrangements, ability and willingness to assume responsibility for employment and management of arrangements were also taken into account).

As it is not part of the authority's 'official' community care policy, the scheme has not been actively promoted, either to social workers or to potential users.

Access to the scheme is, therefore, dependent on individual social workers and users having knowledge of the scheme.

Level of payments: The upper-limit for payments has been set at approximately £500 a month, although two of the current users receive payments in excess of this limit.

Number of users: There are currently 11 people using the scheme. There are also approximately 300 people receiving payments from the ILF.

Support for scheme users: At the time the original scheme was started (1988/89) there was only one social worker to work with people with physical disabilities throughout the county. Assistance for scheme users was mostly provided by this worker, although access to peer support from other users was also arranged in some cases. Other assistance was provided in the form of guidance materials produced by a CIL. It is not the social services department's policy to become directly involved in the recruitment of support workers, unless this is requested by users.

Legal status: The decision to switch to indirect payments was taken by the authority's finance department in the light of the government pronouncements on the illegality of direct payments. In particular, the authority took the view that there is an issue of 'vicarious liability for staff employment' when entering into direct payment arrangements. However, there is support for returning to direct payments if and when circumstances allow.

Other comments: The changes to the scheme have resulted in an 'unprecedented' increase in the level of intervention by care managers. This has been attributed to a combination of complex needs and conflict with, and between, the care agencies used by scheme users. The new third party arrangements have also led to a significant increase in the level of administration required. This is due to the need for monitoring budgets and approving agency invoices for payment - a function which was previously unnecessary as users purchased their assistance directly.

## AUTHORITY C1

Type of scheme: Although the authority had been in the process of setting-up a new third-party indirect payments scheme at the start of this research (and had even started taking applications), the scheme has since been abandoned. This decision was taken in the light of the government pronouncements on the illegality of direct payments during the debate on the Disabled Person's Grants Bill, and an about-turn by the authority's legal department.

The local authority had also been making direct payments to a small number of individuals for some time before this although, in the light of the present legal situation, this scheme will also be discontinued.

Eligibility criteria: The criteria for proposed scheme were that a person applying for payments should be 'an adult with a considerable level of need for support, for whom existing services were inappropriate'. There were to be no restrictions on how the money was to be spent, although there would have been a requirement for payments to include a personal assistance component.

Level of payments: There would not have been any ceiling on the level of individual payments under the proposed scheme.

Support for scheme users: An independent living co-ordinator had already been appointed at the time the proposed scheme was shelved. The co-ordinator's role would have been to train people in independent living skills and to monitor the scheme on behalf of the authority.

Legal status: Given the uncertainty over the legal status of the proposed scheme, the authority is now looking at alternative options for making payments for personal assistance. These include setting-up trusts funds to administer payments on behalf of individual disabled people, and making payments via a local charity. Another option being considered is the placing of 'spot contracts' with friends and neighbours who would then invoice the authority for support provided to individual clients.

## AUTHORITY C2

Type of scheme: This authority's independent living scheme originally used Community Services Volunteers (CSV's) to provide personal assistance to disabled people living in their own homes. However, the scheme has evolved over time it evolved and now includes a range of ad-hoc arrangements for different individuals. These include both direct and direct payments.

In a few cases, individuals employ their own support workers directly, while in others workers are recruited by individual disabled people, but are technically employed by a care agency. Another receives money for 70 hours of direct provision. Some people who used to use CSV's now receive payments to purchase support from private care agencies.

Aims and development of the scheme: The original scheme was aimed at people moving out of residential care and who had high levels of support need. When the scheme first started, all of the users were people requiring 24 hour support.



Consequently, CSV's were chosen to provide this support as this was considered to be the cheapest option available.

Although this arrangement worked well initially, it was subsequently found to be inadequate for a number of reasons.

First, the turnover of volunteers was too high to maintain continuity of support for users. (Most volunteers stayed for an average of only four months). Second, the high turnover of volunteers meant that training costs were wasted as they often left as quickly as they were trained; constant training of new volunteers was also considered to be a source of considerable inconvenience for users. Third, most volunteers were young people; while this may have been acceptable at the start of the scheme, the age gap between existing users and volunteers has subsequently increased and is no longer considered acceptable by some of the users. Fourth, the original scheme was not seen as giving users a genuine choice over their support arrangements as volunteers could only be chosen on the basis of a brief description.

Finally, although the option of using volunteers was originally selected on the basis of cost, the degree of administrative and supervisory support required has made the scheme increasingly expensive to manage. The existence of the scheme has also highlighted gaps in existing service provision which the authority has felt obliged to fill in other ways.

Number of users: Only 5 people out of an initial 13 still use the scheme as it was originally designed. The remainder have a range of different arrangements as outlined above. There are also just under 100 people receiving payments from the ILF.

Other comments: The authority recognise that the scheme is inadequate in its original form. There have also been some concerns about the increased expenditure on a scheme which was originally chosen on the basis of cost. Although there has not been any firm decision on a possible replacement for the scheme, the authority is considering contracting a local voluntary care agency to provide personal assistance to a larger number of users.

This scheme also offers a useful illustration of some of the problems with volunteer based schemes, and of the ways in which an authority can end up making payments even though this was not the original intention.

### AUTHORITY C3

Although the authority does make cash payments to a few individuals, the main independent living scheme utilises volunteers and does not meet the definition of a payments scheme used in this research. Users are involved in the recruitment of a local pool of support workers and can also choose individual workers from the pool once they are employed. However, as this recruitment is done on a collective basis, individual disabled people are not necessarily allocated workers which they have recruited themselves. Further, although disabled people using the scheme have a big say in how the scheme is run, support workers terms of employment are set by a standard contract rather than negotiated on an individual basis. This means that the scheme fails to meet one of the essential criteria for payments schemes as it does not give individual disabled people full control over their day to day support arrangements. Consequently, it has been classified as a service for the purposes of this study.

### AUTHORITY C4

Type of scheme: People on the scheme enter into a standard form of contract undertaking to discharge the authority's obligations under the 1970 Chronically Sick and Disabled Persons Act and the 1948 National Assistance Act by purchasing services to meet their individual needs.

Aims and development of the scheme: The scheme was first introduced in 1986 as a straightforward direct payments scheme. It was aimed at enabling people to make their own care arrangements in order to remain living in the community. However, as the scheme has encountered a number of difficulties, its wider application has been suspended pending a full review.

Eligibility criteria: The scheme is intended as an alternative to residential care for clients with 'significant social care needs'. Although there are no formal age criteria, there is an expectation that most clients will be 'younger physically disabled people'. Assessments also take into consideration clients' ability to manage their own support arrangements 'exercise the necessary judgement'.

Level of payments: Details not supplied.

Charges: Cash grants are made net of any Attendance Allowance received. However, this has proved to be too inflexible in practice and the authority is currently considering various options for introducing a means-tested sliding-scale of charges.

Support for scheme users: None. Clients are expected to make their own arrangements for any 'administrative support' they require (eg. assistance with managing payroll).

Number of users: Details not supplied.

Legal status: Legal counsel has advised that the scheme is legal but has also criticised the form of contract employed and the absence of guidance for scheme users.

Other comments: The scheme run by Authority C4 is a particularly interesting variation on the idea of using existing legislation to justify cash payments. The scheme originally attempted to make direct payments legally by asking people on the scheme to sign a contract undertaking to discharge the authorities obligations under the 1970 Chronically Sick and Disabled Persons Act and the 1948 National Assistance Act by using the money to purchase services to meet their individual needs. The justification used to support this arrangement was that Section 111 of the 1972 Local Government Act empowers local authorities *'to do anything which is calculated to facilitate, or is conducive or incidental to the discharge of any of its functions'*. However, this section of the Local Government Act has met with increasingly strict interpretation by the courts. Further, the Audit Commission have subsequently advised that authorities should exercise caution in trying to use it to justify actions which are not explicitly authorised.

Surprisingly, perhaps, the local authorities own legal counsel concluded that direct cash payments were still 'almost certainly legal'. However, they also concluded that the form of contract between the authority and people using the scheme was unenforceable in its current form and needed to be tightened up. Consequently, the wider application of the scheme has been suspended while alternative mechanisms are being investigated.

## AUTHORITY D1

Type of scheme: This local authority was originally operating a genuine direct payments scheme. This was subsequently changed to third-party indirect payments scheme. However, the authority's legal department withdrew its support just as plans for the revised scheme were being finalised. Payments continue to be made to those already on the scheme while alternative options are being considered.

Aims and development of the scheme: The aim of the scheme is 'to enable people with severe physical/sensory disabilities to live independently in the

community'. Interestingly, the scheme was originally aimed at older people (paid for out of the authority's residential care budget) and was only extended to younger disabled people during the last few years.

The main benefits of the scheme are seen as extending choice and control for disabled people, and meeting a level of need which the authority found difficult to accommodate through direct service provision.

Eligibility criteria: The scheme is aimed at people for whom services are inappropriate. Applicants must be aged between 16 and 65; living alone (or with someone who is unable to provide all of their personal assistance needs); or be planning to move out of residential care. Originally, applicants were also required to apply for ILF funding before they could be considered. However, this requirement has subsequently been dropped.

There is no formal application procedure for the scheme. It would appear that decisions on whether or not to place people on the scheme are made at the discretion of individual social workers.

Payments are intended for the purchase of personal assistance only. However, it would appear that the lack of a dedicated administrator means that checks on how the money is spent are not always made. (Although there has been one case where a social worker decided that a particular individual was not using the money properly and, consequently, withdrew payments and switched to agency provision).

Level of payments: Payments vary quite widely, with one individual receiving as much as £595 per week and one as little as £34.50. The average is payment is £270. However, in response to concerns expressed by the Finance Department a ceiling of £400 has recently been introduced.

Pay rates for support workers are restricted to the levels paid to full-time employees of the authority's own home care service (although this does not apply to people who use payments to purchase assistance from private care agencies). There is no allowance made for recruitment or employment costs, and people using the scheme are expected to apply to the ILF to cover these costs.

Number of users: There are 12 users on the scheme currently, but no new applications are being considered until further notice. Approximately 80 people also receive payments from the ILF.

Support for scheme users: The scheme has very little structure to support it. Payments are made direct to users, and they are literally left to get on with it. Most use the money to hire their own support workers, but some use it to purchase assistance from private care agencies.

Annual reviews with users, which were meant to form part of the scheme, have not taken place. No member of staff has been appointed to administer the scheme or support the scheme users; however, some people do get support from individual social workers on an ad hoc basis. Existing plans to appoint a dedicated support worker have been postponed because of the uncertainty about the future shape of the scheme.

Charges: People applying to the scheme must be in receipt of higher rate Attendance Allowance or the higher rate care component of Disability Living Allowance; half of this allowance is deducted from payments made under the scheme.

Legal status: There would appear to be a considerable degree of confusion over the current legal status of the scheme. Although the authority had already planned to switch from direct to indirect payments, the Legal Department are not prepared to support the scheme. It has not been possible to establish the precise reasons for this, although the fact that support workers are treated as self-employed is likely to be a relevant consideration. However, the actual payment mechanism proposed - payments being handled by a third-part voluntary agency - has been sanctioned by legal advisors in other authorities.

Other comments: The uncertainty surrounding the legal status of the scheme has prevented it from being actively promoted. Awareness about the scheme amongst local social workers also appears to be patchy. The local organisation of disabled people is aware of the scheme (and has members who are users), but does not actively promote it.

The local authority also recognises that the scheme requires revision and only intends to retain the present arrangement until an alternative scheme is agreed with the legal department. It is also recognised that the scheme requires a dedicated administration and support post and there are plans to address as part of the review.

## AUTHORITY D2

Type of scheme: Technically, this is an indirect payments scheme as no cash is paid direct to individual disabled people. However, the scheme does retain some of the essential elements of direct payments as people recruit and

manage their own support workers. The only crucial difference is that, in order to avoid making any cash grants, support workers are paid directly by the local authority on their behalf.

Aims and development of the scheme: The authority places a very high priority of enabling disabled people to have as much choice and control over their support arrangements. The authority also has a long-established reputation for the development of needs-led service provision which pre-dates the introduction of a payments scheme. The present scheme is seen as a logical progression from this existing provision.

Eligibility criteria: People applying to the scheme must be 'severely disabled and totally dependent on others for assistance'. It is hoped that the scheme can be extended to include 'less severely disabled people' in the future.

Applications are considered as part of a community care assessment involving a social worker, the disabled person (or their advocate), an occupational therapist, and the Principal Officer of the Disabilities Team. The assessment includes consideration of a range of other needs (including housing) in addition to personal assistance.

Once someone has been accepted on to the scheme, there are no restrictions on where the money is spent. Some people use the money to recruit their own support workers, and others use agency provision.

Levels of payments: There is no fixed limit to the level of the social services contribution to individual support packages.

Number of users: There are currently 11 people on the payments scheme; between 55 and 60 people also receive payments from the ILF.

Legal status: The authority has experimented with a range of arrangements which would preserve the key elements of a direct payments scheme, without paying cash directly to disabled people. Direct payments themselves were never considered to be a viable proposition, as it was clear to the authority that this would be illegal.

In the main, support workers have been hired by, and subject to the direction of, individual scheme users - even though they are paid by the local authority. Support workers are treated as self-employed by the local authority and paid a gross rate in the same way as any other independent provider. However, the local Inland Revenue have recently informed the authority that they are

unhappy with this arrangement. Their interpretation is that, as workers are working more or less exclusively for a single individual client they are effectively employees; therefore, the client (ie. the disabled person) is responsible for administering PAYE. In view of this, the authority is now experimenting with a contract arrangement whereby support workers are technically employed by social services. (However, scheme users still retain control over recruiting and managing workers and determining rates of pay). At this stage, we do not have any details of whether or not this is acceptable to the Inland Revenue.

Other comments: The changes made to support workers' employment status has also had some unanticipated effects on relations between workers and scheme users. For example, one worker has subsequently joined a private care agency in order to be paid through a third party - while retaining continuity of employment with the same user. Some people who were using agency workers have found that the workers concerned prefer to leave the agency and become local authority employees.

The local authority is currently looking for a third party to take on employment of support workers in the future. However, there are some concerns that any third party might become like a care agency, thereby reducing the degree of control individual users have over their support workers. The plan is for this arrangement to be tested on a trial basis before entering into any extended contract agreement. However; should there be any change in the legal situation, the authority would prefer to avoid these complications by making direct cash payments to individual disabled people.

### AUTHORITY D3

Type of scheme: This is a third-party indirect payments scheme. Payments are made on an individual basis via a local organisation of disabled people on behalf of the local authority.

Aims and development of the scheme: The scheme was originally set up after an approach by a small number of individual disabled people to the Director of Social Services. The philosophy underlining the scheme is that disabled people should have access to 'appropriate and flexible personal assistance as part of a total package of care, which enables them to live independently and with dignity, in the community, as an alternative to residential care'. Also, that they should have 'the right to have the same control over their own lives as the rest of the population'. The authority also recognises that enabling people to purchase their own individually tailored support packages provides

a degree of flexibility which local services have not, so far at least, been able to match.

The scheme is very much needs-led. Users have complete control over choice of support workers and how their personal assistance is organised. As experience shows that people tend to underestimate their needs, users are also encouraged to take a broad definition of need when assessing their support requirements.

Eligibility criteria: The scheme is aimed at people aged under 65 'who are totally dependent on assistance from others to undertake daily living tasks ... and are motivated and have the necessary skills to recruit and employ staff or can acquire such skills, (and) administer and account for finances'.

Needs assessments are carried out jointly with the scheme co-ordinator and individuals applying for payments. In addition to personal assistance payments can be used to purchase domestic assistance, and assistance with social and leisure activities (eg. gardening, classes, and holidays).

Level of payments: There are no limits on the level of payments which are all based on individual assessments, although the amounts paid are restricted by the overall budget available. Some of the payments are quite large compared to other authorities.

Payments include hourly pay rates for support workers; a small allowance for recruitment costs; sickness allowance for regular support workers (up to 2 months in any one year at half pay); and holiday pay for support workers (up to 2 weeks per year at half pay, subject to being in post for six months). Payments also include sleep-in allowances which are calculated on a flexible weekly basis as and when required. The overall level of payments are reviewed annually.

Budget: There is a limit on the overall budget which is currently being revised.

Number of users: The scheme currently has 14 users. There are also around 20 people in the borough receiving payments from the ILF.

Support for scheme users: The scheme has a dedicated Independent Living Scheme co-ordinator (based in the social services department). Apart from administering the scheme budget, the co-ordinators role is to carry out initial assessments and assist people with recruiting support workers (if required). Individual requirements are reviewed on a three-monthly basis.



The authority also purchases places on independent living skills courses for scheme users. These courses cover relevant aspects of setting-up and managing personal assistance arrangements, including dealing with tax and national insurance. The co-ordinator has also set up a user support group which provides a forum for peer support amongst existing and potential scheme users.

The local organisation of disabled people does not currently have a formal support role apart from handling payments. However, plans for expanding their role are under active consideration.

Charges: Charges are made in line with the local authorities standard Home Care Charging Policy.

Legal status: The present arrangement has been in operation since April 1993. Prior to that, the authority had been making straightforward direct cash payments to a small number of disabled people. However, this has since been changed to the current indirect scheme on the advice of the authority's legal department who took the view that direct payments were in breach of the law and, if investigated, carried a risk of a surcharge being imposed.

Financial accounting controls under the present scheme require individuals receiving payments to submit time sheets signed by support workers, plus invoices for any other relevant expenditure, on a quarterly basis. Payments for subsequent quarters are then adjusted to take account of any balances due.

Individuals are also required to keep accounts of all monies paid and received and to maintain a separate bank account for this purpose. Annual statements of account have to be submitted along with bank statements; these are then checked by the scheme co-ordinator to ensure that they reconcile with records of payments made by the paying agency. (The agency is also required to keep records of all payments as specified in the contract with the local authority).

Other comments: The scheme currently has only a small number of users. It is envisaged that significant expansion of the scheme would increase the administrative support required beyond the level which can be accommodated within existing resources. As noted above, expanding the support role of the local organisation of disabled people is seen as one way of helping to address this potential difficulty, as this would reduce the administrative overheads involved.

## APPENDIX C

### CALCULATION OF UNIT COSTS USED FOR COMPARATIVE COST ANALYSIS

Calculation of gross and hourly unit costs of direct service provision

1. Gross weekly costs:

a) Number of hours provided by each service

MULTIPLIED BY

unit cost for each service (see Table C1 to C12)

PLUS

b) Any charges paid to local authority or independent service provider

PLUS

c) Any costs incurred in purchasing additional assistance (eg. weekend cover purchased from private care agencies)

2. Hourly unit costs:

Total (a - c)

Total number of service hours used

Table C1 Unit costs - direct service provision

	Home Care/ Home Help	Care Attendants	Private Care Agencies
Authority A	8.27 (a)	9.78 (a)	7.71 (a)
Authority B	6.79 (c)	11.69 (b)	6.56 (b)
Authority C1	na	11.69 (b)	na
Authority C2	6.79 (c)	13.67 (a)	na
Authority C3	6.79 (c)	11.69 (b)	na
Authority C4	na	na	6.56 (b)
Authority D1	9.58 (a)	11.69 (b)	6.96 (a)
Authority D2	na	na	6.00 (a)
Authority D3	7.50 (a)	11.63 (a)	na
	CSV's	Day Care services	Respite Care services
Authority A	na	6.07 (a)	7.71 (a)
Authority B	na	4.60 (c)	6.56 (b)
Authority C1	na	na	na
Authority C2	1.00 (b)	9.34 (a)	na
Authority C3	1.00 (a)	4.60 (c)	na
Authority C4	na	4.60 (c)	6.56 (b)
Authority D1	na	4.60 (c)	6.96 (a)

Authority D2	na	4.60 (c)	6.00 (a)
(Authority D3 1.00)	(b)	<u>7.35 (a)</u>	<u>na</u>

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	District Nursing	Meals on Wheels
Authority A	19.29 (c)	2.20 (c)
Authority B	19.29 (c)	na
Authority C1	19.29 (c)	na
Authority C2	19.29 (c)	na
Authority C3	19.29 (c)	na
Authority C4	19.29 (c)	na
Authority D1	19.29 (c)	na
Authority D2	19.29 (c)	na
Authority D3	19.29 (c)	na

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Key to data sources:

(a) = based on budget data supplied by local authority (see Tables C2 to C7)

(b) = based on average costs amongst authorities supplying data (ie. average costs in Tables C2 to C7)

(c) = based on national estimates of unit costs compiled by PSSRU (see Tables C8 to C12)

na = service not used by respondents in this authority

**Table C2 Breakdown of costs - Care Attendant Services**

(Local Authority)	(A)	(C2)	(D3)
Direct staff costs	395,996	469,238	nk
Administration, overheads and central establishment costs	148,942	7,069	nk
(Other costs)			
Payments to independent providers na		254,390	52,000
Gross Expenditure	544,968	730,697	52,000
Less revenue	228,887	85,650	na
Net expenditure	316,081	645,047	52,000
Unit cost (per hour)	£9.78	£13.67	£11.63
Proportion of budget spent on:			
a) Direct staff costs	73%	64%	nk
b) Admin. and other costs	27%	36%	nk

Notes:

- i) Overheads include travel, clothing and equipment budget, and office accommodation costs
- ii) Breakdown of total expenditure not available for Authority D3

Table C3 Breakdown of costs - Day Care Services

(Local Authority) (C2)	(D1)	(D3)
Direct staff costs 211,232	1,825,600	292,000
Admin., overheads and central establishment costs 400,122	741,100	75,700
(Other costs)		
Building costs na	na	22,350
Miscellaneous 20,000	na	na
Gross Expenditure 631,354	2,566,700	441,200
Less revenue 12,295	42,000	15,350
Net expenditure 619,059	2,524,700	425,850
Unit cost (per hour) £9.34	nk	£7.35
Proportion of budget spent on:		
a) Direct staff costs 33%	71%	66%
b) Admin. and other costs 67%	29%	34%

Notes:

i) Overheads include meals (for clients), travel, clothing and equipment budget, and office accommodation costs

ii) Separate estimates of building and maintenance costs are not shown for Authorities C2 and D1 as these were included under general overheads and running costs

iii) Unit cost not available for Authority D1 as data on service hours was incomplete

iv) Other unit costs supplied (without budget details):

Authority B = £6.07

Table C4 Breakdown of costs – Home Care/Home Help Services

(Local Authority)	(A)	(D1)	(D3)
Direct staff costs	9,264,331	3,818,000	160,000
Admin., overheads and central establishment costs	1,440,306	179,900	31,000
(Other costs)			
Payments to independent provider	131,851	na	na
Miscellaneous	116,136	na	na
Gross Expenditure	10,952,624	3,997,900	191,500
Less revenue	379,976	111,200	35,000
Net expenditure	10,572,648	3,886,700	156,500
Unit cost (per hour)	£8.27	£9.58	£7.50
Proportion of budget spent on:			
a) Direct staff costs	85%	96%	84%
b) Admin. and other costs	15%	04%	16%

Notes:

i) Overheads include travel, clothing and equipment budget, and office accommodation costs

Table C5 Breakdown of costs - Independent Living Scheme/Community Services Volunteers (Authority C3)

Administration Costs (1 x ft co-ordinator)	£20,723.00
Volunteer allowances	£75,277.00
Total Costs	£96,000.00
(number of users)	(11)
Costs per user per year (costs/no. of users)	£8,727.00
Cost per user per week	£167.83
Unit cost per week	£1.00

Proportion of budget spent on:

a) Direct staff costs	78%
b) Admin. and other costs	22%

Table C6 Hourly unit costs supplied - Respite Care Services

Authority A	£8.14
Authority D2	£4.41
Authority D3	£4.48

Table C7 Hourly unit costs supplied - Private Care Agencies

	Range	Average
Authority A	£6.00 - £7.75	£6.71
Authority D1	£6.59 - £7.32	£6.96
Authority D2	na	£6.00
All	£6.00 - £7.75	£6.56

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Table C8 Estimate of national average costs - District Nursing

Direct staff costs (District Nurse Grade D)	£
- Wages/salary	11,594 pa
- Salary on-costs	1,333 pa
Direct overheads	2,133 pa
Capital overheads	452 pa
Hourly unit cost (contact time)	£18.40
Plus travel (cost per hour)	£0.89
Unit cost per hour	£19.29
Distribution of costs:	
a) Direct staff costs	83%
b) Administration/overheads	17

Source: Netten and Smart (1993), Table 4.11

Table C9 Estimate of national average costs - Home Care

Direct staff costs	£
- Wages/salary	4.04 per hr
- Salary on-costs	0.45 per hr
Direct overheads	0.72 per hr
Hourly unit cost (client related activities)	£6.40
Plus travel (cost per hour)	£0.39
Unit cost per hour	£6.79
Distribution of costs:	
a) Direct staff costs	86%
b) Administration/overheads	14%

Source: Netten and Smart (1993), Table 4.15

Table C10 Estimate of rational average costs - Local Authority Day Care

Capital costs	£7.89 per place per day
Revenue costs	£15.06 per client per day
Use of facility by client	250 days per year
Daily unit cost	£23 per client per day
Hourly unit cost (assuming average attendance for 5 hours per day)	£4.60

Source: Netten and Smart (1993), Table 1.5

Table C11 Estimate of national average costs - Respite Care

Cost of a place in Local Authority Residential Care	£323.70 per week
Contact time per day (estimated)	7.5 hours per client
Total contact time per week	52.5 hours per client
Hourly unit cost (£323.70/52.5)	£6.17

Source: Netten and Smart (1993), Table 1.4

Table C12 Estimate of national average costs – Local Authority Meals on Wheels

(Costs per meal)	London	Outside London
Meals	£3.13	£1.87
Direct overheads	£0.63	£0.37
Unit cost per meal	£3.70	£2.20

Source: Netten and Smart (1993), Table 1.7

## Calculation of gross and hourly unit costs of support financed through payments schemes

### 1. Gross weekly costs:

a) Number of hours worked by regular support workers/personal assistants                      x     hourly pay rate

b) Number of hours worked by occasional support workers/personal assistants                      x     hourly pay rate

PLUS

c) Weighting factor based on costs of administering payments by either a local authority or by the ILF (see Tables C13 and C14 for details)

PLUS

d) Recruitment costs (nominally averaged over a 12 month period to produce an estimate of weekly costs)

PLUS

d) Average weekly expenditure on incidental and recurring costs met from personal income:

holiday pay, sick leave;

running costs (eg. meals, telephone calls, postage);

employer's national insurance contributions;

third-party liability insurance.

PLUS

f) Any charges paid for direct service provision

PLUS

g) Any fees or charges paid for administration of payments (eg. handling fees, payroll service)

## 2. Hourly unit costs:

Total (a - g)

Total number of hours assistance provided by paid workers or services

Table C13 Additional overheads for administration of payments schemes

	Equivalent cost per hour (I)
Authority A	£0.38
Authority B	£0.46
Authority C 1	£0.00
Authority C2	no data
Authority C3	no data
Authority C4	no data
Authority D1	£0.00
Authority D2	£0.67
Authority D3	£0.65
ILF (ii)	£0.16

### Notes:

- (i) Administration costs divided by average number of hours per user per week (see Table C14)
- (ii) Based on proportion of total ILF budget spent on administration costs (2.5%) Source: Phillips (1993), p.31

Table C14a Administration costs for payments schemes (Authority A)

(Staff costs)	Annual cost	Proportion of budget
Co-ordinator (1 /3 wte) plus overheads (Agency fees)	10,713	5.2%
Grant to local CIL	8,000	3.9%
Monthly handling charges	2,100	1.0%
Total admin. costs	20,813	
Payments to clients	185,187	89.9%
Total annual budget	206,000	100.0%
(Equivalent cost per hour)	(£0.38)	

Table C14b Administration costs for payments schemes

(Authority B)

(Staff costs)	Annual cost	Proportion of budget
Co-ordinator (16 hrs per wk)	8,459	9.1
(Agency fees)	na	
Total admin. costs	8,459	
Payments to clients	84,041	90.9%
Total annual budget	92,500	100.0%
(Equivalent cost per hour)	(£0.46)	

Table C14c Administration costs for payments schemes

(Authority D2)

(Staff costs)	Annual cost	Proportion of budget
Co-ordinator (1/4 time wte)	2500	4.5
(Agency fees)		
Payroll/invoicing	6,000	10.7%
Total admin. costs	8,500	
Payments to clients	47,500	84.8%
Total annual budget	56,000	100.0%
(Equivalent cost per hour)	(£0.67)	

Table C14d Administration costs for payments schemes

(Authority 133)

(Staff costs)	Annual cost	Proportion of budget
Co-ordinator (2/3 wte)	16,500	15.3%
(Agency fees)	na	
Total admin. costs	16,500	
Payments to clients	91,500	84.7
Total annual budget	108,000	100.0%
(Equivalent cost per hour)	(£0.65)	