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CHAPTER I

Background to the study

I.1 Introduction

This report is based on a study of the National Pilot to implement direct payments in mental health which took place across five Local Authority sites in England from February 2001 to July 2003. The evaluation used the experiences of the pilot sites as a vehicle through which to understand the factors involved in successfully implementing direct payments in mental health. The evaluation took place in 2002-2003 during the last year of the pilot. This chapter provides an overview of the direct payments and mental health literature and outlines the background to both the National Pilot and the evaluation.

1.2 Overview of Direct Payments and Mental Health Literature

Recent national government policy has increased pressure to develop and extend the take-up of direct payments. From April 2003, there has been a requirement that Local Authorities offer direct payments to all people assessed as needing community care services and who are judged to be capable of managing their own support through direct payments by themselves or with assistance (Department of Health 2003). A number of disabled people, people with learning disabilities, people with mental health needs, older people, carers and their advocates are demanding greater choice, control and flexibility over their support arrangements through such initiatives as direct payments. However, the quality and availability of support, information and the promotion of direct payments in practice is still largely dependent on local circumstances. This evaluation focuses specifically on the process of implementing direct payments for people with mental health needs.

The Community Care (Direct Payments) Act (Department of Health 1996) came into force in April 1997. This gave Local Authorities the power to offer direct payments to people currently assessed as eligible for community care services. However, in practice, for a number of years accessibility to direct payments was largely confined to people with physical difficulties. Over the past few years, there has been a concerted effort by those advocating on behalf of people with learning difficulties to increase their access to direct payments, particularly through the organisation 'Values into Action' (see Holman and Bewley 1999; Holman and Collins 1997). There has been no similar initiative by a national organisation to promote direct payments in mental health.

It is now widely recognised that there has been a neglect of mental health and direct payments in both policy and practice and that low take-up is a concern. A recent text on social work and direct payments makes the point that it should be 'deeply regretted that so few people with mental health problems have been enabled to access direct payments' (Glasby and Littlechild 2002 p75).

Despite attempts to exclude people with mental health needs from direct payments legislation¹, the 1996 Community Care Act did make mental health service users, in theory, eligible for direct payments. However, it has been rarely promoted or taken up due to a number of factors working against its realisation. The 1996 consultation paper on direct payments made no specific reference to mental health, except in relation to people excluded on the grounds of their being currently detained under certain mental health legislation or subject to compulsory treatment under a court order (current exclusions in relation to direct payments are listed in Appendix A). The majority of mental health clients are not subject to this legislation, nor ongoing compulsory treatment, therefore this should not in itself have limited their access².

However, there are ongoing misunderstandings about eligibility in relation to the exclusion criteria. Currently, whilst clients on leave from hospital under Section 17 of the 1983 Mental Health Act are not eligible for direct payments, it is often wrongly assumed that clients are not allowed to have direct payments if they are receiving services provided under section 117 of the Mental Health Act (after care). The Community Care (Direct Payments) Act (1996) has been described as a 'silent victory' for mental health service users because, despite legislation, direct payments are still inaccessible to the majority of mental health clients due to misunderstandings, assumptions and lack of awareness (Maglajlic et al 1998 p33). Similarly, Ridley and Jones (2003 p643) draw attention to the 'untapped potential' of direct payments for mental health service users. However, recent guidance on direct payments issued by the Department of Health in September 2003 recommends that Local Authorities should monitor take-up of direct payments across care groups to ensure that direct payments are equally accessible to all care groups (Department of Health 2003). Local Implementation Teams (LITs) are now being required to provide figures on direct payments.

Most Local Authorities have not yet given serious consideration to the implementation of direct payments in mental health nor to the support that mental health service users may need in order to access direct payments. In 2003, the Social Services Inspectorate (SSI) reported that the numbers of mental health service users making use of direct payment schemes remained very low, even though numbers have slowly but significantly increased since autumn 2001 (SSI 2003). At the end of September 2003, SSI figures indicated that only five Local Authorities had ten or more mental health service users on direct payments and 57% of councils had no mental health service users using direct payments. The report concluded that 'the potential of direct payments for reducing stigma and social exclusion, and promoting independence and rehabilitation among people with mental health problems... is simply not being exploited' (SSI 2003 p32) and that there was much to do to extend the use of direct payments to this group.

A survey of all Local Authorities in Scotland found that out of a total of 143 people across Scotland who were receiving direct payments, these did not include any users of mental health services (Witcher et al 2000). Whilst Local Authorities were making limited moves to promote take-up among people with learning disabilities through working with the Values into Action guidance, they were giving considerably less thought to promoting take-up among users of mental health services (Witcher et al 2000). For example, one authority viewed mental health as the last care group in a 'staged' approach to implementation. Two years later, a study by the Scottish Executive found that only two mental health service users in Scotland were receiving direct payments (Ridley and Jones 2002).

Outside the UK, there is little evidence of any countries in which a direct payments or Independent Funding scheme has been made widely accessible to people with mental health needs (Brandon 1998; Glasby and Littlechild 2002). Indeed, a recent study of the ten 'most promising initiatives' in Individualised Funding schemes across Canada, the US and Australia found that mental health service users were generally not included (Lord and Hutchinson 2003). In addition, a study of 41 states in the US reported that there was no current initiative operating such schemes (Pita et al 2001). This background makes the National Pilot extremely relevant to widening the accessibility of these initiatives to people experiencing mental distress.

Although mental health professionals may not actively discourage their clients from pursuing direct payments, research has indicated that they were generally sceptical about the practicality of direct payments (Stainton 2002). Resistance to direct payments in the mental health field has been 'very strong' (Brandon 1998 p25). Previous research has identified a number of key barriers to implementation. Most significantly, there has been a profound lack of knowledge and awareness of direct payments amongst users and workers (Bamber 2002; Brandon et al 2000; Maglajlic et al 1998;2000; Ridley and Jones 2002;2003). Thus, the most comprehensive study of the barriers in accessing direct payments in mental health was entitled 'Direct What?' drawing explicit attention to the continued lack of understanding of some of the basics of direct payments (Ridley and Jones 2002;2003). Brandon et al (2000 p19) reported an 'appalling lack of relevant literature' relating to mental health and direct payments. The majority of mental health service users and professionals did not know about direct payments and, if they did, were unsure about eligibility (Maglajlic 1999; Ridley and Jones 2002). Although there has not been as great a demand for direct payments from mental health service users as there has been from people with physical disabilities, Ridley and Jones (2003 p656) argue 'the information deficit is so acute, that it would be inaccurate to conclude that the lack of demand equates with a lack of interest'. In this study, professionals were unaware that service users could be offered as much support or assistance as needed to manage a direct payments package (Ridley and Jones 2002). Any mental health professional³ acting as a client's 'care co-ordinator' can carry out a community care assessment for direct payments. However, many service users will have more contact with health service professionals, specifically community psychiatric nurses (CPNs) rather than social services staff. This has been identified as a potential barrier because direct payments are still viewed primarily as a social services initiative (Glasby and Littlechild 2002).

1.3 Outline of the National Pilot

Evaluation of direct payments amongst other care groups has demonstrated that the mental health of already existing direct payments recipients has improved significantly across care groups, particularly when users employed their own personal assistants (PAs) (e.g. Glendinning et al 2000a; 2000c; Halliwell and Glendinning 1998). This is even more reason to explore the possibility of direct payments for people with mental health needs. Indeed, there has been some anecdotal evidence suggesting that direct payments can have a positive impact on for people with mental health needs through giving people more control, in turn seen as crucial to maintaining mental health (Irish 1998; Glendinning et al 2000b; 2000c).

As one direct payments recipient noted:

I benefit a lot from direct payments. The idea of getting cash, which you control, is brilliant... Instead of a social worker or nurse dictating what I can and cannot do, it gives me real control. If I'm going to get back to being me again... It gives me so much freedom... I'll fight to get more control over my life. Now I have more energy and can think more clearly I want to direct what happens to me more and more (Irish 1998 p32).

Within this context, the Institute for Applied Health & Social Policy (IAHSP), King's College London secured funding from the Department of Health and the King's Fund to establish a national pilot project to promote independent living through the implementation of direct payments for people experiencing mental distress. Ridley and Jones (2002) argue that one way of addressing the barriers to wider access to direct payments is through setting up pilot projects to support and evaluate the process in order to develop the lessons learned for wider implementation.

The purpose of the National Pilot to implement direct payments in mental health was to promote independent living through the increased take-up of direct payments. It sought to draw upon the philosophy and practice of Independent Living developed by the international disability rights movement (see Barnes 1992; Kestenbaum 1996; Hasler et al 1999; Charlton 1998). The Independent Living philosophy⁴ is based upon the idea that disabled people are oppressed and social structures frequently operate in ways which disable people from exercising their rights and from fully participating in communities and activities of their own choosing. The notion of self-determination which is inherent in this philosophy does not assume that people could necessarily meet their needs alone but 'with assistance' (Morris, 1997). It argues that many people require personal support or other services to ensure their citizenship and social inclusion and that these supports must be funded and provided in such a way that the individual, as far as possible, remains in control. The right to have Individualised Funding or direct payments to purchase one's own support and assistance is central to the Independent Living philosophy and has been campaigned for vigorously by disabled people (Campbell, 1998; Glasby and Littlechild, 2002; Hasler 1999 Stainton and Boyce, 2002; Zarb and Evans 1998; Evans 2003).

The National Pilot aimed to enable service users to have greater choice and control over their support arrangements through using direct payments. It supported individual Local Authorities to offer direct payments to mental health service users and to set up local structures necessary to facilitate implementation (Bamber 2002). The National Pilot was launched in February 2001 and ended in July 2003. Five Local Authorities were recruited to take part in the pilot project. These were the London Borough of Barnet, Hampshire, Leicester City, Surrey and Tameside (Greater Manchester). A specific target was set in relation to facilitating up to 50 mental health service users across the sites to take-up direct payments, i.e. ten people within each site.

Local Authorities were recruited on the basis of agreeing to the following criteria:

- To be excited by and interested in the project
- To be already implementing direct payments for other care group(s)
- To have a progressive approach to or have active user involvement and empowerment in service commissioning and/or provision
- To try to target black and minority ethnic communities (3/5 sites)
- To be willing and able to directly provide direct payments advice and support for up to 10 people or invest resources into a centre providing direct payments support (approximate cost £15k)
- To be willing and able to provide some overhead resources for local administrative support, training, networking and travel for the area's pilot project and to support the involvement of service users (approximate cost £2-5k)
- To be prepared to contribute to the national and local dissemination of outcomes from the pilot site
- To designate a local senior manager to be the local contact for the pilot.

Professionals' ongoing concerns about eligibility and interpretation of the 1996 direct payments legislation which states that service users must be 'willing and able' to manage direct payments (with assistance if necessary) had a number of significant parallels during the National Pilot. During this report, reference is made to this 'willing and able' clause in relation to the implementation process as much as to the criteria used for determining a client's eligibility. One of the key lessons which became apparent early in the pilot was that within Local Authorities, key senior managers and individual care co-ordinators had themselves to be 'willing and able' to support take-up in order for implementation to be effective. These factors are explored throughout this report.

There were five key components to the National Pilot: site co-ordination, local steering groups, 'All Sites Days', the e-group and a newsletter. These are outlined in turn.

SITE CO-ORDINATION

The National Pilot was co-ordinated by the Director of the Leadership and Organisational Development Programme at IAHSF who oversaw the setting up and development of the pilot and liaised with the local sites. Part-time⁵ local site co-ordinators were recruited from within local service user networks to support implementation at the local level and to ensure that service users had considerable input into the direction of the pilot. The site co-ordinators worked together with local stakeholders such as Local Authority leads⁶, local direct payments support services and/or Independent Living Centres (ILCs) and mental health teams to assist with implementation and to raise awareness about the National Pilot within local sites. Site co-ordinators met together regularly during the duration of the pilot to share learning and provide peer support. The site co-ordinators specifically raised important questions and provoked discussion. They were seen as key to helping with presentations, providing information, linking with local user groups and helping to develop procedures such as self-assessments and advanced directives⁷.

LOCAL STEERING GROUPS

The site co-ordinators supported the setting up of a local steering group to facilitate implementation. The local steering groups invariably acted as the active forum for overseeing the progress of the pilot. Membership of the groups was carefully considered to ensure multidisciplinary and multi-sector representation and commitment to the pilot process. Thus, where possible, they were chaired by the Local Authority lead for direct payments in mental health. As well as the local pilot site co-ordinators, membership included representation from the direct payments support service or ILC and, where possible, local user groups, voluntary sector organisations, mental health team managers, care co-ordinators, a Local Authority training officer and finance/contracts officer.

Their aim was to provide a regular forum to address ongoing practical issues in relation to implementation and to provide a focus for the pilot to ensure that implementation was kept on the local agenda. They enabled a positive environment where key questions and difficulties were raised, discussed and addressed⁸, developed appropriate local guidelines, pathways and procedures and facilitated greater communication across the various sections of the Local Authority and mental health services.

ALL SITES DAYS

The National Pilot organised regular 'All Sites Days' approximately every six months during the pilot. Each Local Authority took turns to host the day and all participating sites took part to bring together discussion and progress regarding implementation. Invitations to the day were sent to steering group members and other individuals identified as being key to implementation, as well as any clients accessing direct payments. Often, the individual site that hosted the day had a mental health direct payments recipient in attendance for at least part of the day.

Feedback from the evaluation participants suggested that the days were particularly useful for sites to find out more about what the other Local Authorities were doing, to make comparisons and to generate ideas from how different sites worked. In particular, the aspect of the days considered most beneficial was the opportunity to share across the sites⁹.

However, there was a strong consensus that the days did not fulfil their potential as an active forum for cross-site discussion and learning. Site participants were keen to develop information regarding local guidelines and specific practice issues¹⁰. Most importantly, sites often requested more information on the actual uses of direct payments across sites. However, as will be seen, given the slow process of implementation and take-up, this information was often not forthcoming until later on in the pilot. In addition, due to the varied level of knowledge and involvement of key participants and time constraints, some participants¹¹ felt that they required a forum in which they could discuss the complexity of implementation, including broader strategic issues.

E-GROUP

In light of the need to focus on national learning and develop cross-site discussion, the National Pilot organised an e-mail discussion group focusing specifically on implementing direct payments in mental health. All local sites were encouraged to take part in the discussion group as well as other Local Authorities in England and any other individuals and organisations keen to progress implementation. The e-group encouraged debate and information-sharing about specific issues relevant to mental health and direct payments¹². Service users trying to access direct payments in other areas shared some of their experiences with the e-group and it provided a useful mechanism for people to be put into contact with each other. Significantly, it was service users who used the e-group as much if not more than Local Authority managers and mental health service professionals. It was also used more often by people from Local Authorities outside the National Pilot sites.

NEWSLETTER

In addition, the National Pilot launched a Newsletter entitled 'It's Your Voice' which was given out to all the participating sites to circulate within their local areas and also provided an information resource about the National Pilot for other areas. The newsletter gave information about the National Pilot, basic information about participating sites and reported on any relevant national policy documents and guidelines. Due to various difficulties with production, only two newsletters were issued during the pilot: the first was issued in the middle of the pilot and the second towards the end of the pilot period.

SERVICE USER CONFERENCE

In addition, IAHSF and the National Centre for Independent Living (NCIL) developed a series of strategies to promote direct payments in mental health. In February 2002 they jointly hosted a national conference for mental health service users to share information and ideas about direct payments. This was funded by the Joseph Rowntree Foundation and was written up in 'Making Choices, Taking Control' (Davidson and Luckhurst 2002). The conference was heavily oversubscribed and over 50 survivors and users of the mental health system attended from across the UK. Participants listened to presentations from disability activists and campaigners, a National Pilot site co-ordinator as well as from a mental health service user who had been successfully using direct payments. Participants discussed the potential of direct payments, peoples' concerns and difficulties regarding access to them and possible ways forward. Following on from this conference, further funding has been secured from the Joseph Rowntree Foundation to host another conference. This conference will specifically address care co-ordinators' concerns and anxieties and provide working examples and practice guidelines to practitioners. Thus, although the National Pilot finished in July 2003, work started by the project is still being carried through by various organisations involved in the pilot. Further, it is hoped to produce a video specifically targeted at mental health service users detailing peoples' experiences of using and managing direct payments. The lack of support offered to mental health service users generally in accessing direct payments and the overwhelmingly positive response to the service user conference¹³ specifically highlights the necessity for this project.

1.4 Outline of the Evaluation

In 2002, the National Institute for Mental Health in England (NIMHE) commissioned IAHSF¹⁴ to conduct an evaluation of the implementation of direct payments for people with mental health needs. The study commenced in October 2002 and was conducted within the five Local Authorities sites that took part in the National Pilot.

AIMS AND OBJECTIVES OF THE EVALUATION

The overall aim of the evaluation was to collate and evaluate the collective learning generated from the National Pilot about the implementation and take-up of direct payments in mental health. In doing so, it attempted to facilitate a variety of accounts that were open, honest and reflective about the process of implementation. Most importantly, it sought to explore in-depth the early experiences of accessing, receiving and managing direct payments from the perspectives of clients, workers, managers and other key stakeholders.

In pursuit of these aims, the key objectives were:

1. To identify the range and variable use of direct payments and to provide 'real life' examples of their implementation in practice.
2. To provide a profile of the characteristics of the recipients of direct payments across pilot sites.
3. To compare and contrast the approaches to implementing direct payments within each site, in particular any differences arising from the models adopted for the management of direct payments. This comparison considered any difference arising from whether direct payments are provided through an in-house (Local Authority) model or through an externally commissioned independent organisation (e.g. ILCs).
4. To highlight the factors which support and hinder the implementation of direct payments for people with mental health needs.
5. To explore the process, experience and short term impact of implementing direct payments for service users, especially in relation to the exercise of choice and control, the facilitation of independence and social inclusion, and the development of user-centred and culturally sensitive services.
6. To explore the benefits and difficulties arising from direct payment use.
7. To analyse the research findings within the context of national guidance, local policies and published literature.
8. To deliver a final report which provides a thorough evaluation of the implementation and use of direct payments by people with mental health needs, draws conclusions about the kinds of services and types of support arrangements people need and want and makes recommendations about the development of this initiative at local and national levels.

1.5 Report Structure

The remainder of this report is structured as follows:

- Chapter two outlines the evaluation methods. It gives an overview of the study focus, research design and approaches to data collection and analysis. It identifies methodological issues encountered in conducting the research and points out the limitations of the study.
- Chapter three gives an overview of the sites that participated in the pilot and outlines various similarities and differences in implementing direct payments across sites. The chapter goes on to map progress in facilitating access and take-up of direct payments across all five pilot sites during the pilot period.
- Chapter four gives a number of examples of the various ways in which recipients have used direct payments.
- Chapter five focuses on participants' views of the benefits of using direct payments.
- Chapter six explores the contextual and organisational factors that supported or hindered the implementation of mental health direct payments within the national pilot sites.
- Chapter seven looks at the key role of the care co-ordinator in the process of implementing direct payments in mental health. It focuses on their gate-keeping role in direct payments. In particular, it considers factors which contribute to their selection and referral of clients for direct payments as well as the factors which have supported and hindered implementation in practice.
- Chapter eight reviews a range of issues raised by care co-ordinators and the key concerns they highlighted about progressing direct payments in mental health.
- Chapters nine and ten present more views of direct payments recipients themselves. Chapter nine looks at the process of getting on direct payments and chapter ten summarises the issues recipients raised about managing payments.
- Finally, Chapter eleven draws together the main conclusions from the evaluation findings and makes recommendations for the development of direct payments within mental health.

Throughout the following chapters, all extracts from the data have been anonymised in order to protect participants' identity. Where attributions are given, these refer only to participants' roles or professional groups, and not to named individuals. Individual sites are only identified in relation to illustrating specific points in Chapter three.

1.6 Terminology Used

In this report we refer primarily to 'people with mental health needs' rather than various other terms that could be used (e.g. mental distress/mental health problems etc). Direct payments are based on providing support in accordance with a person's assessed mental health needs and should involve a high degree of self-definition of those needs.

The term 'direct payments support worker' is used as a generic term throughout the report to include those staff members working for a direct payments support agency whether or not this is run by a Local Authority or independent organisation¹⁵. Likewise, the term 'direct payments support service' is used whether or not the Local Authority or an independent organisation (e.g. an ILC) provides this service.

Specific local pilot sites involved in the national pilot are not necessarily identified unless a specific comparison is made between different sites. Also specific job titles are not attributed to individual research participants. Job titles vary considerably across sites so using general terms helps to maintain confidentiality and to identify general issues raised.

More generally, there are difficulties with applying terminology that has developed in direct payments and the Independent Living Movement in relation to mental health. Two examples are discussed below.

The Independent Living Movement often uses the term 'Personal Assistant User' to describe people who use direct payments to organise their own support arrangements. However, many of the people using direct payments who took part in this research did not employ Personal Assistants (PAs). Therefore, in this report we use the rather inadequate term 'direct payment recipient'. Furthermore, where recipients did employ workers, the term 'Personal Assistant' did not necessarily capture the variety of tasks in which workers were involved¹⁶. In particular, whilst people with physical disabilities often used PAs to assist with personal care, this was less likely amongst those with mental health needs. However, for consistency of approach and in line with the Independent Living philosophy, we continue to use the term PA. Until alternative terms are developed, these terms seemed the most appropriate for the purposes of this report.

In addition, it should be noted that this year the Department of Health will launch a public consultation about renaming 'direct payments' as the same term is used by the Department of Work and Pensions in relation to the paying welfare benefits directly into beneficiaries' bank accounts. Therefore, the term 'direct payments' as used within the context of this report is likely to change in the future.

Having outlined the background to the study, the following chapter gives an overview of the evaluation methodology.

- ¹ For example when the 1996 direct payments legislation was being debated in parliament (see Beresford 1996).
- ² Proposed reforms of the Mental Health Act calling for greater use of compulsory treatment in the community are cause for concern and it remains to be seen how this legislation, if passed, may affect progressive initiatives such as direct payments.
- ³ This is usually the service user's social worker or CPN but it could also be a psychiatrist, occupational therapist or psychologist etc.
- ⁴ See the First International Conference on 'Self Determination and Individualized Funding', Seattle 29th-31st July 2000 which provided a 'Declaration on Self Determination and Individualized Funding' for further explanation of the Independent Living philosophy.
- ⁵ One day a week.
- ⁶ i.e. the person identified as having lead responsibility for the pilot in the local authority.
- ⁷ Advanced directives are statements made by a person about what they would (or would not) like to happen to them in the event of a mental health crisis or lessened capacity that may result in mental health intervention. They are like 'living wills' and although not, as yet, recognised in law they can be used to influence treatment decisions etc. (Szmukler et al 2000).
- ⁸ Such as lack of referrals and training.
- ⁹ For example, there were sessions when people were divided into their distinct groups across sites (Local Authority leads, direct payments support service workers/Independent Living Centre workers or voluntary organisations/other steering group members) and had the opportunity to share experiences and discuss issues of concern.
- ¹⁰ Such as local site interpretation of national policy and practices such as usage of direct payments, local eligibility criteria, charging, training, funding issues etc.
- ¹¹ In particular the Local Authority leads, commissioning managers and senior mental health managers.
- ¹² Such as discussions and queries about Health Act Flexibilities and the 'willing and able' assessment criteria.
- ¹³ Most notably, the response to the presentation given by the direct payments recipient was especially positive.
- ¹⁴ It should be noted that during the course of the National Pilot, IAHSP closed (at the end of July 2003). Following this, the National Pilot evaluation was co-ordinated and supervised by the Health and Social Care Advisory Service (HASCAS), although King's College London continued to employ the lead researcher. HASCAS was formed from a merger between the mental health programme of IAHSP (the Centre for Mental Health Services Development) and the Health Advisory Service.
- ¹⁵ This term also includes Independent Living Advisors.
- ¹⁶ See Pita et al (2001) which discusses using personal assistance services in mental health in the US.

CHAPTER 2

Methodology

2.1 Study Focus

Previous research has identified a variety of attitudinal and practical barriers to implementing direct payments for mental health service users (Maglajlic et al 1998; Ridley and Jones 2002; Witcher et al. 2000). For example, the low level of knowledge about direct payments amongst users, staff and carers is frequently cited as a barrier across client groups (Zarb and Naidash 1994, Holman and Bewley 1999) and specifically in mental health (Ridley and Jones 2002). The co-existence of this evaluation alongside the National Pilot made it possible to consider these barriers in more detail. More importantly, it provides tangible examples of how these barriers were being addressed in practice. Research and evaluation of new initiatives are able to capture issues that are often overlooked in more established projects (Clark and Spafford 2002). However, as will become apparent, implementation and take-up was very slow. In view of this, the data collected referred mainly to the early stages of implementation and take-up.

2.2 Research Design

In order to meet the aims and objectives of the evaluation, a multi-method approach was adopted. Predominantly, qualitative methods were employed to elicit the views of key informants on the process of implementing the direct payments and the short-term impact of direct payments for recipients. However, quantitative approaches were also adopted to collect data on referral and take-up of direct payments.

2.3 Data Collection

Data collection was carried out between November 2002 and September 2003. This comprised five main strands:

1. Semi-structured questionnaires and guided group discussions with members of site steering groups.
2. Semi-structured interviews with direct payment recipients, care co-ordinators and the Local Authority leads for direct payments.
3. Participant observation of a sample of meetings held as part of the National Pilot (All Sites days, site co-ordinator and steering group meetings).
4. Document analysis of minutes of meetings held throughout the duration of the pilot.
5. Collection of quantitative data on sources and outcome of referrals for direct payments, direct payment packages and the demographic characteristics of people referred for and those receiving direct payments.

In addition, interviews were conducted with members of the National Pilot team (the National Pilot co-ordinator and site co-ordinators) to explore their perspectives and observations on progress within and between sites. These interviews gave a more national perspective from key players who were influencing implementation from 'outside' actual local processes and structures. Furthermore, ongoing discussions were held with staff from local direct payment support services to ascertain progress in implementation. At least two visits were made to each local direct payments support service during the duration of the pilot where informal interviews were carried out with the manager and the local direct payments support workers.

A range of research instruments were devised to support data collection. Their design was informed by published direct payments literature, the study aims and focus, instruments used in previous studies and local implementation of direct payments within the pilot sites. The study was designed to be flexible and responsive to local arrangements and circumstances. The process for data collection was as follows.

STEERING GROUP MEMBERS

Initially, all steering group members in each site were asked to fill in a questionnaire. This was followed up by a guided group discussion with each steering group which was audio-taped. Analysis of the questionnaires and group discussions helped to identify local contextual factors and to establish the key stages in implementation, the extent of progress made and the factors that had helped and hindered progress from the perspectives of a cross-section of informants within each locality. An average of eight people took part in each site.

LOCAL AUTHORITY LEADS

The group discussions were followed up by individual interviews with the Local Authority lead in each of the five sites, i.e. the person who was assigned the task of overseeing implementation at a local level. These interviews offered an opportunity for exploring the issues raised within the group discussions in greater depth and gave an overview of the key local issues helping and hindering implementation from a strategic commissioning/service perspective.

CARE CO-ORDINATORS

It has been well documented that although care co-ordinators are the main point of access to direct payments, their lack of knowledge and awareness about direct payments is still a key barrier to enabling mental health service users to access direct payments (Maglajlic 1999; Ridley and Jones 2002). Therefore, rather than repeating the focus on establishing the extent of professional knowledge, the evaluation specifically targeted care co-ordinators who had benefited from the increased awareness of direct payments through the National Pilot and who, as a consequence, had actually referred one or more clients onto direct payments. This offered opportunity for more in-depth investigation of the beliefs, ideas and practices of individual care co-ordinators and of how they facilitate (or prevent) access to direct payments.

During the pilot, social workers and CPNs made approximately equal numbers of referrals for direct payments. In view of this, a cross-section of care co-ordinators were selected for interview across the five sites proportional to the amount of referrals generated in each area. Thus, more care co-ordinators were interviewed in areas where greater numbers of referrals for direct payments had been made. Care co-ordinators were recruited once they were identified as referring clients onto direct payments.

In total, 20 care co-ordinators were formally interviewed individually: ten social workers and ten CPNs. As the evaluation progressed, a number of informal discussions were held with other care co-ordinators. In addition, a visit was made to one Community Mental Health Team (CMHT) where more than ten clients had been referred for direct payments. Informal discussions were had with a selection of the care co-ordinators in the team and the researcher attended their team meeting. The formal interviews covered a number of topics including their views on the appropriateness of direct payments for their clients, their experience of referring onto direct payments, any difficulties with the process and any identified outcomes and benefits.

DIRECT PAYMENT RECIPIENTS

All clients who had been offered direct payments¹⁷ by the end of the National Pilot (July 2003) were invited to take part in the evaluation. Letters were sent out via the direct payment support services. In addition, individual care co-ordinators and local support workers followed up these letters to invite participation. As with the care co-ordinator sample, attempts were made to recruit a cross-section of recipients across the five sites proportional to the numbers of people on direct payments in the different localities. In the event, approximately one third of the clients who had been offered direct payments in each site were interviewed.

Twenty-two in-depth individual interviews were carried out with clients and/or a nominated carer¹⁸. In addition, one group interview was conducted with a group of service users who were collectively using direct payments to access a creative arts group. Therefore, a total of 27 mental health service users were interviewed who had been offered direct payments. Interviews with recipients included:

- a semi-structured interview focusing on the experience of accessing and receiving direct payments. These questions were devised on the basis of the evaluation's aims and objectives and adapted from the interview schedules used in two similar studies (Witcher et al 2000; Ridley and Jones 2002)
- a questionnaire examining the impact on quality of life resulting from using direct payments. The categories for these questions were informed by reference to the Lancashire Quality of Life interview schedule (Oliver 1991).

Interviews were carried out with clients at various stages of accessing direct payments. The service user interviews included two clients who had initially been offered direct payments but for whom payments had been subsequently withdrawn. Of these, one client had been offered direct payments but had been admitted to hospital before they could be taken up. When discharged, direct payments were no longer seen as appropriate. The other client had been offered direct payments but was unable to find a suitable PA and decided not to take the payment up.

The rest of the interviews were carried out with clients who were receiving direct payments but at different stages in this process. Thus, three clients had received payments but were not currently using them due to difficulties setting up their support arrangements¹⁹. The five clients interviewed as a group had been in receipt of payments for about six weeks and another client had been using direct payments for only two months. The remaining 16 interviewees had been receiving direct payments for anything between a period of three and 17 months.

QUANTITATIVE DATA COLLECTION

Two databases were designed to gather information for the study and sent to staff at the five sites for completion. The first was designed to collect data in relation to implementation issues, local structures and progress. The second was sent out to each direct payments support agency following the end of the pilot in July 2003. It sought information on referrals to the scheme and take-up of direct payments during the pilot period. Background information was gathered in order to develop a profile²⁰ of those referred for direct payments during the pilot and of actual recipients. In addition, information was gathered via this database on:

- who had referred clients onto direct payments
- date of referral and outcome of referral i.e. whether the package was agreed or rejected and whether it was taken up
- if the package had been taken up: a) the number of hours of the package; b) what the payments were being used for.

¹⁷ i.e. if a direct payment package had been agreed by this date.

¹⁸ Three interviews were carried out with the direct payment recipient and their nominated carer/significant other. In addition, two interviews were carried out just with the nominated carer where the direct payment recipient was not in a position to be interviewed. Whilst there is not enough data here to specifically comment on the views and perceptions of carers or significant others, this additional material helped supplement the data from clients directly.

¹⁹ For example, difficulties in recruiting PAs.

²⁰ For example, profiles in relation to gender, age, ethnicity, living arrangements, CPA level.

²¹ The intention was to conduct interviews with recipients at the point at which payments had been agreed and then six months later to investigate short-term outcomes of receiving direct payments.

²² As previously indicated, the content of this questionnaire was informed by reference to a standardised Quality of Life assessment tool. It was then adapted to incorporate questions deemed to be potentially relevant to mental health and direct payments.

²³ For example, questions were asked under the categories of leisure and outside interests, relationships, self-concept and health.

2.4 Data Analysis

With respondents' permission, interviews were tape recorded and subsequently transcribed or otherwise extensive notes were taken. Qualitative data were analysed using a systematic thematic content analysis method. Quantitative data were analysed using a database developed in Microsoft Excel and descriptive statistics produced.

It is important to note that in general the interview data have been analysed and reported in relation to sample groups rather than being broken down by local sites. Given the relatively small base numbers within each of the sample populations, it was considered that this approach would be best to ensure both respondents' and sites' anonymity. However, where site-specific information was identified, this was noted and has been included in the analysis.

2.5 Ethical Approval

In view of the fact that the study was being conducted in five study sites and involved some NHS staff and users of mental health services, ethical approval for the study was sought from a multi-centre research ethics committee (MREC). Despite the fact that the application for ethical approval was submitted at the very start of the study, delays in processing the application contributed to the decision to reorder the sequence of interviews. However, this did not unduly affect the conduct of the research and ethical approval was subsequently awarded. A study protocol that incorporated and developed the procedures outlined in the ethics application was devised and adhered to within the conduct of the research.

2.6 Methodological Issues and Study Limitations

Overall, the study has been successful in relation to meeting the objectives of the research. Despite this, three main methodological issues arose during the conduct of the study concerning the recipient sample, evaluating outcomes for direct payment recipients and the quantitative data collection. These are considered in turn.

RECIPIENT SAMPLE

In general, the participant samples recruited to the study were representative of the range of interests within the pilot sites and were consistent with the criteria established for selection. However, the slow rate of take-up of direct payments within the pilot meant that the potential sample population of direct payment recipients was relatively small. Whilst adhering to the procedures established within the research protocol, time constraints within the study and the approach taken to recruiting direct payment recipients undoubtedly limited the numbers of direct payment recipients who were ultimately interviewed.

Furthermore, the length of time it took to process and set up direct payment packages, particularly if recipients employed their own PAs, meant that most recipients only started using direct payments in the last year of the National Pilot. On the other hand, the numbers of respondents were maximised by not specifying that individuals had to have been in receipt of direct payments for a set period of time. In conducting the interviews, the individuals who had been receiving direct payments the longest were interviewed first.

OUTCOMES FOR DIRECT PAYMENT RECIPIENTS

In the original study design, the intention had been to carry out a two-stage interview process²¹ with direct payment recipients to examine short-term impact and outcomes. Again, the slow process of implementation meant that it was not possible to do any significant assessment of progress 'before and after' direct payments. The variety of stages that individuals were at in relation to setting up and using their direct payments raised questions about the validity of any comparisons that might be drawn. As a consequence, the findings primarily relate to the early stages of individuals actually getting on and setting up direct payments, rather than impact or outcomes.

However, in order to gather some preliminary data in relation to impact, a quality of life questionnaire²² was devised which explored individuals' perceptions of the impact of using direct payments on various aspects of their life. Recipients were asked whether they thought that the direct payment was having an impact on these aspects²³. They were given the option of either selecting if it had a positive or negative impact, if there was no change, or if the question was not relevant to them. It is important to highlight that the findings presented in this report concerning self-reported impact on quality of life relate only to the 16 clients who had been using direct payments for at least three months at the time of interview. These data, alongside other information gleaned from the semi-structured interviews with both recipients and care co-ordinators, allowed the identification of perceived benefits and short-term impact of using direct payments. Clearly, this signals the need for further longitudinal research to establish the outcomes for recipients in the longer term.

QUANTITATIVE DATA COLLECTION

As previously indicated, a database was developed to gather background information from participating sites about referrals and about those in receipt of payments. However, difficulties were encountered with getting hold of the requested information and ensuring the consistency of data across sites, reflecting differences in the way information was recorded and collected within the participating sites. This was often related to the varying size of sites. For example, two sites were large counties that incorporated a number of different local districts each with their own procedures and systems. It was also linked to whether the local direct payment support services were in-house or independent. Overall, this raises questions about the systems for monitoring direct payments implementation at the local level; for example, clients' ethnicity was not routinely recorded. Although it was possible to collect most of the information required, where the accuracy of the information was in question or data were missing these are noted.

Having outlined the methods used within the evaluation, the following chapter presents the findings on the progress of implementing direct payments in mental health within the pilot sites.

CHAPTER 3

Progress in Implementation

This chapter is divided into three main sections. The first section describes the different sites that participated in the pilot. Based on a cross-site comparison, section 3.2 outlines various similarities and differences in implementing direct payments. The third section maps out the progress in facilitating access to and take-up of direct payments across all five pilot sites during the pilot period. It details the numbers and sources of referrals, the outcome of referrals and the characteristics of direct payment recipients. It then goes on to give an overview of the range, usage and level of agreed direct payment packages.

3.1 Overview of Participating Sites

Box 3.1 provides an outline of the five participating sites. Population figures are taken from the UK Census 2001.

BOX 3.1 PILOT SITE CHARACTERISTICS

Barnet has a population of 314,561 people. It is an Outer London borough with relatively high ethnic diversity (26%) including people from Jewish, Chinese, African and Caribbean communities. Barnet currently has an in-house Local Authority direct payments support agency.

Hampshire has a population of 1,240,032 people. It is a large shire county in the south-east of England with a small ethnic population (approx 1.4%) including Asian, African, Caribbean and Chinese people. Hampshire has an independent direct payments support agency (Southampton Centre for Independent Living). It was the first Local Authority to develop an independent direct payments scheme and has a long history of offering direct payments to people with physical disabilities dating back to the early 1980's.

Leicester City has a population of 279,923 people. It is part of a unitary authority covering an inner city urban area with relatively high ethnic diversity (24%) including people from Asian, African and Caribbean background. Leicester has an independent direct payments support agency (Mosaic).

Surrey has a population of 1,059,015 people. It is a large home county with a small ethnic population (2.8%) including people from Asian, African Caribbean and Asian communities. Surrey has an independent direct payments support agency (Surrey Independent Living Council).

Tameside has a population of 213,045. It is a small metropolitan borough of Greater Manchester, with a mixed urban and rural community and a 4.1 % minority ethnic population of mainly South East Asian origin (Indian, Pakistani and Bangladeshi). It currently has an in-house Local Authority direct payments support service.

3.2 Similarities and Differences in Implementation

The following sections outline specific similarities and differences across the participating sites in relation to their procedures for implementing direct payments in mental health. In order to preserve site anonymity, the findings focus on general themes rather than identifying particular sites.

FUNDING OF DIRECT PAYMENT PACKAGES

During the pilot, two sites had put aside a small amount of funding²⁴ to resource individual direct payment packages once they had been accepted. In the other three sites, direct payment packages had to be funded out of the usual local community care purchasing budget as and when they were agreed.

All sites applied their own local criteria for eligibility and determining the level of funding for direct payment packages. Officially, all sites applied the same criteria as those used to access directly provided community care services. Towards the end of the study, all of the sites were revising their eligibility criteria in accordance with the Fair Access to Care Services guidelines. In practice, this usually meant that only clients considered as falling under priority of need '1' (critical) or '2' (substantial) were being considered as eligible. However, as might be expected, there was variation in local and individual interpretation of these guidelines dependent on a number of factors which will be considered in later chapters.

VARIATIONS IN FUNDING PACKAGES

Firstly, take-up and use of direct payments depended on the overall community care budget available to a Local Authority in relation to the local client population and how flexible their funding and commissioning arrangements were²⁵. In one area, direct payments were awarded to clients who were not currently accessing support services (apart from a CPN or social worker) or were provided in addition to what they were currently receiving in-house. However, in another area, direct payments were primarily only offered to individuals who wanted to directly change to direct payments from an externally provided support agency. The first area may find it difficult to replace an in-house support service but had sufficient resources to be able to fund additional 'unmet needs'. The second area found it easier to replace services provided by an external agency, but did not have sufficient resources to meet unmet needs via direct payments.

Secondly, take-up and use of direct payments also depended on what services were currently available in the local area²⁶. For instance, in one area, clients frequently had to travel long distances to use community or mental health facilities but the Local Authority did not provide assistance with transport. As a result, transport was identified as a key area of need and direct payments were often used to cover transport costs.

Thirdly, interpretation at the individual practitioner and Local Authority level shaped the parameters in relation to what kinds of needs direct payments could be used to meet or what kind of services payments could be used to fund. Most notably, this was linked to the boundaries between 'social' care and the need for other services such as health, leisure and education. Thus, one site had a number of clients using direct payments for gym memberships. However, the Local Authority lead in another site reported that this would not be possible in their area. Whilst they would fund somebody to be assisted in going to the gym, they indicated that they would not fund gym membership as it would not be considered as 'social' care.

Variations also existed in the hourly rate that Local Authorities set for the payment of personal assistants (PAs) which varied between £6.67 to £8.00 per hour. As we shall see in later chapters, the availability of PAs could be a crucial barrier both to the uptake of direct payments and the success of direct payment packages. In one area, where a client with multiple and complex needs²⁷ accessed direct payments, a higher rate of £15.00 an hour was awarded in order to secure an appropriate PA.

Some sites paid additional amounts for setting up costs, payroll services and for contingency, crisis or back-up support where this was assessed as necessary. The availability of these resources affected how flexible a client's support arrangements were and how much support service users were able to get with managing their direct payments. In turn, this was linked to how well-resourced the local direct payment service was and their capacity and skills in relation to this client group.

DIRECT PAYMENTS SUPPORT TEAMS

As previously indicated, three local direct payments support services were independent from the Local Authority and were designated as Independent Living Centres (ILCs). The other two support services were initially set up by an independent voluntary organisation but, at the time of the evaluation, were being provided in-house by the Local Authority²⁸. Both of these Local Authorities were looking to contract out the service again to an independent organisation. However, progress in achieving this had been stalled due to difficulties in finding an appropriate organisation which could serve a mixed client group.

For the duration of the pilot, all direct payments support services were funded to pay for an additional part-time support worker. Three local support services decided to employ a specialist mental health direct payment support worker. The other two sites absorbed the additional money into the service and used it to resource the service generally i.e. such that all support workers could be generic and therefore respond to all referrals (including mental health).

All of the support services had a significant history in supporting people with physical difficulties using direct payments. The role of the support agencies varied, as did the amount of support they could offer potential clients or recipients. All of the services offered a variety of support to clients being referred to direct payments. For instance, assistance could include help with paperwork, advertising for and recruiting PAs, hosting interviews for PAs, help with managing money. However, the degree and length of support offered differed considerably across sites. Thus, two sites reported that they would like to do more to help clients recruit PAs but did not have the capacity to do so. As explored further in Chapter nine, the extent of support offered to clients at the pre-assessment stage had an impact on the outcome of referrals and eventual take-up. In addition, the degree of ongoing support offered to individuals in setting up and managing their direct payments had an impact on the success of individual packages particularly when people employed their own PAs.

All sites offered one-to-one support and/or a tailor-made training package to assist recipients in using direct payments. One site expected recipients to go through a specifically designed training course that covered a variety of issues relating to setting up and running a direct payment. Support services also offered training, information and advice to mental health teams, care co-ordinators and service users. However, the pro-activeness and level of involvement of direct payments teams was notably different across sites. This was most apparent in terms of how early they became involved in the direct payment referral process, whether they helped with clients' needs assessments and how much support they could offer to both individual care co-ordinators and service users.

All direct payments support services were trying to establish arrangements for recipients to access peer support. However, most sites were having difficulty with maintaining active peer support groups and were looking towards alternative ways of providing group support. One in-house direct payment support agency did have an active peer support group which some of the new mental health recipients were beginning to attend.

REFERRAL AND ASSESSMENT PROCEDURES

All five sites indicated that care management and Care Programme Approach (CPA) systems had been integrated or were in the process of being integrated. Three sites were developing self-assessment procedures although these were still in the process of being implemented. In practice, all assessments had to be agreed by the care co-ordinator. However, where self-assessments were starting to be used or where the direct payments support agency was particularly proactive, the direct payments support workers (or other workers from advocacy or voluntary organisations) offered assistance to service users in developing their needs assessments. If accepted, these could be taken up by the care co-ordinators. These data suggest that the success of maximising the involvement of service users in assessing their own needs depends on the existence of active workers able to offer support at this stage and an inbuilt flexibility in carrying out assessments. Likewise, success also depends on ensuring that assessments are genuinely needs-led rather than service-led.

3.3 Progress Across Sites

AGREEING PACKAGES

Sites had a variety of means through which individual direct payment packages were approved. Again, this reflected how individual sites agreed any community care package. In two sites, the senior social services mental health manager agreed packages. In another site, the senior mental health social services manager set up a meeting with a service manager from another care group to agree a package. One site had a panel with representation across health and social services which agreed all community care packages in mental health. In the final site, the decision was devolved to the local mental health team managers. The two largest sites²⁹ had a variety of ways of agreeing packages depending on the area covered.

The remainder of this chapter outlines the progress made in facilitating access to and take-up of mental health direct payments within the five sites. In the main, the findings are presented across the five sites. However, where the analysis suggests important variables, differences and similarities across sites are noted.

Despite a range of practical, ideological and funding difficulties, all of the pilot sites were able to make small, but significant progress towards widening access to direct payments to mental health service users. A specific target was developed at the outset of the National Pilot which aimed to facilitate the take-up of direct payments for up to ten mental health service users in each local site, thereby enabling 50 mental health users in total to access direct payments. Given significant differences in the size of areas and populations, it became apparent that a more realistic target was a total of 50 people across sites, regardless of area. As indicated below, this target was achieved.

Data for this section were gathered from the local direct payments support agency and, where possible, verified with the Local Authority. Numbers do not necessarily reflect national statistics gathered by other bodies such as the SSI and Department of Health. In addition, direct payments teams do not necessarily have a specialist knowledge about how mental health teams work and this may affect how the information was recorded.

The next section is divided into six sections. The first section outlines the numbers of referrals and outcome of referrals during the pilot period (February 2001 – July 2003). Secondly, it identifies the sources and patterns of referrals. Thirdly, it details some characteristics of direct payment referrals and recipients in relation to gender, age, ethnicity and CPA level. The fourth section provides an overview of the range of uses of direct payments agreed during the pilot. This includes whether payments were one-off or ongoing and whether recipients employed a PA. The fifth section indicates the level of packages that were agreed and the final section outlines the time taken to agree individual direct payments.

REFERRALS AND OUTCOMES

In the following tables, 'referred' includes self referrals, referrals from care co-ordinators and others. The category 'refused' indicates that the direct payment package was refused once the package had been presented to the panel or to whoever makes a decision about the application within the Local Authority. A number of other applications may have been effectively turned down before this point if, for example, the care co-ordinator decided that it was not appropriate or suitable to proceed. The term 'withdrawn' signals that the client and/or care co-ordinator did not pursue the direct payment application. Various reasons for this are explored in more detail in the next section. The term 'pending' means that the case was still being processed at 31.7.03 but that the package had not been agreed or withdrawn.

A total of 158 referrals were made for mental health direct payments during the duration of the pilot. As table 3.1 illustrates, a total of 64 direct payments were agreed across all five sites during this period. Of these, six direct payments were offered but not taken up.

TABLE 3.1
REFERRALS AND OUTCOMES ACROSS PILOT SITES

	TOTAL NO. OF CLIENTS
REFERRED	158
REFUSED	11
WITHDRAWN	50
PENDING	33
AGREED	64
TAKEN UP	58

Table 3.2 illustrates the numbers of people who had a direct payment agreed in relation to those who might be potentially eligible for direct payments within each site. For this calculation, the numbers of people on the Care Programme Approach (CPA) have been used as, currently, mental health service users can only access direct payments if their needs have been assessed and a care plan developed under the CPA. Therefore, these figures can be considered as a proxy indicator of the service user population who might be eligible for a direct payment³⁰. The first percentage figure represents the proportion of people out of the total local population who are on the CPA (i.e. the potentially eligible service user population). The second percentage figure represents the proportion of those on CPA who have had a direct payment agreed within each site.

The figures give some indication of the differing levels of mental health need across the five areas. For example, as would be expected metropolitan areas such as Leicester, Barnet and Tameside have a higher proportion of people actually assessed as needing services in relation to their total population than Surrey and Hampshire, which are more affluent and southern shire counties.

However, caution should be adopted in drawing simple comparisons and in interpreting these data. Clearly, they indicate that take-up of direct payments in the pilot sites were still a very small proportion (less than 1%) of those who might be potentially eligible. At the same time, Local Authorities operate different eligibility criteria with implications both for service receipt and access to direct payments.

Table 3.3 illustrates the numbers of referrals and the outcome of these referrals broken down by site³¹. Whilst sites provided accurate figures in accordance with their local systems for recording information, these systems differed between sites. For example, it was unclear at what point a case was recorded as a 'referral' and when referrals were deemed as 'withdrawn'. The absence of any 'withdrawn' referrals in Surrey and the relatively large number of recorded referrals 'pending' was partly due to differences in how information was recorded. In this example, most clients who did not proceed to direct payments were recorded as 'pending'. Further, it was unclear whether there were any other cases that were withdrawn which were not recorded. Therefore, these figures indicate a very high rate of referrals which proceeded through to an agreed direct payment package in Surrey. However, there was a high level of support for direct payments from the Local Authority and senior mental health managers in Surrey, and the direct payments support service acted independently and proactively to help service users access direct payments. As we shall see in later chapters, these were two crucial factors in implementation. The available information suggests that Surrey did have the highest throughput onto direct payments both in terms of total numbers and success rate of referrals.

It is important not to consider these figures as indicators of success in themselves. These figures need to take into consideration the overall size of areas as well as the levels of need and characteristics of the populations served. Overall, referral rates were relatively consistent across sites in relation to the size of areas. However, one smaller site (Tameside) did have a higher rate of referrals in relation to other sites with a comparable population size.

TABLE 3.2 DIRECT PAYMENTS (DPS) BY CPA POPULATION

LA SITE	TOTAL POPULATION	TOTAL NO. ON CPA	% OF POPULATION ON CPA	TOTAL NO OF DPS AGREED (31.7.03)	% OF THOSE ON CPA USING DPS
BARNET	314,561	4,570	1.45%	6	0.13%
HAMPSHIRE	1,240,032	10,838	0.87%	12	0.11%
LEICESTER	279,923	4,317	1.54%	2	0.05%
SURREY	1,059,015	6,907	0.65%	29	0.42%
TAMESIDE	213,045	2,677	1.26%	15	0.56%

TABLE 3.3 REFERRALS AND OUTCOMES BY PILOT SITE

SITE	REFERRED	REFUSED	WITHDRAWN	PENDING	AGREED	TAKEN UP
BARNET	12	0	5	1	6	6
HAMPSHIRE	41	2	21	6	12	10
LEICESTER	16	0	8	6	2	2
SURREY	48	4	0	15	29	27
TAMESIDE	41	5	16	5	15	13

Another way to measure successful implementation would be in relation to the quality and size of all direct payments packages. Some sites with higher numbers of agreed direct payments included a greater proportion of smaller and/or one-off payments. During the pilot, all sites were recognised as having achieved small but significant success in relation to individual packages. Thus whilst Leicester had the lowest number of clients actually using direct payments, the two packages taken up were two of the most intensive and complex packages, involving exceptional circumstances such as employing a relative as a PA. In addition, Barnet had the highest number of packages agreed for clients from black and minority ethnic communities.

WITHDRAWAL AND NON TAKE-UP

Reasons for non take-up were often related to anticipated and actual difficulties in finding a suitable PA, managing the money and paperwork, changing circumstances and changing support arrangements. Other clients who were using direct payments sometimes experienced difficulties with setting up their support arrangements through direct payments, especially recruiting PAs (see Chapter nine for further discussion).

There were a variety of reasons given for withdrawing direct payment applications. To look at this in more detail, data were analysed from one site (Hampshire) that had a relatively high number of withdrawn cases and was able to provide information regarding these. Analysis of this small sample indicated that the decision to withdraw applications came mostly from clients themselves. For instance, 14 clients decided not to pursue their application either because they were happy with their current support arrangements, because they felt that it involved too much responsibility and paperwork or for other reasons. Other reasons included moving out of the area and having difficulties opening a bank account. On the other hand, four applications were withdrawn because the care co-ordinator did not support it and three were not pursued because of illness and/or hospitalisation. One application was unable to be pursued because the client was caught between two services.

More generally, despite repeated efforts, Hampshire were unable to retain an additional mental health-specific support worker in the direct payment support service throughout the pilot. This may have had an impact on direct payment cases being pursued and followed up.

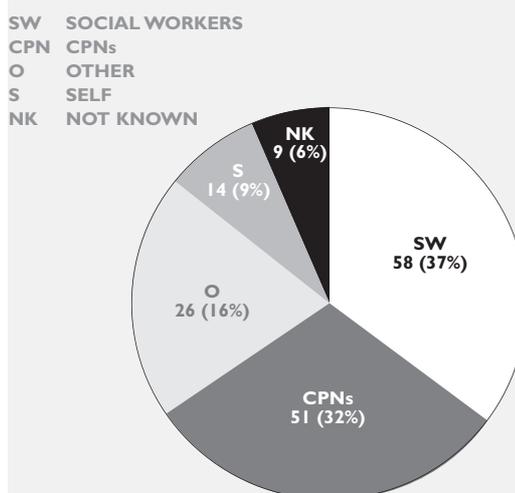
REFERRALS FOR DIRECT PAYMENTS

As might be expected, the majority of referrals came from the local Community Mental Health Teams (CMHTs). This is where most care co-ordinators are based and provides the majority of statutory mental health support. Although in one site, the majority of referrals came from the local Rehabilitation Team, on closer inspection it appeared that this team operated essentially like CMHTs did in other areas. In one area, members of an Assertive Outreach Team made six referrals. By the end of the pilot, the majority of CMHTs had been involved in one or more direct payment referral. On the other hand, approximately one third of CMHTs across the sites still had not referred at all. Whilst most teams had made less than three referrals, a handful of teams in two areas had generated five or more referrals. This was often related to a particular care co-ordinator seeing the benefits of direct payments and offering it as an option to more than one or two of their clients. It was also linked to team leaders or senior workers involved in supervising other care co-ordinators who regularly raised direct payments as an option. Box 3.2 provides a case study to illustrate these points further.

SOURCE OF INITIAL REFERRALS

Figure 3.1 categorises the source of initial referrals for direct payments based on the total numbers of people referred to the direct payments support service.

FIGURE 3.1
SOURCE OF INITIAL REFERRALS (TOTAL NUMBERS)



BOX 3.2 COMMUNITY MENTAL HEALTH TEAM CASE STUDY

This was a large CMHT with over 30 team members including community support workers. Approximately 11 workers had made referrals for direct payments including six CPNs, four social workers and one occupational therapist. This had resulted in ten clients in the team being offered direct payments and an additional five pending agreement. A group discussion was held with CMHT team members about their views and progress on direct payments. A number of factors were identified as contributing to the progress made.

Firstly, team members were aware that some ring-fenced money had been set aside to help finance direct payment packages during the pilot. This helped to create a more positive atmosphere, and a greater awareness and knowledge about direct payments in the team. In addition, the team had lost a number of their community support workers so direct payments were often seen as being able to fill this gap. Direct payments were often pursued for services that were not available in-house (such as transport and child care). From starting to see direct payments as a way of getting additional services for clients, more generally care co-ordinators began to see the benefits of offering direct payments. One care co-ordinator noted that one of the local consultant psychiatrists had been surprised at how direct payments had seemed to really benefit certain clients. The team have been actively pursuing direct payments for some of their clients and were able to be creative about care packages. A senior social worker encourages care co-ordinators to think about direct payments in supervision and team meetings. Direct payments have been put and kept on the team's agenda. Workers now think about direct payments and suggest it to other colleagues. This happened partly through word-of-mouth in relation to existing cases as well as through local involvement in the National Pilot. This has also been aided by creative use of self-assessment tools such as encouraging and supporting clients to complete a 'how I see my needs' form.

After the first few successful referrals, the process became much clearer, so workers knew who does what, who they needed to speak to and so on. In addition, workers acknowledged that the role of the local independent and active direct payments support service was crucial. Indeed, a number of workers noted that without their support and involvement throughout the process they were much less likely to pursue a direct payment for their clients.

This indicates that the majority of referrals came from social workers (37%) and CPNs (32%) and that there was a relatively even split between them.

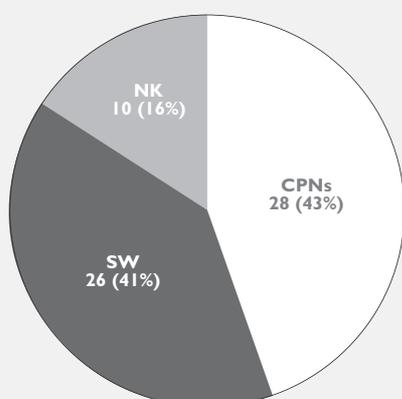
The category of 'other' included a variety of people including relatives³², support workers, advocates, user involvement workers, an occupational therapist, a clinical psychologist and workers from other agencies (such as the Citizens Advice Bureaux).

REFERRALS RESULTING IN AGREEMENT OF DIRECT PAYMENTS

As figure 3.2 illustrates, the numbers of care co-ordinators who were involved in processing direct payment applications resulting in a successful take-up of direct payments³³ was roughly equal between social workers and CPNs.

FIGURE 3.2
CO-ORDINATOR INVOLVED IN AGREED DP PACKAGES

CPNs CPNs
SW SOCIAL WORKER
NK NOT KNOWN



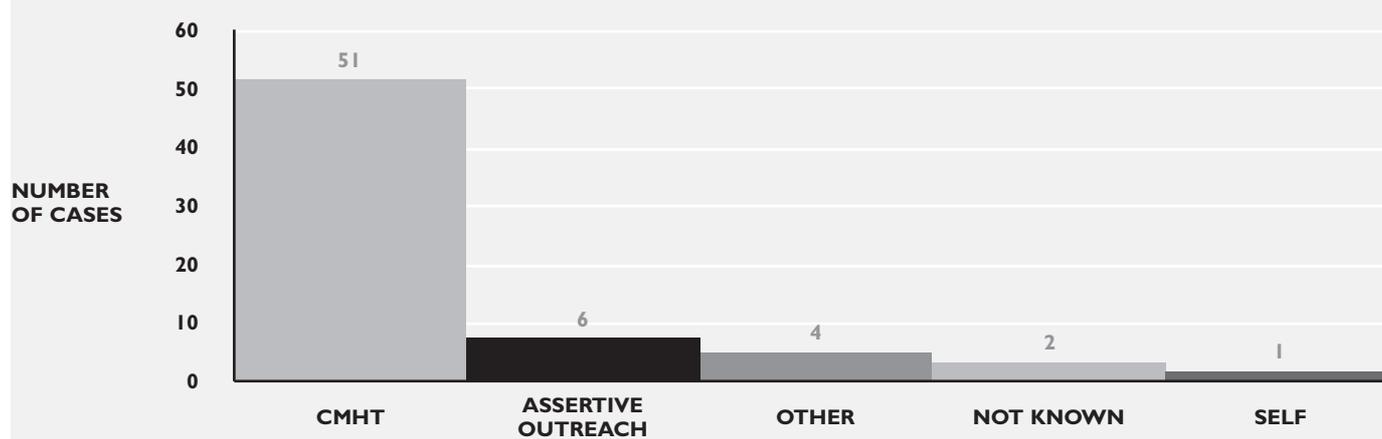
This indicates that CPNs were as successful as social workers in accessing direct payments for clients. Previous literature suggesting that CPNs were less likely to be involved in direct payments due to their 'health' rather than social care background was not necessarily borne out in the pilot. However, there were some significant differences across sites in relation to the profession of workers involved in referring and conducting the relevant assessments for direct payment packages. For example, there were a high number of referrals from CPNs in one area that had a high number of agreed packages.

In addition, despite national guidance making it clear that any professional working as a client's care co-ordinator could be involved in doing the assessments and paperwork necessary to access direct payments, this was interpreted in different ways at the local level. Thus, in one site the clear message was given that only social workers could do an assessment for direct payments. In this site, there were less referrals made and these tended to come either from social workers or from clients themselves if they did not have a social worker. At the same time, many social workers who referred clients for direct payments were often involved in highly complex cases in terms of need and service package.

Successful individual direct payment applications were tracked back to see which organisation had initially referred. This is illustrated in figure 3.3 below. The term 'other' includes an in-patient unit, day hospital, a relative and one referral from another local agency.

As would be expected, the majority of successful referrals came from CMHTs. It is worthy of note that all six recorded referrals from an Assertive Outreach Team resulted in successful applications. In addition, in the vast majority of cases, self-referrals did not usually proceed to a successful agreement in that only one out of 14 self-referrals resulted in an agreed package.

FIGURE 3.3
SOURCES OF SUCCESSFUL REFERRALS



CHARACTERISTICS OF DIRECT PAYMENT REFERRALS AND RECIPIENTS

As table 3.4 shows, women were more likely both to be referred for direct payments and more likely to have a direct payment agreed.

TABLE 3.4 GENDER OF THOSE REFERRED FOR AND IN RECEIPT OF DIRECT PAYMENTS

GENDER OF CLIENT	NO. OF REFERRALS (%)	NUMBER AGREED (%)
MALE	64 (41%)	21 (33%)
FEMALE	94 (59%)	43 (67%)
TOTAL	158 (100%)	64 (100%)

Approximately three fifth of all referrals involved female clients and they made up two thirds of all agreed packages. This may reflect the fact that more women use mental health services generally. It might also relate to women being considered to be more suitable for direct payments and/or women being more likely to ask for, and to be assessed as needing, specific help and support around practical, domestic and emotional tasks.

TABLE 3.5 ETHNICITY OF DIRECT PAYMENT RECIPIENTS

ETHNICITY	NO. OF DPS AGREED	%
WHITE BRITISH	51	80%
ASIAN	2	3%
JEWISH	2	3%
NON BRITISH EUROPEAN	1	2%
BLACK BRITISH AFRICAN	1	2%
MIXED HERITAGE	0	(-)
NOT RECORDED	7	11%
TOTAL	64	101%³⁴

As table 3.5 illustrates, there were few people from black and minority ethnic communities accessing direct payments. Most of the black and minority ethnic clients were in Barnet which has a higher than average black and minority ethnic population. In addition, one African Caribbean client, not recorded here, was in the process of having a direct payment package agreed but unfortunately went into hospital before she could proceed with it. However, once in hospital her social worker changed and the hospital staff did not feel that it was appropriate to keep it on her care plan. There was insufficient continuity in her care to enable the direct payment to be picked up again when she was in a position to pursue it.

Therefore, despite the hope that direct payments could provide more culturally sensitive support arrangements for mental health service users from black and minority ethnic communities, there was insufficient evidence from the National Pilot to be able to offer more than anecdotal evidence of this possibility. However, an example of direct payments being used by an Asian client is detailed further in Chapter four.

Table 3.6 illustrates that the majority of referrals and take-up involved clients over the age of 25 and under the age of 60. It may be that younger clients are less likely to be viewed as being suitable for direct payments. However, there were two clients aged 18/19 who were offered direct payments in one site. In addition, the pilot was specifically aimed at implementing direct payments for adult service users between the ages of 18 and 65 in accordance with how services are organised. However, some sites did generate a number of mental health referrals from clients over 65. Where information was recorded and given about these individuals, it has been included in the figures.

TABLE 3.6 AGE OF DIRECT PAYMENT RECIPIENTS

AGES	NO. OF DPS AGREED	%
UNDER 18	0	-
18-24	2	3%
25-35	14	22%
36-45	16	25%
46-55	14	22%
56-65	6	9%
OVER 65	2	3%
NOT KNOWN	10	16%
TOTAL	64	100%

CPA LEVEL

The Care Programme Approach (CPA) applies to all clients who receive services from secondary mental health services. Eligibility for direct payments should be no different from eligibility for community care and to access these clients will have to be on the CPA. There are two levels of CPA: 'standard' and 'enhanced' with clients on 'enhanced' CPA requiring more intensive and frequent input than those on the 'standard' level from more than one professional or agency.

In-house direct payment support services were more likely to record the CPA level of referrals than independent support services. Therefore the comparison of the CPA levels of clients referred for direct payments and who were then subsequently offered direct payments (table 3.7) is based on data from two sites only (Barnet and Tameside).

TABLE 3.7 CPA LEVEL OF DIRECT PAYMENT RECIPIENTS FROM TWO SITES

CPA LEVEL	NO. OF INITIAL REFERRALS (%)	NO. OF DPS AGREED (%)
STANDARD	17 (32%)	6 (29%)
ENHANCED	33 (62%)	13 (62%)
NOT KNOWN	3 (6%)	2 (9%)
TOTAL	53 (100%)	21 (100%)

Based on this limited information, it appears that once referred, there is no significant difference between whether a client is on standard or enhanced CPA as to whether it is likely to proceed to an agreed package. For both CPA levels, a third of clients went on to have a direct payment agreed. In addition, table 3.8 below illustrates the total number of clients across all five sites who were offered direct payments by CPA level.

TABLE 3.8 CPA LEVEL OF ALL DIRECT PAYMENT RECIPIENTS

CPA LEVEL	NO. OF DPS AGREED	%
STANDARD	17	26%
ENHANCED	42	66%
NOT KNOWN	5	8%
TOTAL	64	100%

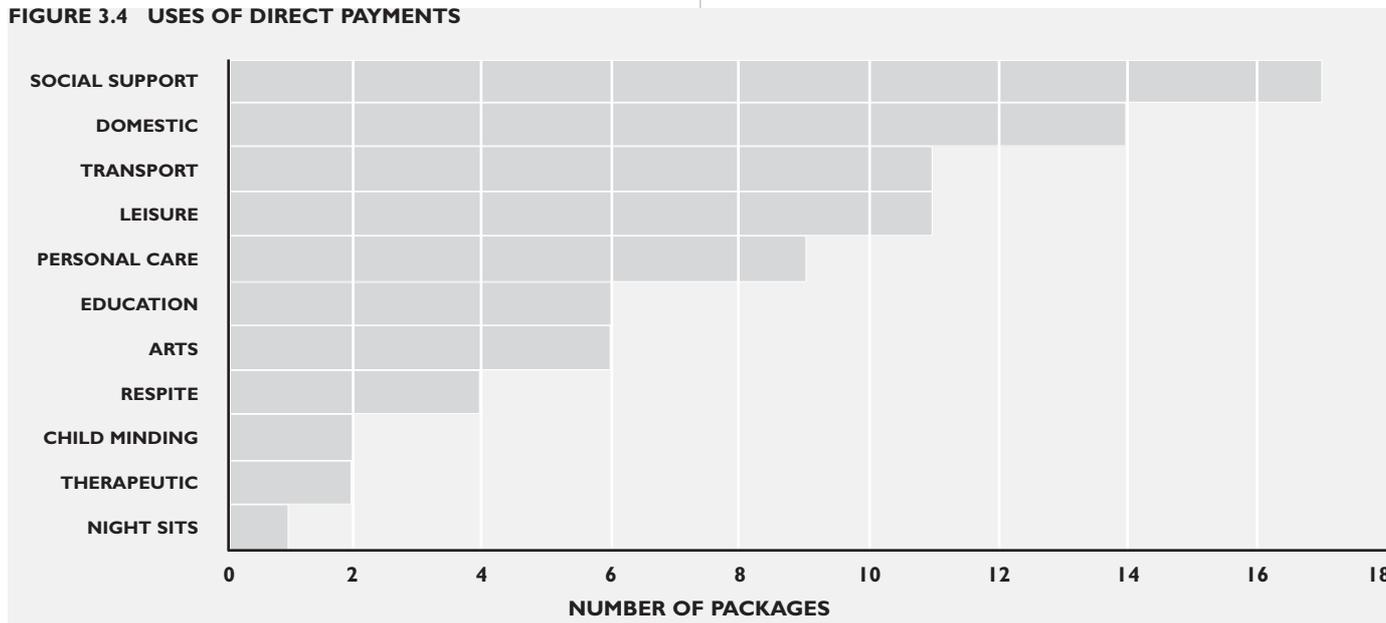
Although the majority of people with mental health needs are more likely to fit the criteria for standard CPA, this demonstrates that more clients on enhanced CPA were receiving direct payments. This indicates that a number of clients who had considerably higher assessed needs were being able to access direct payments during the pilot suggesting that access was not necessarily restricted to clients with less severe mental health needs. This may reflect the different eligibility criteria for community care services. On the other hand, this may also be due to an increased focus on clients on enhanced CPA due to heightened eligibility criteria, funding restrictions and crisis work. Many clients assessed as being on standard CPA may not be considered eligible for additional personal and social support which direct payments could be used to access.

USES OF DIRECT PAYMENTS

This section provides a brief overview of some of the ways in which direct payments were being used in mental health. Figure 3.4 illustrates the range of activities or support that direct payments were agreed for across the pilot sites. The numbers correspond to how many individual packages were agreed for that category. A number of packages were recorded as being agreed for multiple uses.

The most common packages were agreed for social support. This could encompass a variety of activities which usually involved employing a personal assistant to provide additional emotional and practical support outside the home. However, this also included use of alternative day centres. Thus one recipient paid for use of a day centre which was out of the area but provided specific social support to the service user that they could not get locally. Domestic support often involved employing someone to help around the house with cooking, cleaning etc. Personal Care could include support with eating, getting up and more intimate emotional support. Transport usually involved payments for taxis or to cover other transport costs in order to get to specific activities which were difficult to get to by public transport or were out of the local vicinity (e.g. voluntary work and specific therapeutic groups, courses or centres)³⁵.

FIGURE 3.4 USES OF DIRECT PAYMENTS



Educational support either involved paying for specific courses fees and/or paying for someone to support the service user attending. In addition, one client received direct payments for driving lessons and another for swimming lessons, although these were counted as transport and leisure respectively. Using direct payments for arts included paying for a creative arts worker for a group of service users. Respite involved the service user being able to pay for a week out of their usual environment in a place of refuge to give the service user and their usual carers a break. One client had a direct payment agreed to pay for respite for one week in every three months. Leisure usually involved membership of a gym or other leisure facility and occasionally also included the purchase of specialist equipment.

Child minding involved paying for additional support for service users who were experiencing difficulties with child care due to their mental health. Therapeutic support included paying for sessions with a private therapist. Night sits enabled one service user to employ someone to stay over during the night to enable her to feel safe and to be able to sleep.

There was an even spread of uses of direct payments across different sites in terms of the most two most common categories of usage (i.e. social and domestic). However, it is notable that there were some marked differences between sites as regards the other uses of direct payments. Thus, some sites tended to generate similar packages. For example, one particular site had the majority of transport packages and all of the child care and therapeutic direct payment packages. Another site had a predominance of leisure packages, specifically gym

memberships. This is likely to be related to local interpretation and decision-making about what direct payments can be used for, to budgetary priorities and considerations and to what is (or is not) provided or available locally. Thus, the site with a substantial number of direct payments for transport was one of the larger Local Authorities that encompassed rural areas and where transport was often seen as a crucial issue. Furthermore, there was some evidence that where a precedent had been set in relation to direct payment use that this prompted further referrals along similar lines. Thus, in one site, following their first direct payment recipient who used direct payments to use the local gym, a number of referrals were made for similar leisure activities.

Table 3.9 below illustrates the number of packages that were agreed and taken up in relation to whether they were ongoing or one-off payments.

TABLE 3.9 TYPE OF DIRECT PAYMENT		
TYPE OF DP	NO. OF RECIPIENTS	%
ONGOING	48	83%
ONE OFF	10	17%
TOTAL	58	100%

The majority of payments were for ongoing support arrangements. For example, this included payments for ongoing transport costs and monthly payments to leisure facilities as well as payments for hourly support and assistance. One-off payments included things like payments of educational course fees, membership costs of leisure facilities, respite, and purchase of equipment.

In terms of the Independent Living philosophy which underpins direct payments, payments should be agreed for 'needs' rather than 'services' and the direct payment recipient should be able to decide how they want to meet these needs. However, in practice, what payments would be used for tended to be agreed in advance. Thus, it should be up to the individual whether they wish to employ a worker or workers with their payments. Table 3.10 illustrates the number of recipients who took up direct payments and were recorded as having used payments to employ any workers or personal assistants (PAs).

TABLE 3.10 NUMBERS OF RECIPIENTS EMPLOYING PAS

EMPLOYING PAS	NO. OF RECIPIENTS	%
PAS	29	50%
NON PAS	19	33%
NOT KNOWN	10	17%
TOTAL	58	100%

At least half of all of the 58 clients using direct payments were employing one or more PAs. However, there were some distinct differences across sites in relation to employing workers. Two sites only had packages agreed where PAs were employed. In one of these sites, this was primarily because direct payments were closely tied with a direct transfer of an externally provided support worker service to a system of PAs funded by direct payments. Other sites that were financially able to respond to needs unmet within existing services were more flexible about using direct payments in other ways. In Surrey, which had 27 clients on direct payments, over half were using direct payments to purchase non-PA services such as transport, therapy sessions, educational courses and leisure activities.

LEVEL OF PACKAGES AGREED

Not all direct payment packages were calculated on an hourly rate as this depended upon what the direct payment was agreed for. Therefore about half of the packages that were agreed were not recorded at an hourly rate. Packages that were agreed at an hourly rate tended to be those packages where a client was employing a PA. Moreover, there were some cases where a client may not have decided to employ a PA (or was unable to) and elected to meet their needs in other ways. This is illustrated in table 3.11.

TABLE 3.11 LEVEL OF PACKAGES AGREED

NO. OF HOURS	NO. OF DPS AGREED	%
0-4	6	9%
5-10	13	20%
11-15	4	6%
16-20	3	5%
20-25	2	3%
26-30	4	6%
30+	2	3%
N/A	30	47%
TOTAL	64	99%

The majority of direct payment packages were less than ten hours per week and the most common was between five and ten hours. Packages that were not recorded at an hourly rate (N/A) tended to be for lesser amounts for accessing transport and leisure facilities. However, they could also pay for other costs such as paying for respite and for attending alternative day centres. The two packages that were agreed at more than 30 hours involved clients with additional and complex physical and mental health needs. Thus one client with a diagnosis of schizophrenia and early onset dementia was able to purchase a live-in PA organised by their family/carers.

TIME TAKEN TO AGREE DIRECT PAYMENTS

The time taken to agree individual direct payments packages was based on the difference between the date recorded on the initial referral to the local direct payment support service and the date a direct payment package was agreed. These data are presented in table 3.12. However, this does not reflect the additional time that may be taken before a referral is actually made. The length of time taken was due to a number of factors including care co-ordinators needing to do the relevant paperwork and their level of understanding of the process. In addition, doing needs assessments could be a lengthy process, particularly where the service user is assessed as having complex and fluctuating needs resulting in multi-disciplinary involvement. It also depended on service users themselves who may have taken a while to decide whether they wanted to pursue direct payments or not.

TABLE 3.12 TIME TAKEN TO AGREE DIRECT PAYMENTS

TIME TAKEN	NO. AGREED	%
0-2 MONTHS	24	38%
2-4 MONTHS	14	22%
4-6 MONTHS	9	14%
6-8 MONTHS	3	5%
OVER 8 MONTHS	3	5%
NOT RECORDED	11	17%
TOTAL	64	101%

The majority of direct payment packages took less than two months to agree but this was highly dependent on what direct payments were being agreed for. For example, packages for more straightforward costs such as gym membership and transport or for one-off payments were often agreed quicker. In one site, such packages were often agreed in less than a month. For instance, in this area, five packages took one month, three took two weeks and four took only a week to be agreed. In keeping with this, more complex packages took longer to agree and, two packages were recorded as taking over ten months to be agreed. In addition, the referrals where this information was not recorded were more likely to be cases that took longer to agree^{35a}.

This chapter has given an overview of progress in referrals and take-up of direct payments during the pilot. The following chapter explores in more detail how direct payments have been used in practice at the individual level based on interviews with direct payment recipients themselves.

²⁴ In one site this amounted to £26,000 per year; in the other £30,000 was put aside.

²⁵ i.e. whether funding for services was tied up in contracts or services were spot purchased.

²⁶ For example, services provided in the voluntary sector, the availability of community support workers, transport etc.

²⁷ This client had mental health needs and a learning difficulty as well as language and cultural needs.

²⁸ In both cases, the independent organisation was not in a strong enough position as an organisation to offer the level of support necessary to fulfil the requirements of the Local Authority.

²⁹ i.e. the two county sites serving populations of over one million people.

³⁰ CPA figures were taken from the latest information that Local Authorities provided during 2003. However, the specific date at which these figures were actually collected by the Local Authority may vary slightly between sites.

³¹ These figures come from the recording systems of the local direct payment support agencies and therefore may not be entirely consistent across sites. Thus, for example, some sites may log a referral at a different stage of an initial enquiry.

³² Such as wife, husband or mother.

³³ Whether or not the care co-ordinator made the initial referral.

³⁴ Totals may not add up to 100% because of rounding off.

³⁵ In a survey in the US, mental health service users rated assistance with transport as being the most important potential benefit of having consumer directed personal assistance services (Pita et al 2001).

^{35a} In cases that were more protracted and complex, it was harder to calculate the time taken for the package to have been agreed from the initial referral.

CHAPTER 4

Using Direct Payments

The last chapter gave an overview of uses made of direct payments across all of the participating sites. Based on the interviews with recipients, the first section of this chapter considers in greater detail how direct payments were being used. Following this, section 4.2 presents a series of case studies to provide further illustration.

4.1 Recipient Use of Direct Payments

As previously indicated, while the number of clients using direct payments remained low, there was still a great diversity in the ways payments were being used. A substantial proportion of recipients employed their own PAs. Workers employed by service users were called PAs, helpers, carers, workers, cleaners and so on, dependent in part on what they were being employed to do and the term with which recipients felt most comfortable. Some recipients employed different PAs for specific roles and jobs³⁶. Recipients were able to use their direct payments to do a variety of activities and tasks and these could change over time according to needs. As one recipient described:

I do anything I want with it. I get exhausted sometimes, so she helps me with housework and we go out shopping for food... If I get a letter off anyone and if it's official, she will sort it out...she comes to doctor's appointments with me... I go and see a friend, we go for a walk, you know, different things... If the weather is nice we might go to [a country park] and we always have dinner out, because I have got an eating disorder, so it's like that's part of the care plan, going out for something to eat.

Recipients often used direct payments to employ a PA for 'befriending' purposes, going out to places they had not been to before or to accompany them if they found it difficult to go somewhere alone or to go shopping with them.

There are some things that I couldn't do, like I can't go in to a busy shopping centre... and shop, although I would like to, but if I have got somebody with me, then I will do it, I don't like to go to crowded places on my own. You see it's just not so much for the company, but I just feel scared of what might happen to me, and I have had quite a lot of panic attacks and agoraphobia as well. So I use it for shopping and to do a new course.

Two recipients saved up hours that they were allocated each week to go out for whole days. This meant that they could go to places that would take much longer to get to and that they could take their time. Thus, one client had gone to London for the day and another had gone to the seaside over the summer. Furthermore, one client was able to use her direct payments for respite.

Any surplus I save up for respite. So I have had a break for a week to a special mental health residential place – it's a break for me and my mum who's my main carer – it gives her a break. It's a different environment and gives me a complete break.

Direct payments have also been used for a variety of leisure activities. One recipient employed a PA to go to museums and art galleries with her. Other leisure activities people were able to do because of support they got from their PA included going walking in the countryside, swimming and going to the gym.

I decided that I wanted to go walking to get exercise to get my weight down, also go swimming because I enjoy swimming and to go food shopping which frees [my husband] up a lot because he could do things at home while I am doing food shopping with one of the helpers. Walking, yeah I often tell them where I would like to go for a walk and they will take me in their car and take the dog along with us.

Some recipients did not need someone to go with them but did need a direct payment to pay for leisure membership and transport to get there. For one client who had a diagnosis of an eating disorder, this helped to provide a social outlet, to improve general fitness and to alleviate clinical difficulties around their eating, self-esteem and weight. Another recipient used the gym to alleviate weight gain (due to medication) and for improving self-esteem and general health. One Asian recipient was also able to get direct payments to pay towards a TV channel specialising in Asian films and programmes.

Some clients were using direct payments for support to get to the places where they were involved in voluntary work out of their local area. Two recipients used direct payments specifically to pay for taxi fares. One recipient used direct payments for a taxi to and from a church-run organisation that worked with people with mental health needs and learning difficulties where she helped to run a day centre and to give emotional and religious support to members. Direct payments also paid for this client to have driving lessons so in the future she would be able to drive there by herself. Another recipient used direct payments to travel to and from an animal sanctuary in the country where he did voluntary work cleaning out the hutches of small animals.

Recipients also were using direct payments for educational purposes, for instance attending courses. They either used the money to pay for the course fees, for transport, and/or for company and support in attending the course.

I didn't have to pay for doing the course, because I was on income support...but so I can be taken there and [my PA] comes with me. So I can be brought home, so I don't have to worry about parking in the dark, because it really used to freak me out to park there and then find myself into the room, then to do it all in reverse. She doesn't always come with me now, because I have made friends there and I know people then I sort of meet them in the car park, but it enabled me to actually start it.

A number of recipients used direct payments for domestic and household support. This involved employing a PA to do things such as helping with cleaning, cooking and preparing food, budgeting, making phone calls, assistance with opening and answering mail. In addition, several recipients had employed a gardener to help maintain their garden. Thus, in one example, where the service user rarely went out, a gardener was employed on a temporary basis to clear the garden which was overgrown and dangerous. This enabled the recipient to actually go and sit outside.

An older client who had a diagnosis of dementia as well as other mental health needs used direct payments to employ a live-in PA. A member of her family assisted with the management of the payment and employed a PA on her behalf to do domestic jobs, personal care, cooking, cleaning, washing and getting her out of bed etc. This enabled her to stay in her own home rather than have to live in a nursing home.

A number of recipients also used their PAs to accompany them to hospital and other important appointments. In addition, one client was offered direct payments to support her to care for her children during a mental health crisis. Unfortunately, they could not find a suitable PA and this was not taken up.

4.2 Case Studies

The following sections look at particular examples of support arrangements that individual clients have developed through direct payments.

NIGHT SITS

One client used direct payments to employ someone to stay with her during the night. She employed a PA to do two waking night sits per week when she felt she needed it most (for example at weekends). This client had ongoing serious and escalating self-harm, difficulties sleeping and would often feel particularly unsafe and vulnerable at night. The PA would either help out with household chores while the client slept, or sit up with her if she couldn't sleep. This enabled her to sleep and has helped reduce the severity and amount of self-harm.

It's very flexible. She comes in the evening and we have a drink and chat and take the dog for a walk sometimes and then I'll go to bed at whatever time and she might do some cleaning for me or whatever... then she sits up all night and when I get up during the night, I have got someone to talk to. That just gives me a chance to get some sleep, because I don't sleep very well, and I self-harm quite a lot... Just knowing that somebody is going to come in and spend the night and it gives me a bit of a break, somebody to talk to and I know I can phone her up too.

CULTURALLY SENSITIVE SUPPORT

A South East Asian family used direct payments to employ a PA to help support a young man with complex needs. He needed to have another Asian worker from a similar background and culture to whom he could relate. He was extremely isolated and slept irregularly. Social services had been unable to provide him with an Asian social worker or support worker and he could not relate to mental health services. His mother employed an Asian PA and a cleaner on his behalf. The PA was employed to develop a relationship with him and to facilitate greater social contact. Because of the nature of the young man's support and the necessity of finding a suitable PA with specific cultural, language and mental health skills, it was agreed to pay a higher hourly rate than usual. The mother guides the PA and facilitates communication between the PA and the client and helps him to decide what he would like the PA to do with him before s/he arrives. She reported that her son is slowly beginning to relate to the new worker.

We have been asking for over two years for an Asian social worker and social services haven't helped us. We just want Asian people who can give a service to him... We didn't have anyone coming round no visitors. He doesn't sleep at night and is awake during the day... The PA just comes and talks to [him] and tries to go out with him. It takes so long just starting to say 'hello'. Before she comes I ask him what he'd like her to do and then I tell her when she comes... whether it's to get some shopping in or whatever... It's like I'm helping her to help him helping people to communicate with him. They also need to know that they need to be careful e.g. not to wake him up when he's sleeping.

EMPLOYING RELATIVES

Another client employs her mother as a PA for a variety of social, personal, and domestic support³⁷. In this instance, it was agreed that the client's mother was the best person to provide the intensive support this particular client needed and was someone whom the client trusted and accepted:

I don't have to tell mother what to do, because she knows what to do, she knows about my medications, she is always aware of my appointments, and also the care involved with my daughter. Also, she recognises the nature of this illness so she can see when I am becoming ill. If my mother says I am going high, she will go and make an appointment and seek further help for me before it escalates... She takes me out and encourages me to do things and be amongst people.

USING DIRECT PAYMENTS COLLECTIVELY

Finally, a group of five clients were using direct payments to attend a creative arts group. The group employs two trained artists who work with a local mental health arts-based charitable organisation. The artists work alongside the individuals providing ideas and motivating them to explore their own creativity, and helping them turn ideas into reality. All group members live in a rural area on the border of two counties, an area which is quite cut-off and not well-served by services or local transport. It is really important to the individuals that the group is local and within walking distance. The group was formed in a local Community Centre and prior to direct payments, the group had to constantly fundraise to just to keep it going. However, this was causing the group considerable anxiety and affected morale. They shared a care co-ordinator (a CPN) who had heard about direct payments and suggested it as an option for the group, who responded enthusiastically. The CPN knew how important the group was for its members and pursued it for them. The group recognised that getting direct payments was very much dependent on their having had a supportive care co-ordinator. Each client gets an individual payment which they then pay to the creative response artists.

Since getting funding from direct payments, group members reported that their morale has significantly improved. They still fundraise but this contributes towards exhibitions and other developments of the group³⁶. It would have been impossible for each individual to get the input of trained artists alone. In getting direct payments, not only has each individual been able to access support with their creative art, but also the payments have facilitated the development of an environment where clients can benefit as a group from each other.

DIRECT PAYMENTS FOR HEALTH?

Whilst it is difficult particularly in mental health to separate out what is a 'health' need and a 'social' need, no client had been specifically offered direct payments for any health-related services. However, a small number of clients had been able to use back payments which had accrued³⁷ for time-limited sessions of alternative therapies such as reflexology and counselling. However, a number of recipients expressed an interest in purchasing other health-related treatments via direct payments.

One recipient said that she was unable to get psychotherapy on the NHS because it was not seen to be suitable or appropriate because of her diagnosis. However, she felt that she would benefit from long-term psychotherapy and queried whether this would be possible via direct payments. In another example, an Asian man expressed a desire to have Ayurvedic health treatments⁴⁰ for both his physical and mental health difficulties. He was dissatisfied with the treatments he had received in hospital and through western medicine and wanted to be treated at home. In addition, the members of the creative arts group (discussed previously) were developing ideas about other ways of using direct payments collectively, for example for aromatherapy and massage.

The following chapter explores participants' views of the benefits of direct payments.

³⁶ Such as for cleaning/domestic help and social support.

³⁷ Such as shopping, helping her keep appointments and general support etc.

³⁸ e.g. the group now has a separate drop-in which continues on a voluntary basis.

³⁹ This was because the payments took a while to come through.

⁴⁰ A long established natural health treatment developed in South India.

5.1 Self-Reported Impact on Quality of Life

CHAPTER 5

Understanding the Benefits of Direct Payments in Mental Health

The vast majority of research across different care groups identified a wide range of benefits of direct payments (e.g. Glenninning et al 2000c; Morris 1993; Zarb and Naidash 1994; Kestenbaum 1996; Hasler 2003). Due to relatively slow take-up, Ridley and Jones (2002) argued that the benefits of direct payments for mental health service users have yet to be demonstrated. As previously highlighted, the majority of mental health direct payments recipients only started accessing direct payments in the last year of the pilot. Therefore, this evaluation is only able to report on relatively short-term and early reported benefits. However, in qualitative terms, recipients identified significant benefits.

The findings here draw on interviews with 16 clients who had been actively using direct payments for three months or more. Of these, the longest a client had been receiving direct payments was 17 months while the average length of time was eight and a half months.

The first section of this chapter presents an analysis of the quality of life questionnaires that recipients completed. Following this, a more in-depth analysis of perceived benefits is presented which draws on the semi-structured interviews with recipients, carers and care co-ordinators. Unless otherwise specified, all quotes in this chapter are from mental health direct payment recipients.

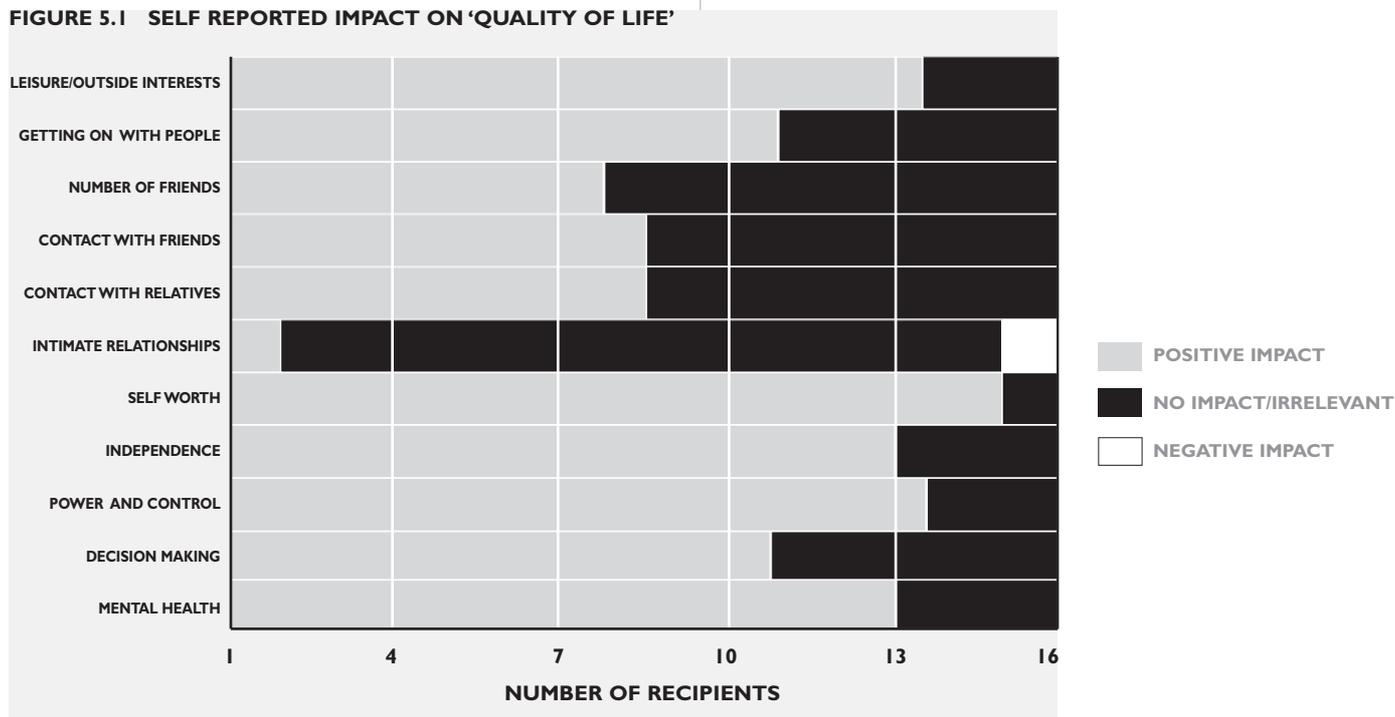
All 16 clients were asked if they thought that direct payments had had a positive, negative or no impact on various aspects of their lives. They could also indicate if the question was not relevant to them, either because the direct payment was not intended to have any impact in this area of their life or if the question itself was irrelevant⁴¹. Responses to the questions are presented in figure 5.1 overleaf.

The first issue to note was the lack of reported negative impact. This may be because recipients were generally satisfied with receiving direct payments⁴².

Bearing this in mind, the following is a brief overview of these findings. Direct payments seemed to have the most significant impact in terms of firstly increasing recipients' access to and enjoyment of outside activities and, secondly, in improving recipients' feelings about themselves in relation to the world around them. Whilst using direct payments had some impact on improving and facilitating personal and social relationships, this was less marked.

For example, 14 people thought that direct payments had had both a positive impact on the amount of time spend on leisure and the degree of pleasure they got out of these activities. Such activities included swimming, going to the gym, shopping, socialising, going to a museum or art gallery, days out to places they had not been to before, walking, doing courses and so on. In addition, the direct payments used to pay for transport helped some people to do voluntary work. Only two people responded either that direct payments had not had any impact or that the question was not relevant.

The most significant positive response was in relation to recipients' reported feelings of self-worth where only one person felt that this had not improved. In addition, the vast majority of respondents felt that direct payments had increased their independence, that they had more control and power over their life and environment and that it had had a positive impact on their mental health in general. Whilst 11 people reported that direct payments had increased their ability to make decisions about their life, five people thought that this remained unchanged.

FIGURE 5.1 SELF REPORTED IMPACT ON 'QUALITY OF LIFE'

In general, most recipients felt that direct payments had had a positive impact on how well they got on with people. The perceived impact on generating more close friendships and improving already existing relationships was less significant. Many of the people who reported direct payments as helping to increase the number of friends they had, related this to relationships they developed with their PAs which, in itself, amounted to a growth in their friendship networks. Thus, where recipients were not using direct payments to employ PAs, this was less marked. Of note, only two people reported that using direct payments was having a positive impact on their relationship with their partners, wife, husband etc. This was partly due to the fact that nine of the respondents did not have a significant intimate relationship and therefore the question was inappropriate. Four people felt that a direct payment was not having any impact. One person felt that direct payments had had a negative impact on their relationship because their husband had to do a lot of the paperwork and this was exerting extra stress and pressure on their relationship.

Recipients were also asked if a direct payment was having any impact on their being able to turn to someone for help if needed⁴³. Many recipients indicated that this depended on the sort of help being referred to. Most recipients who employed PAs felt that they could call upon them to help them with 'everyday' tasks such as accompanying them to hospital appointments. However, for help with more significant mental health needs and emotional support, recipients tended to call on those people they had previously turned to before receiving direct payments. This was usually their care co-ordinator, family members, carers or significant others. One person indicated that direct payments had a small but notable negative effect in this regard. This person reported feeling unable to turn to their PA for help in the same way they had been able to with their support worker before direct payments. They subsequently saw their social worker more often. However, this was a minority experience.

These findings were explored in more detail during the accompanying interviews and are discussed in the next section.

5.2 Identifying the Benefits of Direct Payments

As suggested in the previous section, the benefits associated with using direct payments were highly dependent on what the payments were being used for. Direct payments were used to help develop personal contact, reduce isolation, and increase social networks and open up wider opportunities. In addition, direct payments provided people with practical support which enabled recipients to do the kind of activities they wished to do, in the way they wished to do them. As one recipient commented:

I think it's a coming together in a logical way of what I was trying to do on my own and struggling to do on my own...all these obstacles are now going, so I am getting a clearer way forward, it's meant a lot to me.

This demonstrates that when direct payments worked for people with mental health needs, they have similar benefits to those reported in other care groups (e.g. Kestenbaum 1996; Halliwell and Glendinning 1998; Glendinning et al 2000c; Morris 1993; Stainton and Boyce 2002; Zarb and Naidash 1994).

The following sections break down perceived benefits under three key headings relating to individual personal change, ability to engage in the social world and impact on service usage⁴⁴.

Personal Change

Various participants highlighted the extent of personal change as a result of using direct payments to get the help they needed and wanted. As one recipient's husband commented:

It has, it made a huge difference to her...Even the [PAs] commented after some time how much she'd changed, just in her outlook and the way she looked, how she was talking to them. It was kind of like an awakening.. She has just changed in so many ways because of the help that she now gets. (Husband)

PERSONAL AUTONOMY AND CONTROL

Greater independence, enhanced personal autonomy, choice and control over one's own life are frequently reported benefits of direct payments in previous literature across care groups (Glendinning et al 2000c; Carmichael and Brown 2002). Illustrative of this, one care co-ordinator reflected:

Direct payments have helped because she can feel more empowered that she is in control of things. She has become a victim of services over the years, she has become very institutionalised, dependent and that was what we needed to look at. So I think direct payments has given her choices, power and control, all the things that she has not had, she has now got. (Care co-ordinator)

In particular, support developed through direct payments could help recipients become more independent from their family who may be too over-protective:

I used to go places with my daughter and although she's great, but she can be stifling at times...it inhibits me...they are very protective... it doesn't help me because I think they used to decide and sometimes I don't want to go there...Whereas having a PA I can say 'I want to go to London next Saturday, can you come with me?' This gives you that bit of independence that you can go and do something, all right you are taking somebody with you, but it's on a different relationship, you know the dynamics are different and you're the one that is in control because so it's like being on my own in a way having that freedom.

Greater independence can relieve a sense of guilt that service users often experienced when having to call upon unpaid carers to support them. Thus, direct payments often allowed clients to use their payments to secure support that they previously had to rely on the goodwill of others to provide.

It's given me a lot more control over what I do and given me more independence from my family so don't rely on them as much and just knowing that I've got someone to support me during the day, it means I can do some of the things I want to do. It's made things a lot easier for me, things usually my mum would have done with me. I can do a lot more leisure activities and actually have a social life.

Furthermore, direct payments sometimes formalised already existing caring relationships which could be under considerable strain because of the lack of financial compensation.

I don't feel so guilty about calling upon my mother to help out because I know she is being paid and that my mother can come out to me, because she is being paid direct payments and isn't doing the other job that she was doing before.

SELF-ESTEEM AND ASSERTIVENESS

Many recipients noted that receiving and using direct payments had significantly increased their confidence and self-esteem. As one commented:

I think it has made me be more positive about myself, instead of having negative thoughts all the time, because I suffer from low self-esteem and it's giving me my confidence back.

In addition, using direct payments often had a positive effect on clients' assertiveness:

It's taught me an awful lot, things that I haven't realised in my life before about myself and not being assertive enough and not saying what I want. I think that's part of what led me to having mental health problems, because my life felt totally out of control ... A lot of my illness has been about not having any self-esteem and not being able to exert any control over my life and going with the flow as it were or being dragged along by the current. So in a way, although I don't know if it's intended to be like that, but it gives you back control and you suddenly realise, 'yeah I have got a right to be in control of my life, I'm not going to let other people tell me what to do or control my life'.

Growing assertiveness could lead to a greater ability to negotiate relationships where clients feel more equal and more in control.

HOPE AND OPTIMISM

A consistent theme to emerge from the client interviews was that direct payments helped increase their motivation and gave them a sense of purpose and optimism about their life. The experience provided encouragement, challenge, and a sense of hope in being able to pursue some goals in life that mattered to them. Recipients talked about it giving them something 'to aim for', 'to look forward to' and 'to get up for':

Direct payments has given me a boost, a little bit of a boost along that way, it's really been positive, it really has.

I enjoy it, it gives me a sense of purpose and I feel good about myself, feeling like I'm not completely useless, that I do something.

In addition, managing direct payments itself could give recipients a sense of achievement:

Also for me it was the challenge of it – giving you something to strive for, to succeed, to improve my quality of life and it's an added bonus taking on the role of an employer, a sense of satisfaction, reward, a sense of achievement, stuff like that, something to challenge me and push me forward cos I've never done anything like that before.

TRUST AND RESPONSIBILITY

Workers in particular identified responsibility as a key benefit of using direct payments. Where support becomes the client's responsibility they are more likely to assume responsibility over its success and/or failure:

I still feel optimistic about it all really – the control and empowerment it can give to service users and about gaining greater responsibility. Often in mental health it's hard to stop offering something and if things go wrong it's easy to blame someone else. With direct payments people have to assume more responsibility over getting it right. (Care co-ordinator)

In some cases, care co-ordinators noted clients becoming less dependent on services:

I don't think she is quite as dependent on the service as she was, say a year ago. So if she has got a problem, she's looking at well 'what can I do about it?' She is kind of not ringing me so much anymore. So she is not as dependent. (Care co-ordinator)

In addition, care co-ordinators noted that trusting people with the responsibility of managing direct payments could play an important part in their being able to respect clients as worthy responsible adults worthy of trust and dignity in being able to make decisions. This could have an important side-effect of improving the relationship between the care co-ordinator and the client and gave the worker a greater sense that they are facilitating more empowering ways of working:

It's like treating people with respect and dignity as an adult not as a baby... Also the trust – it was indicative of the trust we put in her, that's really important to feel that you're trusted, like she's been honoured and she's living up to that honouring.' (Care co-ordinator)

Clients often told they can't do things and are criticised. Direct payments helps make it ok to actually make demands. It also shows that clients are not stupid. It has a really different feel to it, actually being able to say 'this is what I would like'. (Care co-ordinator)

Clients often recognised and appreciated this increased level of trust being placed in them:

It's good that they trust me – to get the receipts and all that. That's very important to me.

Social Inclusion and Participation

Direct payments enabled clients to purchase the support or assistance they needed to be able to play a greater part in their 'social world' and contribute to their community. This included participating in educational, leisure and creative activities. Direct payment recipients often noted how direct payments had enabled them to 'do more' in the world:

It gets me out and about more, I can choose where I want to go. Now I can go places I couldn't have gone to before.

Before direct payments she would be in the house not doing anything really other than the necessary. When direct payments came in she has been going out nearly every day of the week...it has been a huge benefit to her, she is doing a lot more, so she has just changed in so many ways because of the help that she now gets. (Carer)

In some cases it also enabled clients to access paid or unpaid work. One client specifically referred to the support she purchased through direct payments as being like a 'security blanket' giving her specific support in the home enabling her to go back into paid work.

Other evaluations of direct payments have concluded that direct payments frequently enable disabled people to participate in activities and pursuits in the community which many non-disabled people take for granted. In turn, this promotes social inclusion and participation and facilitates clients living what they saw as a 'normal life' (Witcher et al 2000; Carmichael and Brown 2002). What is important is not simply about inclusion in society but more about taking an active part in communities and activities that a person would like to be part of, in the way that they choose:

I felt excluded from everything, because I had no routine really to my life, whereas having direct payments and having somebody come everyday started to give me routine, because I always looked forward to that, because I know that somebody was coming. I suddenly felt part of things again rather than being excluded, rather than being in my own little bubble and I wasn't really part of anything, that's how I used to feel.

DE-STIGMATISING ACTIVITIES

Using mental health services over a long period of time can erode people's sense of self-worth so people are viewed and see themselves as synonymous with their mental health diagnosis. This can result in being seen solely as someone with mental health problems or a 'mental illness' rather than as a person with mental health needs amongst other facets of their life. Thus, in many instances direct payments enabled clients to take part in activities which were non-stigmatising:

I try to find more things in the community and get away from mental health for a bit and into more everyday life. I don't want to be stuck in the mental health system and think this is all there is, that's all I am worth, I am not worthy of interesting hobbies, like anyone else. I am an individual, but I am not treated as an individual, I am treated as a mental health case.

Clients can too readily feel pathologised within the mental health system and using direct payments enabled some recipients to feel that their needs and feelings were respected in their own right without being seen as part of an 'illness':

It's enabled me to do normal things, you know not doing things just in the mental health system with other mental health people so I can go down the pub or go shopping in another town or whatever. It's important to be able to do things not just with other people in the mental health system so you're not just mixing with other people with psychiatric problems all the time. You can talk about ordinary, little things with other people and get things into perspective a bit more. Things get analysed as part of your mental health problems all the time, you know, like if you're feeling good one day then it's cos you're going high or whatever. Now if I'm feeling good it's just 'oh you're in a good mood today!'

Care co-ordinators recognised these benefits especially in relation to 'normalisation' and moving away from being dependent on mental health services for support:

The support, I suppose for her, it's normalised a lot. It's kind of like she was going to the dietician for managing her weight, well now she has joined Weight Watchers. There's certain things where she would have used hospital services and now she's well 'OK, I could actually do this at Weight Watchers, I don't really need to go to a hospital dietician'. So she's kind of bringing herself out of services, which I think is a really good positive move for her because that's where she's been stuck. It's like those benefits have had a knock-on effect. So I think it's had a shift of thinking. (Care Co-ordinator)

In addition, this can have an effect on how clients are viewed by others. For instance, one recipient noted that since getting direct payments to enable her to do voluntary work in a local community centre, her parents seemed to respect her more and that she felt like she had more of a valued role in the world.

LESSENING SOCIAL ISOLATION

A crucial element of these benefits was lessening the social isolation that many mental health clients feel. Thus, some care co-ordinators noted a growth in their clients' social networks:

It has increased her confidence, it reduces her social isolation, she's more positive and because she's had to deal with things like interviewing people etc, it's helped move her on in terms of social interaction etc. It's all helped make a change from [her] being in a very small world to building a bigger social world. (Care co-ordinator)

Service Use

HOSPITAL ADMISSIONS

In the short term, it was too early to say whether direct payments has had any significant impact on reducing episodes of mental ill-health or had contributed to lessened service use. However, given the slow uptake and length of time on direct payments, this may be demonstrated over a longer period of time.

Although service users still experienced periodic mental health crises, it began to become apparent that through the support structures that they had developed through direct payments, many recipients were able to spend less time in hospital during or following an acute crisis. Thus, one client managed to avoid going into hospital and, with the support of her PA, just went in on a daily basis during a mental health crisis.

I am pretty sure I would have been hospitalised quite some length of time, it would have meant me having longer spells in hospital and as our local hospital, mental hospital isn't particularly good, I think I would have given up by now, and would have killed myself.

Hospital admissions, she has only had five weeks in eleven months, where she would have probably been in for about six months now, so it's helped with that, so there's been massive benefits really. (Care co-ordinator)

In addition, it was noted that admissions were more likely to be voluntary, rather than compulsory. Also having the support of a PA through direct payments made clients' time in hospital more bearable and could enable them to leave hospital earlier:

It meant I could get out of hospital during the day otherwise I'd have been ward-bound, it was the only way they could let me out of hospital, and it prevented me from being sectioned.

IMPLICATIONS FOR WORKER ROLES AND RELATIONSHIPS

Participants made reference to other impact on service use. These included improving the clarity of roles and relationships between workers and clients. For example, in some cases, having direct payments meant that the care co-ordinator was freed up from doing some support work which could enable them to engage clients in more of their specifically 'therapeutic' work⁴⁵. Similarly, Witcher et al (2000) argued that direct payments may enable social workers to use their time differently with service users and more productively.

ACCESS TO SUPPORT

In a number of examples, direct payments made a difference for clients in getting support. In part, this was due to clients not accepting support unless it was something (or someone) they chose. Relevant here, a number of clients reported bad experiences of statutory services. In addition, because of the nature of the support possible via direct payments, some clients were able to access support which was previously unavailable to them because it was not provided directly by local mental health services.

'RECOVERY'

The identified benefits bring us close to the emerging concept of 'recovery' in the mental health field (Jacobson and Greenley 2001; Turner-Crowson and Wallcraft 2002; Ralph 2000). Rather than having a pre-set agenda of what 'recovery' may mean for people with mental health needs, this evaluation indicates that what is crucial is having assistance to be able to pursue one's own self-defined goals and aims. Thus, one recipient clearly identified her goal as getting back into paid work:

For me recovery meant being able to work again, that's what it has always meant to me. I think if I didn't have [direct payments], I don't think I would have been able to go back to work. I know direct payments is only a part of it but it's all of those things combined have helped me to get to the point where I felt like I am recovering. I think that it's whatever you feel is normal for you...it's not what everybody else feels, it's how you feel that that's appropriate, you know, because it might be that you don't want to work again, you might want to be able to pursue a hobby or go somewhere else and live, but it's whatever it is for you.

Turner-Crowson and Wallcraft (2002) have identified a number of themes that should be part of a recovery agenda. These included being believed in and encouraged by at least one other person; taking personal responsibility for one's own life; acting to re-build one's own life; developing valuable relationships and roles; changing other people's expectations; gradually gaining a sense of greater well-being; developing new meaning and purpose in life etc. Many recipients reported improvements in a number of these aspects of their lives after setting up support through direct payments. That recipients reported a growth in self-worth is particularly significant given that mental health service users often argue that the experience of using psychiatric services can contribute to low self-esteem, confidence and self-worth (Johnstone 2000).

5.3 Flexibility, Choice and Control

It is important to bear in mind when considering these benefits that it is the quality of support possible through direct payments that is crucial rather than direct payments per se. As has been continually pointed out by advocates of the Independent Living Movement, direct payments are merely one means to the greater end of independent living and not an end in itself. With this in mind, it is worth noting that direct payments may be just one way to achieve the kinds of support and services that service users want and need.

A number of service users had a direct increase in personal input following accessing direct payments, especially if it was developed to meet a need currently not being met through directly provided services. Therefore, it may be hard to determine what benefits directly relate to using direct payments and what is due to a greater level of support input. However, it is clear that there are some benefits which are directly linked to the greater choice and control which direct payments facilitate. As Stainton and Boyce (2002) have argued, the flexibility of being able to organise support around one's life rather than having to live one's life around support was extremely important in generating the other benefits. In turn, this helped to open up new opportunities and began to enhance quality of life⁴⁶.

In addition, the support with 'everyday' tasks that service users have developed through direct payments was important because of the way in which it was provided. This can be difficult to achieve through 'traditional' mental health services. Direct payments may enable individuals to have specific social contact or company that suits them and is not professionalised or medicalised.

When direct payments work for clients it seems to be based on the greater flexibility, choice and control they are able to exercise. In particular, this relates to the flexibility about when and how they wanted to do things, the increased range of activities they could do and places they could go:

It's given me a choice, given me the ability to choose for myself who I employ, who I make as a friend, you know, it's given me that choice.

It's given me a lot more control...Before I was told 'it's at this time, and at that time, or you are not getting it at all' or whatever.

This was also recognised by care co-ordinators who had seen these benefits for their clients:

It certainly has given her the flexibility to decide how, and to define the service she needs. It's certainly meeting her needs in a much more flexible way than the other service was. One of the problems with the other service was the frequent change of workers, workers being so busy or crises occurring so that they were having to cancel appointments or couldn't come at the time that was specified and there wasn't the consistency that she needed. Part of it is the consistency of workers and being able to come at the time and for the amount of time that was arranged and things like that...It's much more flexible and much more empowering, so it is meeting her needs much better than the other system was. (Care co-ordinator)

However, difficulties arose when clients found it hard to make choices and decisions, especially if there are constraints and pressures that limited their ability to exercise choice. Such difficulties emerged most acutely when clients attempted to employ their own PAs⁴⁷. Whilst reported benefits were significant, there were some accompanying disadvantages around losing a certain amount of security and occasionally experiencing greater uncertainty, at least in the short term. Greater 'choice' is accompanied by responsibilities, constraints and consequences. Many mental health service users may feel that their capacity for exercising choice and control has been undermined by their experience of mental distress and long-term use of mental health services. This means that the benefits of direct payments and independent living may take some time to realise. The process may be a long and difficult learning process both for professionals in giving up, and service users in taking more control. This also reaffirms the point that 'control and choice' are not all or nothing fixed points but rather a process:

It's been a long learning curve. I now know that it's about what I want. I didn't grasp the fact that this was about me – me to choose – I didn't have any concept of it at all. It's taken me all these months to grasp that I needed to know what I wanted.

However, if as we have seen, this is a crucial element in the benefits that service users have started to realise, then the impact may be even greater for it. Thus some clients referred to direct payments as potentially being able to facilitate them to reclaim their life and/or make their lives worth living:

I think independent living is all about getting your life back and organising your life. It means really claiming what you have lost, after disasters, traumas, everything that's happened to you and reclaiming it bit by bit.

I can come home from work and things are done and I know that I haven't got anything to worry about and I can sit and relax and start to enjoy my life again, to have some really good quality to it, rather than just existing, because that's what I was doing, you know. You can get so despairing of living your life like that, that you don't want to live it any more, so it gives you quality and choice, and I think it's really set me well on the way of recovery, so I am hoping to maintain that.

In view of key concerns in mental health about levels of suicide and self-harm (Department of Health 2003) and the degree of hopelessness and despair that are often experienced by service users, this benefit is significant. As one care co-ordinator recalled:

People with serious mental health needs often have little self-confidence and no sense of control over their lives, particularly when they have a lot of control taken away from them when in hospital or whatever. This can contribute to people's despair and their feeling like their life just isn't worth living. After all, many of our clients are at a high risk of suicide. [Direct payments] helped her to feel good about herself and give her back some control and confidence – this can help people actually feel like life is worth living. In this case it's helped her get back her life and to keep it. I know it's a massive task and it might not always work out, but this is what it's all about. That's no small thing.

Support with 'everyday' things, such as befriending, is very much in line with the philosophy of the Independent Living Movement and the social model of disability (Barnes 1992; Campbell and Oliver 1996; Morris 1991; 1993). As previously suggested, these argue that regardless of someone's 'impairment', they should be able to do the things that other (non-disabled) people take for granted, with the provision of assistance. Given that many mental health clients may be socially isolated, the befriending aspect of the support that PAs are able to provide seems significant and goes some way to incorporating the needs of mental health service users within the broader definition of independent living. However, a lack of clarity about the function of PAs, and a limited conception of their role may mean that they do not necessarily facilitate a person's wider social network, if indeed that is their purpose.

Having presented the findings in relation to the perceived benefits of using direct payments, the next chapter moves on to draw out some key issues relating to the implementation process.

⁴¹ e.g. if they didn't have a personal/intimate relationship.

⁴² However, this may also reflect a self-selected sample of clients who were more satisfied with direct payments and/or were encouraged by their direct payment support worker or care co-ordinators to take part in the evaluation. Although it was not possible to control for this, a range of recipients was interviewed with a variety of experiences of using direct payments and they were able to give thoughtful and considered answers which are worthy of consideration.

⁴³ This is not indicated in figure 5.1.

⁴⁴ For example, reducing hospital admissions.

⁴⁵ e.g. CPN's supporting clients with Cognitive Behavioural Therapy.

⁴⁶ For example, through controlling the times at which support is provided and being able to select staff that people could trust and feel comfortable with (Stainton and Boyce 2002).

⁴⁷ For a more general discussion on employing PAs see Glendinning et al 2000b.

CHAPTER 6

Implementing Direct Payments in Mental Health Contextual and Organisational Issues

This chapter explores the contextual factors, infrastructure and mechanisms that supported or hindered the implementation of mental health direct payments within the national pilot sites. As with any implementation process, a wide range of factors emerged from the analysis of interview and questionnaire data which, in combination, influenced outcomes. Key issues are explored in relation to the changing national and local context, leadership for the initiative, the role of the local steering groups in co-ordinating the project, the pathways, policies and procedures for direct payments, funding for the initiative, knowledge and awareness among care co-ordinators, the role of the direct payments support agencies and other organisations.

6.1 Changing National & Local Context

The pilot took place during a time of unprecedented change in the national and local organisation and structure of mental health services. Attempts at increasing direct payment take-up in mental health happened against a backdrop of other new policy imperatives which could detract from the ability to focus on implementation. Participants raised issues relating to changes at both the national and local levels.

NATIONAL LEVEL

At the national policy level there is commitment to the wider implementation of the direct payments across care groups. They have been described as 'a key step in the Government's commitment to promoting independence and freedom of choice for those needing care and support...By giving individuals money in lieu of social services, people have greater choice and control over their lives, and are able to make their own decisions about how their care is delivered'⁴⁸.

However it is not clear, as yet, how the guidance on direct payments fits with mental health policy. The National Service Framework (NSF) outlined new ways of working and new models of service delivery for people with mental health problems (Department of Health 1999a). It set seven standards for mental health with implications for action at all levels and across a broad range of organisations. One of the underlying principles of the NSF is that people with mental health needs can expect that services will offer choices to promote independence. This theme has been further articulated in broader health and social care policy⁴⁹ and in mental health policy with an increasing emphasis on 'recovery' (Department of Health 2001).

There has been a sustained focus on the implementation of the NSF and on the development of new teams⁵⁰ and new workers⁵¹ as also described in the NHS Plan (Department of Health 2000a). Targets have been established for Primary Care Trusts (PCTs) to meet the commitments within the NHS Plan and Local Implementation Teams (LITs) are required to self-assess their performance against a number of targets which relate to the NSF. Although more recently the numbers of people receiving direct payments has become a performance indicator for Local Authorities⁵², the focus on NSF targets means that, in reality, the implementation of direct payments has not been a priority in mental health services.

LOCAL LEVEL

National mental health policy has also impacted on the organisation of mental health services at a local level. Services have been restructured to promote the integration of health and social services through the development of integrated mental health services. In some areas this has involved the development of Care Trusts whilst many others are pursuing alternative organisational arrangements to support the integration of health and social care in mental health services. At an operational level this agenda has meant the development of integrated line management and integration of care management with the Care Programme Approach (CPA). Alongside this there has been the development of specialist mental health Trusts, changes to commissioning with the development of PCTs and the creation of new organisations such as the National Institute for Mental health for England (NIMHE).

These restructurings have consumed staff time and energy. They take time to understand, have resulted in changes in personnel and management structures, particularly at senior and middle management level and have impacted upon local capacity in some instances leaving posts unfilled. These changes have created confusion and uncertainties about roles and accountability and responsibility in relation to new initiatives and challenges such as direct payments.

6.2 Leadership

At all levels, local leadership was identified as an important factor in providing a framework and direction for successful implementation within the pilot. Effective leadership helped facilitate local sites to fully engage with the pilot by providing a context in which workers were encouraged to risk-take, experiment and test out limitations and possibilities of direct payments.

However, leadership could be demonstrated in a variety of ways and at different levels amongst the pilot sites. There were different aspects of leadership ranging from 'formal' leadership structures (e.g. management) and 'informal' leadership from key workers⁵³. Informal leadership or involvement from workers at the 'practice level' will be considered in the next chapter. This section considers formal leadership: the senior mental health managers and local mental team managers.

SENIOR MANAGEMENT

Where senior management provided a framework and direction for the pilot⁵⁴, this helped develop the cultural context to support implementation. Other research has identified the contribution of leadership as an important factor in facilitating implementation (e.g. Dawson 2000). The evaluation data suggested that it was essential that senior management in the Local Authority and mental health services offered guidance and provided the co-ordinated infrastructure that was necessary to ensure implementation. They could also provide answers to more strategic issues that needed addressing in order for direct payments to be available, accessible and viable. This included ensuring that resources could be freed up for direct payments and that direct payments were prioritised and kept on local mental health teams' agenda.

In addition, they needed to ensure that various key workers in the system were adequately supported and informed to be able to carry out the necessary tasks to ensure that the direct payments process worked. Establishing a link between strategic and operational managers emerged as important. For example, in order for direct payments to be considered more widely, senior managers needed to ensure that local team managers were aware of direct payments and were themselves encouraging their teams to regularly consider direct payments as an option.

In most cases it was important that a senior Local Authority manager with a responsibility for commissioning chaired the steering group.

The service manager chairs the meeting. That's very good because when we have identified issues and concerns about the way we felt things need to improve, people can bring issues back and [s/he] will go away and address those, you know. (Steering group member)

Conversely, broader national and local reorganisations often resulted in changes in senior management, which in turn impacted on the ability of sites to develop consistent leadership and ownership of the implementation process. This was identified by local site co-ordinators as a key factor where progress was slow. For example, in one site the Local Authority lead was the third acting Divisional Manager in two years. However, a formal commitment to implementation did not necessarily translate into active promotion; the active commitment of senior management was also identified as important. Direct payment support services were critical of what they considered to be token support provided by senior management and sometimes felt that, whilst they liked to be associated with an innovative national initiative, this did not always translate into real support:

There are various people doing different things but there's no one really pushing it or driving it through... It's like they like the headlines without doing the work. (Direct payment support worker)

TEAM MANAGERS AND SENIOR PRACTITIONERS

Leadership at senior practitioner and team manager level was a key factor in successful implementation. Increased take-up of direct payments requires imaginative thinking to be built into practice and support at management level. Thus, in some instances, team managers supported workers in having time off for direct payment training, and facilitated the development of a culture of creative and reflective thinking. They could also 'nurture' the interest of care co-ordinators in direct payments as and when this arose. Like senior managers, it often helped if team managers or senior practitioners with effective influence in a team were on the steering group. More specifically, direct payments could be regularly raised as an option in individual supervision and team meetings where their possibilities and limitations could be discussed. Thus, one particularly influential senior ASW team leader recalled:

I sit in on all the team meetings, and sit in all the allocations meetings which has all the team members there, so that's the best forum to push direct payments really.

Similarly, one care co-ordinator reflecting on the team manager's role commented:

He has not let up, he is passionate about direct payment, and he supervises all district staff and sells it to them. He always urges the team to consider direct payments. He has weekly team meetings and regularly reminds care co-ordinators of direct payments. He is always asking whether a particular case is appropriate for a direct payment. I do not think it would have happened without him.

On the other hand, a low level of involvement from mental health team managers frequently made it hard to develop a keen and active interest in direct payments within local teams:

If we did this again we would do it differently. We would have more involvement and ownership from team managers. We were wrong in missing this out. (Local Authority lead)

CARE CO-ORDINATORS

In addition, individual care co-ordinators who took a lead in developing the option of direct payments were often described as 'product champions' and were able to engender collective enthusiasm for direct payments in local teams and help enable direct payments to be part of the culture or thinking of local teams. The role of care co-ordinators will be considered further in the next chapter:

Participants flagged up the value of cross-sector commitment to ensure successful implementation. Joint working and co-ordination of different aspects of the services such as mental health teams, training, finance, commissioning and direct payments teams enabled a team approach to implementation. In many cases, it was actually the steering group, set up specifically during the duration of the pilot, which facilitated the communication that was necessary for implementation.

6.3 Co-ordination: the Role of the Steering Group

The steering group has kept the work on track, questioned practice and taken decisions e.g. use of under-spent monies, given support and encouragement and raised awareness. (Steering group member)

It would not have happened without the steering group – it has set a framework and plan for implementation and also helped to encourage those involved to ‘spread the word’... It was a platform for launching it, in terms of just getting started off with marketing it to a wider audience and practitioners. (Steering group member)

The impact of the steering group was often dependent on good cross-sector representation where membership involved all key players including Local Authority training officers and finance/contract officers as well as strategic and operational managers, local team leaders, direct payment support workers/managers and local pilot co-ordinators. It was also beneficial to have the active involvement of user groups or user involvement workers who could generate interest and provide information and support to users.

In addition, it was important that key people in the steering group developed each necessary stage of the process⁵⁵ and reported back so that all the essential parts of the process were being developed and co-ordinated.

We have all kind of been involved in different pieces of work and that’s possibly the success. It’s not been a steering group for people who have gone away and they just wait for the next meeting, you know the kind of thing...it’s so co-ordinated and you feel as if you have touched all the bases really. (Steering group member)

I remember one time, [the direct payment support worker] came in, and just even before the meeting started she said, ‘what are you going to do about all these referrals that are not coming in?’ That prompted people like [a team manager] to go back and do something. Then the training was run and that prompted [the senior mental health service manager] to send out a memo as well to managers saying, you know, ‘start using this service’, so I think that’s just kept things going. (Steering group member)

In one site, good relationships were developed with the training section of the Local Authority and they found it beneficial to have a senior mental health training officer on the steering group. Respondents described this as being instrumental in facilitating access to training and training budgets as well as helping to develop new training initiatives in relation to direct payments. In some cases, steering group members planned and delivered training sessions for professionals which capitalised on their interagency working. In turn, this helped to raise the profile of direct payments:

I think the training has been a highlight in terms of interagency working from all of us, so there’s King’s and the ILC and the Local Authority, so bringing everybody together to look at what needs to be said. (Steering group member).

It was also helpful if an individual who was actively involved in the pilot was also part of the process of agreeing direct payment packages. This was seen as facilitating the process, because they had the knowledge and awareness about direct payments that could support any direct payment packages and could also help to smooth out any problems in the process. Thus, in one area, a team manager who was very involved in the pilot looked through each direct payment request and, if appropriate, recommended it to the funding panel. Effective co-ordination at this level could enable greater flexibility in the system, facilitating take-up and reducing unnecessary paperwork and bureaucracy.

6.4 Pathways, Policies & Procedures

The process of getting on direct payment for those with mental health problems is very different from that for other care groups. This is particularly true of direct payments for people with physical disabilities where the process has become clearer and is more frequently used. The experience of direct payments support workers who were working across all care groups highlighted the difficulties of finding out who was responsible for different aspects of the process. One direct payments support worker commented that 'it has been like working with a whole new Social Services Department'. Workers felt that the pathways that an individual had to go through to access a mental health direct payment were unclear. There was a lack of clear guidelines and procedures for staff to follow when trying to access direct payments for mental health clients. At best this could delay the process, at worst it could put workers off pursuing direct payments as an option.

Developing effective communication and appropriate processes to access mental health direct payments was essential. Once the processes were in place, any hold-up should then, theoretically, arise only from users themselves who were working at their own pace.

SPECIFIC MENTAL HEALTH PROCEDURES

It was important for sites to set up and develop specific mental health procedures for direct payments in mental health. The steering groups were frequently influential in developing specific guidelines and pathways and providing advice and information on such things as the referral process, financial requirements, the support infrastructure available to service users, the assessment process and eligibility criteria. Pathways needed to be simplified both for care co-ordinators and service users to be able to understand and use them effectively. Due to the predominance of fears about workload and extra paperwork, a couple of sites found it useful to develop a 'Who's Who' guide. This included information about to whom different aspects of the paperwork should be sent and about the roles and responsibilities of various key players in the system.

ELIGIBILITY CRITERIA

Participants in all pilot sites reported difficulties with eligibility criteria. They perceived these as a potential barrier to people with mental health needs accessing direct payments. Direct payments have the same eligibility criteria as those of general community care services. However, because criteria were being tightened up in relation to the Fairer Access to Care Services guidance (April 2003), some participants claimed that increasingly people were only eligible if they were 'critical' and, for example, are at risk of being hospitalised. However, the critical nature of their mental ill-health could mean that such clients are less likely to be judged 'willing and able' to take-up direct payment. One direct payments support agency commented that their longest and most 'successful' direct payment client might no longer be eligible for direct payment once the new eligibility criteria came into force.

Eligibility criteria differed across sites, both in terms of what needs were deemed eligible and in what ways they could be met by direct payments. The application of additional local criteria, for example that direct payments cannot be used to replace services already provided by the local authority, often resulted in difficulties in access. A high eligibility criterion for access to social care support has been cited elsewhere as a barrier to mental health service users (see Maglajlic 1999). Similarly, Witcher et al (2000) reported considerable variation in the conditions which people in different parts of the country are required to meet in order to qualify for direct payments.

FLEXIBILITY OF USE

Against this background, enabling a greater take-up of direct payments required a willingness to be flexible about the ways in which direct payments could be used. Where take-up of direct payments was high, local areas were more conscious of and able to operate outside of exclusionary limitations on what direct payment *could not* be used for⁵⁶ and also avoided deciding in advance what it *can* be used for. As the following quotes illustrate, this also required a willingness to operate more clearly within the principles and philosophy of the Independent Living Movement whereby direct payments are a means to greater independence:

Part of it is the flexibility of the direct payment scheme and never putting restrictions on them from day one about what you can and can't do and how small and how large the package is. We have been prepared to go with the spirit of the Direct Payments Act. (Direct payment support service manager)

There's no point in trying to double-guess what it may or may not be used for. We did actually guillotine those conversations on a couple of occasions. We said 'let's see what people are going to come up with' because surely the ethos of direct payments is about independence and responding to individual need. We did not get bogged down in uses of direct payments and that was really important. In social care people think much more in terms of boxes that services operate in, and hence when you come forward with an idea for a direct payment, it can seem fanciful, when in fact it's not, because they're outside of the box. It's been really important that we have been able to be flexible. (Steering group member)

Basically, we would not turn anything down if it is within the parameters of assessed need and meeting that need through whatever way. (Senior mental health manager)

This approach required a commitment to move towards developing self-assessment tools which helped to move beyond service driven assessments and develop more flexible packages of care. Therefore and conversely, a key barrier to the greater usage of direct payments was the limitations in conceptions about the potential of direct payments.

HEALTH AND SOCIAL CARE

During the pilot phase there were no examples of any health authority money being made available for direct payments. This is, in part, related to the complexities around funding and the fact that eligibility for direct payment is still via a community care assessment (Glendinning et al 2000c). Perhaps because of this focus, care co-ordinators were reluctant to pursue any health-related support through direct payments. In a small number of cases, a direct payment referral or initial inquiry was rejected on the grounds that it would be for a health need. For example, common requests from services users for psychotherapy, and alternative therapies such as aromatherapy were frequently seen as 'health' and therefore not deemed suitable for direct payments. As one steering group member commented:

I have got a client who is Punjabi speaking and I think it has been agreed previously that they would benefit from some sort of psychotherapy and there is no one in-house who can provide that. I have written to health management in the past suggesting that if they cannot provide it, and it's been identified, they ought to be buying it in, but they are not doing that at the moment and we can't get it via a direct payment. (Care co-ordinator)

In practice, direct payments are still tied to needs identified as 'social' care needs, in part because direct payments come under the auspices of Local Authority legislation which does not empower Health Authorities to make payments. However, government policy recommends greater joint responsibility between health and social services to ensure maximum independence of service users. In 1998, the Department of Health issued a single set of service development plans covering both health and social services which placed a joint responsibility on health and social services to ensure the maximum independence of service users (Department of Health 1998). Furthermore, Health Authorities have been reminded to provide services compatible with greater independence created via direct payments (Department of Health 1999b). In addition, Health Act Flexibilities, which came into force in April 2000, give the power to enable pooled budgets between Health and Social Care authorities and greater integrated provision. Health Authorities have the power to transfer money to Local Authorities, particularly in cases of complex needs where care packages are managed by social services (Glendinning et al 2000c). Therefore, it seems that despite national guidance, there is still little evidence of this potential flexibility being used to facilitate greater use of direct payments through contributions from Health Authorities.

One of the solutions to direct payments in mental health must be the greater involvement of health and the freeing up of health money. There is lots of talk about joint working, health/social services etc. – but it does not materialise in direct payments. (Direct payment support worker)

The difficulty in the lack of flexibility in pooling budgets relates to funding issues and the availability of flexible budgets more generally.

6.5 Funding

It is apparent that limited resources are an important constraint to the wider use of direct payments and services more generally. However, it was often unclear how far budgetary restrictions created barriers to people's individual access to direct payments. The broader literature on implementation (for example Hill 1997) suggests that whilst participants often mention financial resources as a barrier to implementing new developments, their availability is not necessarily the key to successful implementation. Indeed, it is the availability of the required combination of resources that is important. This includes money as well as flexible support structures, availability of PAs, motivated and knowledgeable care co-ordinators and so on.

Given that direct payments are just another way of providing services, these should not be any more expensive than traditionally provided services. In theory, this should not act as a specific barrier to direct payments any more than to community care services. However, in effect, direct payments are limited by general community care resource restrictions both in terms of the amount of money available and in what they can be used for⁵⁷. As already mentioned, eligibility criteria may affect access to direct payments and this is tied to more general budget restrictions and cutbacks in welfare provision. More specifically, an important barrier to successful implementation in mental health is the limited rates available for direct payments, for example, the pay rates available for PAs.

As well as the *amount* of money available for direct payments, greater take-up was also affected by the degree of flexibility of budgets, for example being able to shift money between budgets or divert monies from Local Authority or agency provision to direct payments. This difficulty generated concerns about taking money away from other services provided under block contracts. This could result in money being 'locked up' in services often valued by staff and users. In turn, services provided through the Local Authority through block contracts often influenced what individuals were able to get via a direct payment. Thus, if a particular service, such as home care or day care, was funded through a block contract, it was hard to free up any of this money to provide any home care or day care for individuals through a direct payment. In addition, some services were commissioned in such a way that it was difficult to separate out aspects of support that a person may want to be provided by direct payments. For example, some individuals who lived in supported accommodation found that some of their support was tied into their housing agreement. This meant that it was hard to get a direct payment for support that their housing project already provided directly as part of their supported accommodation.

In other research, a lack of flexibility between budgets has been identified as a major barrier, particularly where there were no ring-fenced monies for direct payments (Witcher

et al 2000). In the National Pilot, two local sites had a ring-fenced budget for direct payments for the duration of the pilot. This helped to overcome difficulties with budget flexibilities, at least temporarily, as these sites experienced the greatest increase in take-up⁵⁸. This strategy seemed to be successful because it prompted Local Authority leads to encourage awareness of direct payments across local teams. In turn, this encouraged care co-ordinators who, in a climate of limited resources, wanted to ensure that they used every available avenue of funding for their client's needs and because it was considered an 'additional' pot of money they did not want to lose it. As one participant put it:

It was put to us that it's a separate pot of money so it was a bit like 'use it or lose it'.

Within these sites, there was consensus that ring-fencing direct payment money had 'made a huge difference, it created an atmosphere, awareness and knowledge about direct payments in the team' (Mental health team manager and steering group member). Further evidence for this came from care co-ordinators who acknowledged that if they had known that money from direct payments would come of the general community care budget they may have been more reluctant to have pursued it.

Therefore, in the long term, greater knowledge about the actual source of direct payments and it being part of, not additional to, the community care budget may decrease the likelihood of promotion of direct payments if it is no longer viewed as an 'additional' source of funding. That is, unless other positive benefits to receiving direct payments are identified. In addition, once this pot of money was used up, more general budgetary tensions and concerns arose about where the money for direct payments would come from. Participants raised concerns about what would happen after the pilot or after the ring-fenced money was exhausted.

There's a real awareness in [an area within the site] about direct payments and a wish that people will use them, it's seen as a positive thing... The panel are getting quite excited about direct payments at the moment so we're getting lots of stuff agreed. But I'm sure this will change and they'll start being more selective about what they fund. (Care co-ordinator)

Thus, whilst ring-fenced money for direct payment packages may help initially to kickstart implementation, it could engender a false sense of budgetary security which does not necessarily address wider problems with freeing up money for direct payments unless a more flexible commissioning strategy is developed. Indeed, there was little discussion of the potential to actually redesign service provision and commissioning which would enable greater flexibility in how services are provided.

6.6 Knowledge and Awareness amongst Care Co-ordinators

Lack of knowledge and awareness amongst care co-ordinators remains a key barrier. Despite the National Pilot which made some inroads into raising awareness, care co-ordinators still lacked sufficient knowledge about direct payments. Care co-ordinators were confused and unclear at first, and often continued to be confused about direct payments. They were uncertain about what direct payments could be used for, how they were funded and how they could work in practice for their clients:

Although colleagues tend to be fairly positive about it and people have gradually received training about direct payments, it's difficult for people to actually see how it works. (Care co-ordinator)

In relation to training, feedback from care co-ordinators suggested it was important to include positive working examples or 'live' case studies. Case studies highlighted issues that needed to be addressed and helped workers look for positive ways around any potential difficulties with individual take-up. What specifically helped this process was where the case studies actively connected with people on care co-ordinators' caseloads and with concerns about their clients' needs not being met:

In the training we had case scenarios and care co-ordinators were very imaginative about the care packages they put together... They very quickly got their heads together and put a very constructive care package together and actually said how they would use direct payments in those cases. They were not extraordinary cases, you know, they were fairly typical cases that get presented to CMHTs. (Senior mental health manager)

The potential difficulty of access to direct payments for people with serious and long-term mental health needs is considered in the next chapter. However, this perceived difficulty highlights that rather than just training and awareness-raising sessions presenting working examples, it might be better to encourage care co-ordinators to consider how direct payments might work for their particular clients. Otherwise care co-ordinators could continue to think that this could not work for their clients.

In addition, training sessions were particularly beneficial when they built in enough space for the articulation of concerns and questions⁵⁹. This helped to assuage any cynicism about direct payments. In addition, care co-ordinators found it helpful if sessions could facilitate practical, creative and positive solutions to difficulties in access and develop possible strategies to overcome any problems that could arise (e.g. advanced directives to address fluctuating need/crisis etc.). This also highlights the need for raising awareness to emphasise the positive benefits of direct payments and not just the potential problems.

I went on a half-day training course about two years ago. I can't remember going back and thinking about it or thinking that I must do something about it to be honest. People tended to focus on the problems really, like 'how will it work, how could it apply to our clients' etc. It would have been much better if we would have had someone who is actually using it coming in and saying 'this is how I'm using it and this is how it's helped me and that the benefits outweighed all the work. (Care co-ordinator)

On a slightly different point, some care co-ordinators had difficulties accessing training and getting appropriate and comprehensive information about direct payments. Direct payments support services often reported that training sessions had frequently been difficult to organise and prioritise. Comments included that there was often insufficient support for training, insufficient time devoted to it, and/or that sessions had been cancelled. Increasingly, excessive workloads and crisis work often made it difficult to get time off to do training, especially if workers were insufficiently supported by management. In addition, limited opportunities for training meant that direct payments had to compete with other demands for training, which related to more immediate and pressing concerns⁶⁰. One Local Authority worker reported that a recent training course on personality disorders was three times oversubscribed and yet it was hard to get workers on direct payment training. On the other hand, when training sessions went well they could be really beneficial:

Most of the people that came on the training were a bit 'I'm not quite sure why I'm here' and 'what's this all about?' The best results were that people walked out of the room on the second day and moved from saying, 'not only do I not know about this, but I do not really believe it's going to work', to saying 'we really have changed our minds'; a lot of people said that and that was the best part of it...it was amazing. (Senior mental health manager)

However, despite having been on training sessions or having heard presentations, many care co-ordinators still expressed uncertainty and confusion about direct payments. It was clear that training sessions required follow-up to keep direct payments on peoples' agenda and to prompt thinking about direct payments. As one care co-ordinator pointed out:

*I think there's a much greater awareness now, but it still needs to be kept on the agenda. It's something that you're not thinking about really, unless you hear about it, and then it prompts you again about direct payments. I think it would be good for people to come to CMHT meetings regularly and talk a little bit about direct payments. It would be good to do this every so often to keep it on the agenda... If it was part of the ongoing promotion of it, then that would be really useful I think and would be picked up a lot more...It's about having a way in which it is constantly put back on the agenda, keeping it at the forefront of people's minds.
(Care co-ordinator)*

The importance of personally relevant accounts of clients successfully using direct payments has been highlighted elsewhere. Such research indicates the need for more supportive introductions to direct payments which include examples that workers can relate to and adequate time for questions and answers (Holman and Collins 1997, Maglajlic et al 1998). Furthermore, Ridley and Jones (2002) recommend that information about direct payments should be made accessible and relevant to mental health service users by including their perspectives and stories of individuals with mental health problems who have used direct payments (Ridley and Jones 2002). Ideally, training sessions should involve service users themselves who are currently using direct payments.

6.7 Direct Payments Support Agency

A crucial element in increased take-up was the direct payments support team. This confirms previous research which recognises that a well-resourced direct payment support service is necessary for increased up-take of direct payments (Barnes 1992; Hasler et al 1999; Hasler 2001; Witcher et al 2000; Ridley and Jones 2002; Stainton and Boyce 2002). In particular, the support offered by the direct payment support service to both the care co-ordinator and the individual service user was crucial to the care co-ordinator's experience of the ease of the process of direct payments. Indeed, many care co-ordinators felt that without this support they would not pursue direct payments as an option. As two commented:

The role of [the ILC] is crucial. If I had to manage all this myself I would not even want to go there.

I think we definitely needed their support to go through it because it was the first time I had gone through this process. Without her, I do not think I would have been able to do it, no definitely not.

INDEPENDENT AND PROACTIVE

The pro-activeness of local direct payment teams was very important in promoting direct payments to mental health teams and service users. One direct payment support worker reflected on the effectiveness of the continual and active 'promotion' of direct payments both to local mental health teams and to service users:

It became a process of continual movement ensuring there is a constant coverage of awareness and information delivered across all areas...so there's been a lot of going back to the day centres, it's that movement, it's about not keeping still and staying quiet.

This pro-activeness was particularly helpful in assisting clients with planning possible care packages in the run-up to their needs assessment, and particularly in moving towards developing self-assessments (see Hasler et al 1999; Ridley and Jones 2002; 2003). In addition, the earlier on in the process the direct payment worker intervened, the more helpful it appeared to be for both service users and care co-ordinators. The importance of a pro-active and independent support agency in promoting take-up has been demonstrated previously in other care groups (Campbell 1997; Hasler et al 1999; Witcher et al 2000)

In general, the data suggested that the earlier the direct payment support service became actively involved in assisting clients develop ideas about their care needs, the more likely a direct payment may eventually go to decision/assessment. This was related to the support and information the direct payment team can offer users in going through the process prior to assessment. In this way, the direct payment support services can play a crucial role in preparing clients in advance, in helping them think about their needs and generating ideas for direct payment packages. This alleviated a lot of the concerns and extra work for care co-ordinators and service users. In particular, care co-ordinators often valued working closely with the direct payments support workers in developing an appropriate care package. Where direct payments support services got involved later in the process, care co-ordinators tended to struggle more with the process:

Although [the direct payment support service] were excellent, they could only really start when we have had a provisional agreement that they can pursue it. After that they were excellent but I really needed them earlier on. (Care Co-ordinator)

MODEL OF PROVISION

Overall, it was more important how independent and autonomous the local service acted, than whether or not they were an independent or an 'in-house' support service. One in-house support service was able to operate to a large degree independently and offered intensive support in the early stages and in the process of setting up of direct payment packages. This service was also very proactive in promoting direct payments and raising awareness amongst care co-ordinators and service users. Having a ring-fenced budget for direct payments and the employment of a specialist mental health direct payment support worker further helped this process.

SPECIALIST MENTAL HEALTH SUPPORT WORKER

As highlighted earlier, all five pilot sites had additional resources to employ another part-time worker during the pilot. Three sites employed a specific direct payment mental health support worker whilst the other two sites decided to employ an additional generic support worker:

A specialist worker helped implementation up to a point. It made a difference in helping the support agency to focus on mental health issues, in enabling greater activity and promotion and in helping kickstart implementation. In some cases increased take-up could be directly related to the appointment of a specialist mental health direct payment support worker who was able to be more proactive in promoting direct payments to this client group.

Where a specialist mental health direct payment support worker was appointed, they tended to take on most of the mental health referrals and whilst they were usually part-time posts, it was felt it needed to be a full-time position. Indeed, because of increasing demand in one Local Authority resulting largely from the pro-activity of the mental health direct payment support worker, their post was increased to a full-time position during the pilot.

However, a specialist worker was not always necessary to ensure take-up if the local direct payments services were able to give the necessary time and energy to focus on this client group. Service constraints, approach and mental health awareness was more of an issue than the type of worker employed. Therefore, not having a specialist direct payment mental health support worker was not in itself a barrier, but more the inability of the support service to act independently, proactively and sensitively to mental health issues.

The pressure of the agency's general caseloads, training and referrals meant that many mental health direct payment support workers were often pressurised into taking on other non-mental health related work. Given the slow progress in generating mental health referrals, specialist workers were drawn into working with other care groups where demand was greater. This could make the support service seem relatively cost-ineffective in relation to the number of mental health clients actually supported.

Actually we have put much more energy into the pilot than returns in terms of referrals and number of clients. (Direct payments support worker)

In addition, a specialist worker could mean that the team as a whole did not necessarily have the responsibility of developing mental health support and procedures. Any difficulties filling the post or staff sickness could therefore leave the mental health aspect of the agency vulnerable. Whilst employing generic support workers did not necessarily inhibit take-up of direct payments, it could limit the degree of support offered to mental health clients which may be necessary in relation to their mental health needs and concerns.

MENTAL HEALTH AWARENESS

As support agencies were often set up initially to cater for people with physical disabilities, they did not necessarily have the ability to understand the specific support that may be required for mental health service users.

Some of the support work at times has been in actually educating [the direct payments support agency] about mental health, which is great in one way, but in another way I feel it has slightly detracted from the time they could have spent actually being 'out there' with the services users. (Commissioning Manager)

The direct payments support agency was crucial in offering support to service users in preparing for their direct payment package after it had been approved. However, mental health clients often had a number of difficulties actually getting their direct payment off the ground especially if they were to employ their own PA(s). Thus, sometimes a client's mental health difficulties required a particular sensitivity to their support needs that was not always appreciated within a generic support service⁶¹. Clients often felt that they needed additional support with preparation over and above what they were offered through the support service (see Chapter ten for further details).

Most support agencies were willing to respond to difficulties and increase their knowledge and awareness of mental health-related issues. The local pilot co-ordinators gave some mental health awareness training to the direct payments support services. However, time and resource limitations impeded support workers accessing additional and specific mental health support and training and being able to offer more support to individual clients.

6.8 Other Organisations

In the absence of direct payments support agencies' willingness, ability or resources to offer additional support relevant to mental health clients, some local mental health groups, advocacy projects, black and minority ethnic projects, user involvement projects and workers stepped in to provide additional support to clients. In some of the sites, a strong user group or user-led organisation helped to provide some of these functions. For instance, in one area a local user-led organisation trained some of their user-workers and volunteers to help other service users understand direct payments and develop individual care plans. This helped both in terms of independence and support and particularly in relation to the lack of awareness and resources to be able to support specific issues in relation to mental health. Therefore, this joint work between the direct payments support service and local user groups or other mental health-specific organisations could be beneficial. However, this was also dependent on the ability and resources of local user groups. In the case cited, this support was developed as a local independent initiative that was not built into local implementation plans.

⁴⁸ Department of Health Press release 'Announcement of Successful Bids for Direct Payments Development Fund' 1.8.03.

⁴⁹ Developing choice, responsiveness and equity in health and social care "Fair for all and personal to you" – consultation exercise undertaken in 2003 followed by the publication of the strategy paper "Building on the Best; Choice, Responsiveness and Equity in the NHS".

⁵⁰ i.e. assertive outreach teams, crisis resolution, early intervention teams etc.

⁵¹ i.e. graduate mental health workers, gateway workers, STR workers etc.

⁵² For 2002-2003, a new indicator on direct payments was added to the Performance Assessment Framework for Social Services, providing a mechanism for review of progress. In 2004-2005, this indicator becomes one of the high-level performance indicators for determining Local Authority star ratings.

⁵³ e.g. direct payment support workers, care co-ordinators, user involvement workers or advocates.

⁵⁴ This was often through the local steering groups.

⁵⁵ For example, finance, pathways, training etc.

⁵⁶ e.g. adult education, leisure, education, alternative day centres etc.

⁵⁷ For instance, the examples in previous chapters in relation to leisure activities.

⁵⁸ This was relative to the size of the area.

⁵⁹ For example, queries around eligibility.

⁶⁰ Such as training about risk assessments, specific brief therapies, crisis intervention or the Care Programme Approach.

⁶¹ Such as memory problems, lack of concentration, motivation, confidence, anxiety, fear.

6.9 Discussion

NATIONAL POLICY

The key issues discussed here reflect more general policy issues and concerns. Whilst the expanded use of direct payments is clearly advocated in recent government policy, it is unclear how this fits in with other mental health-specific policy such as the National Service Framework (NSF), the Care Programme Approach (CPA) and possible changes that may arise from the proposed reforms of the Mental Health Act. More specifically, attention needs to be paid to how these fit in with national changes in the mental health workforce including the introduction of new approved mental health practitioners, Support, Time and Recovery (STR) workers and proposed changes to the role of mental health social workers.

The distinction between 'health' and 'social' has been argued as being unhelpful, 'at odds with the reality of ordinary life' and can lead to poorly co-ordinated services and can even be harmful (Glendinning et al 2000c p1). Whilst many mental health services are working towards integrating health and social care, there are still numerous ways in which the health/social care division is maintained, not least through the current mechanisms of funding community care services. It is clear that neither service users nor care co-ordinators can readily clearly distinguish between health and social care needs. Whilst Government Policy enables both the contribution of Health Authority monies to direct payments and the possibility of getting 'health care' through direct payments, it does not stipulate how this could happen.

It may well be that it is precisely those aspects of care which straddle the divide between health and social care that will be the most beneficial and requested support from mental health service users (see Halliwell and Glendinning 1998; Glendinning et al. 2000a). It is widely reported for example that many users would prefer to have various forms of alternative therapies, psychotherapy etc. than traditional mental health interventions (Faulkner & Layzell 2000). Furthermore, it is precisely the ideological struggle about what constitutes social care needs which often dominates much debate in mental health i.e. many service users argue that their needs are primarily social, not medical and require social, relational and personal support rather than medical (primarily pharmaceutical) intervention (del Vecchio et al 2000; Bracken and Thomas 2001). Indeed, direct payments may help to rectify this balance more in the user's favour by enabling service users to assert the social nature of their distress as opposed to its medical emphasis within traditional services. In this context, it is worth considering which aspects of mental health policy may support the development of initiatives such as direct payments i.e. 'recovery'- focused policies (Jacobson and Greenley 2001; Ralph 2000; Turner-Crowson and Wallcraft 2002)

BUDGETS/FLEXIBLE RESOURCES

The relative success of ring-fenced money to fund direct payments in the National Pilot strongly suggests the need for more strategic and long-term planning regarding how direct payments specifically and mental health services generally are funded. This success may mean that an initial injection of money to fund direct payments may be useful in kickstarting the use of direct payments in mental health. However, greater attention needs to be paid towards increasing the flexibility of funding services and a greater flexibility in how direct payments might be used in order to widen the opportunities for direct payments take-up. This may require greater attention towards strategies for investing and/or disinvesting in services.

In addition, greater take-up where direct payment packages were funded from ring-fenced money suggests that there was still a lack of flexibility of community care resources to fund the variety of services that clients need and want. This is particularly emphasised by the fact that direct payments were so readily seized upon as an additional source of funding for clients.

Greater resource constraints and the tightening up of Local Authority eligibility criteria will have an impact on the possible use of direct payments. Some commentators have suggested that due to Local Authority resource constraints, funding is increasingly focused upon risk minimisation and securing safety. On this point, Kestenbaum (1999) argued that 'the icing on the cake of community care' such as household tasks and social activities outside the home are being 'squeezed out' (ibid p53). However, it is often these tasks that mental health service users value the most and are therefore likely to want via direct payments (Hasler 1999).

Furthermore, this very readiness to use direct payments if it is viewed as an additional pot of money also suggests that the way in which direct payments are currently explained and advertised does not necessarily do justice to the principles of independent living, namely increasing clients' choice and control which is at the heart of the disability rights movement for direct payments.

The following chapter concentrates more on practice-based issues explored through the experience of care co-ordinators during the pilot.

CHAPTER 7

Gatekeeping Direct Payments: The Role of Care Co-ordinators

Currently, care co-ordinators are the key point of access to direct payments. The willingness of care co-ordinators to promote, support and enable service users to get direct payments was a highly significant factor in taking forward or stalling the progress and uptake of direct payments (Maglajlic 1999; Ridley and Jones 2002). As previously indicated, whilst the National Pilot made substantial inroads into raising awareness about direct payments, take-up was still slow. At the time of the evaluation, care co-ordinators still largely felt unconfident and uncomfortable with the direct payment process.

This chapter focuses on the experiences, views and practices of care co-ordinators who had accessed direct payments for clients. This offers an in-depth analysis of the day-to-day practices of care co-ordinators, how they responded to the challenge and opportunity of direct payments and the decisions they made with regard to suitability of clients.

Within this context, Section 7.1 summarises the key factors involved in care co-ordinators referring to direct payments. Section 7.2 draws broad conclusions about care co-ordinators' selection of clients for referral for direct payments. Section 7.3 explores the issue of widening accessibility. Lastly, section 7.4 identifies other factors supporting or hindering care co-ordinators' consideration of direct payments. Unless otherwise indicated, interview extracts are taken from interviews with care co-ordinators.

7.1 Key Factors

KEY FACTORS IN CARE CO-ORDINATORS REFERRING TO DIRECT PAYMENTS

It has been suggested that one barrier to people with mental health needs accessing direct payments is that they tend to have more contact with health professionals such as CPNs rather than social workers. Health professionals such as CPNs may be less likely to be aware of direct payments (Glasby and Littlechild 2002). At the same time, people with complex mental health needs are more likely to have some input from social workers. However, as demonstrated previously, it was just as likely for CPNs to refer clients for direct payments as social workers. Whilst any client's care co-ordinator could refer to direct payments and this could include occupational therapists (OTs) and other health professionals, referrals primarily came from CPNs and social workers.

Overall, care co-ordinators who offered direct payments as an option to clients were a small minority. Moreover, out of those who offered direct payments, many workers considered only a minority of the clients on their caseload as having the ability to manage direct payments. Only a very small number of care co-ordinators had really grasped the principles of direct payments and were generally promoting it as a positive option to service users.

The likelihood of care co-ordinators considering direct payments depended upon a number of key factors. These factors are considered in relation to an individual care co-ordinator's approach, their recognition of the benefits of direct payments and the resources which could be accessed through payments.

THE WILLINGNESS AND INDIVIDUAL APPROACH OF CARE CO-ORDINATORS

Research on direct payments has argued that they are permeated by an individualised approach and that the attitudes of individual staff are important in taking forward progress on direct payments generally and as a result they can be driven or stalled by key individuals within teams (e.g. Witcher et al 2000). Evidence from the evaluation supported this position. This section considers the key factors which were involved in individual care co-ordinators pursuing direct payments as an option.

Direct payments are a relatively new concept in mental health and it requires a willingness on the part of individual care co-ordinators to support clients to take it up as an option. In a number of cases, successful take-up depended on the will and pro-activeness of care co-ordinators to support clients, to pursue the option and to progress it through to an agreed package. This often meant trusting that clients would be able to exercise choice and control appropriately. As one care co-ordinator put it she had to 'have an open mind about whether it works or not'. Direct payments support workers often referred to individual care co-ordinators as being willing to 'go that extra mile' and go 'above and beyond the call of duty' to support clients to access direct payments.

At the time of the evaluation, some care co-ordinators were beginning to see direct payments as fitting into their professional role in relation to promoting client autonomy and empowerment and in supporting access to more appropriate, client-centred services (Witcher et al 2000; Stainton and Boyce 2002; Stainton 2002). In addition, one care co-ordinator noted the benefits of direct payments in relation to her role as an occupational therapist:

Potentially direct payments opens up a whole world to us – because of the way in which we use activities anyway – we could use it more broadly. As OTs we pay a lot of our attention to people's day-to-day activities, so anything that helps that and opens up opportunities for developing that really is great. I do not have any worries that it would interfere with my work as an OT.

CONCRETE WORKING EXAMPLES

Hearing about actual working cases was one way to help increase knowledge and awareness of direct payments amongst mental health teams. Referrals or real working cases that had gone through the system gave encouragement and generated interest in direct payments by 'word of mouth'. In one site, a worker from a local day centre had seen the benefits for one of their clients from using direct payments. They reported being more positive about direct payments generally and that this had enabled them to believe it can work in practice. Two other participants echoed this point:

People can now begin to point out people who are using direct payments and this makes a change and has an influence on the teams. They are now actively aware of its workability. (Direct payments support worker)

The key is one or two people getting people on direct payments and then coming back and hearing about it in the team – and thinking 'maybe I could get it for some of my clients' or if a client comes in and asks for it – if it's been discussed and is part of the team thinking then it's much easier to think about it.

In addition, where direct payments were beginning to be used more widely in particular teams, although referrals were still confined to a minority of care co-ordinators, some of them felt that direct payments were beginning to be recognised and utilised as a team resource (see the case study of a CMHT in Chapter three). Personally relevant accounts of other people's success in using direct payments have been cited as an important factor in implementation (Holman and Collins 1997; Maglajlic et al 1998). However, although concrete working examples of direct payments helped, often in practice this was not enough. Examples were not always positive and knowledge of practical examples did not necessarily translate into greater team awareness and usage:

No, it has not rubbed off on other colleagues yet – they saw the difficulties I had with it, finding the information etc. Perhaps they have to go through this process themselves.

Individual care co-ordinators needed to feel that direct payments would be worth the extra effort involved. The benefits of direct payments had to be sufficiently positive for care co-ordinators to put their energy into to it:

I think a lot of care co-ordinators probably see it in the sense of, if it's something you have not done before, you can't really see the benefits. I think people are sceptical and I think until they actually see it actually working, and the benefits from it, I think they are going to be a bit, you know, sitting on the fence a bit.

THE LURE OF 'EXTRA' RESOURCES

As previously suggested, a major factor in care co-ordinators deciding to pursue a direct payment for clients was because they thought it was a separate, additional pot of money they could access for clients. This was partly fuelled in some sites by ring-fencing part of the community care budget for direct payments packages during the pilot.

I'm not saying they should not be given a choice, but I think the reality is it will get taken up much more to the extent that it's a way of getting something that's not available any other way...stuff that's needed in addition to what they're getting at the moment, something over and above that.

In the area where take-up increased most significantly, this was attributed to care co-ordinators' raised awareness of the 'additional pot of money' that they could utilise for clients. This awareness of the 'extra money' in direct payments came from the direct payment support workers and senior practitioners. One direct payments support worker recalled how during regular presentations to CMHTs as soon as the fact that money was ring-fenced was mentioned 'you can see them change, their ears prick up'. Care co-ordinators themselves were clear about this too:

[The direct payments support worker] came down and talked to us about direct payments and we all got very excited about it. Partly about money, partly about empowering users, and also about taking the pressure off the CMHTs, because you see we've lost a lot of our community support workers.

In turn, this raised awareness of the existence of the pilot and care co-ordinators felt that if they did not use the money available for direct payments it would be wasted.

The team manager mentioned it again at one of our team meetings. Basically he was saying there was money available and they were looking for suitable people who might benefit from it and that we could be creative and flexible in how we could use it. This meant the team were much more aware of it as a resource for us, and that basically, the money would be lost if it was not used. That was a bit of a turning point I think.

I am keen to sort of pursue it with clients, if they are willing to do it, because at the end of the day, there is not any other money, or a way of getting things in for people. Anyway we're always desperately looking for new ways to fund activities and find money for things for our clients.

Paradoxically, the confusion and misunderstanding about direct payments could, in a small number of cases, actually help the process. Thus, one CPN recalled that had he known that the money came out of the general community care budget and about the paperwork involved, he may not have pursued direct payments. Although doing so had resulted in a direct payment package with which both he and the client were happy.

The provision of incentives, such as the lure of potential extra resources, might help care co-ordinators begin to engage with direct payments. However, in order for this to continue, the findings suggest that the additional benefits for clients must become apparent. In addition, they indicate that care co-ordinators need to develop a greater understanding about the funding and underlying principles of direct payments.

7.2 Key Factors in the Selection of Clients

Care co-ordinators were generally positive about the idea of direct payments. They recognised their potential in giving clients greater independence, responsibility and a far greater choice. They were also acutely aware of the limitations of services and felt that direct payments could be both empowering for clients and a more creative way of developing care packages. However, despite this, many questioned how possible it would be for direct payments to work in practice, particularly for the majority of their clients.

Yeah it sounds great in theory but in reality how feasible/workable is it?

In the absence of service users asking for or demanding direct payments, the impetus for direct payments has been left to care co-ordinators. The following extracts clearly demonstrate that care co-ordinators make decisions about who they think are suitable for or capable of receiving and using direct payments:

Primarily I have just mulled it over myself first and not necessarily brought it up with them – I think about whether or not it would benefit the client more than it does at the moment.

To be honest, clients have been picked by me rather than clients choosing it themselves, which I suppose, is a bit of an issue. I think in general people will look at their case load and only consider people who they think it would work for and not really give people the choice or ask them first. They do this as an informed decision for good reasons, but perhaps they rule out more people than perhaps would be possible if they were given the option. A lot of this is based on good practice decisions but could be made on assumptions.

Of the minority of care co-ordinators who did refer, most felt that direct payments would only be appropriate for a very small number of clients on their caseload due to particular circumstances. Care co-ordinators used a variety of criteria to make decisions about suitability, often based on an individual approach as well as their particular caseload. However, there were particular patterns identified in relation to the characteristics of clients to whom direct payments were offered. These characteristics are summarised as follows.

HAVING A 'SIGNIFICANT OTHER'

If the client did not have a significant other or was not considered able to manage on their own, they were less likely to offer direct payments or to refer them. However, in a minority of cases, a client's lack of close relationships was considered a reason to pursue direct payments as it was felt that direct payments could help enlarge the client's social network.

PAST WORK EXPERIENCE

Having past work experience increased the likelihood of referral, particularly where the experience was seen as relevant to direct payments⁶²:

If it's someone who's used to working and stuff and then they got ill then maybe they could manage. But if they've never worked, which many of our clients have not, then I think they'll need support on a day-to-day basis to manage it.

STABILITY OF LIFESTYLE/TRUSTWORTHINESS

A number of care co-ordinators felt that they would be more likely to offer direct payments to clients who they thought were more trustworthy. This often involved having what they considered to be a stable lifestyle.

She was quite competent, more so than most of our clients... She was able to manage her own money, run her life, she was quite organised, not chaotic like a lot of our clients. She was clear about what she wanted and good at getting what she wanted. She's good with money, straight and honest.

Some people I would not discuss it with because, either they really could not manage or because they've got like acute substance misuse problems and I'd worry that they would squander the money. If I do not trust them I suppose that's what it's all about really.

Conversely, care co-ordinators were less likely to offer direct payments to clients if they were worried about them using the direct payments money inappropriately, particularly when 'unwell':

I would be worried that some of my clients, without being flippant about it, might benefit from a direct payment and they may want it, but then they might not spend it on what it's meant to be for. I'd worry whether it would be squandered on like alcohol for example. I know this may be a sweeping generalisation but it's an honest worry.

Such decisions could also involve other factors such as the skills and other abilities that clients were seen to have, particularly in relation to employing people:

I take on board whether they have got the skills to work with another worker, that they are not anti-social people, that the gap in their lives is all about another person to do things with and that they have already got ideas themselves and are very clear about what they do and what benefits it will bring to their lives to have that flexibility choice over what they do.

ARTICULATE

Care co-ordinators were more inclined to seek direct payments for clients who were more able to express their needs and clarify the types of support arrangements they wanted. The care co-ordinator below pointed out that this was an important factor in the client that he had supported to access direct payments:

She is very articulate, anyway, you know, she is well able to do this... that was kind of why I thought about it, because I knew that it was something that she would cope with... I knew it's something that she was well able to do.

END OF THE ROAD

Somewhat paradoxically, clients with needs that were difficult to meet within existing services or people who the care co-ordinator felt had gone 'as far as they can' within existing services may be offered direct payments. For example, clients who were seen as difficult to engage, had particular and complex or cultural needs, or were more demanding on services, were sometimes offered direct payments. In addition, as the following care co-ordinator argues, direct payments might be considered if it is felt that services are no longer meeting their needs and they need something else:

Direct payments might be good if clients are not getting any better than they are now. I think that it would be good once people have got through an acute episode and perhaps have gone as far as they can and they are quite stable and not going to improve much more and they are as mentally well as we can get them.

CLIENTS WITH ADDITIONAL/UNMET SUPPORT NEEDS

Where a particular resource was identified as an 'unmet' or additional need for a client and was not available or fundable by any other means, care co-ordinators were more likely to pursue a direct payment as an alternative means of funding.

I've only referred the one client, he had really high physical and mental health needs and I thought the more we could sort of support him the better really. No one else really stood out like that.

I was aware of direct payments...but it was not until I identified a need that was not being met in a particular client that I kind of then thought about direct payments. If I could have had those needs met within the existing services, I probably would not have had changed over, it was only because I felt they were not being met within existing services that I thought it was worth pursuing that provision to see if they could be met in that way. I think this has not happened with clients of other members of the team...so while their needs are being met adequately within these services, you just tend to continue having them met in that way.

THERAPEUTIC PROGRESSION

Over and above this, there were a variety of clients who were felt would benefit 'therapeutically' from receiving direct payments. Such benefits were seen to include negotiating relationships/boundaries, developing greater individual responsibility, promoting independence, facilitating social contact, combating loneliness and social isolation.

7.3 Widening Accessibility

It is clear that direct payments are often pursued for either 'positive' reasons such as a client's perceived potential and competence or 'negative' reasons such as the inability of services to meet their needs. Such reasons may facilitate access for particular clients yet may limit access for others⁶³. Similarly, those who are not viewed as needing 'extra' support or who do not arise as a particular 'difficulty' may be less likely to be considered for a direct payment because they are considered to be content with services. The analysis suggested that direct payments were often seen as a 'way out' or a means to provide a service when there seems to be no alternative.

If a direct payment had worked well with one particular client there was also a tendency amongst care co-ordinators to look for other similar clients on their case load rather than considering it as an option more generically.

I have been encouraged by my experience and I would do it again. I would not hesitate if someone else similar came along.

Likewise, care co-ordinators often had particularly fixed ideas about what direct payments could be used for. They often thought that direct payments were unsuitable because 'that sort of care' was not necessary or appropriate. This could mean that it was difficult to fully grasp the idea of direct payments as being the client's decision about how they decide to meet their needs.

There were a small handful of care co-ordinators who were starting to become aware of the selective criteria they were using. These practitioners were looking at how they might begin to consider clients as 'willing and able' with appropriate support:

Although I think maybe it shouldn't be, I do think that one of the criteria I would apply, is whether the client already has someone around that could help them manage the direct payment, and if the client was not able to manage on their own then perhaps I'd be less inclined to refer them. I suppose really I should be thinking 'lets find a way of supporting the client and then refer them'.

I was subconsciously thinking people would be appropriate if they had a carer or someone else in the background to help them manage it etc. I'm going to rethink that.

Some were beginning to consider the option of direct payments for many of their clients rather than just selecting people out:

I'm sifting through my caseload gradually, what I will do is every other week probably, as I go out to clients and assessing it myself and being careful, looking at their background and think about it. I'm going through every one of our clients each time and look at what's stopping them and it's usually nothing to do with the client being capable, it's the people around them...but that does not mean I would not pursue it... I try and not make the assumption that people are not capable of doing it.

What seems to be necessary in order for this shift to happen is the realisation of additional and wider benefits of direct payments related specifically to the enhanced choice and control at the heart of direct payments. Thus, if a direct payment was offered just as a means of getting a service, the benefits of actually getting this service through direct payments may become apparent. In turn, this may result in care co-ordinators considering direct payments more generally. As one care co-ordinator pointed out:

What happened with the second client I referred... I could actually have met her needs in-house, but I thought that direct payments would be a better way for her in doing it in terms of the challenge it would give her really and the control, the empowerment the responsibility and all of that.

7.4 Other Factors

Care co-ordinators identified a number of other crucial factors which affected their willingness to consider and pursue direct payments as an option. These are summarised under the headings of 'workload', 'paperwork', 'preparation', 'crisis work', 'staff changes' and 'service-driven assessments'.

WORKLOAD

Although I'd like to think I would push direct payments, in reality pressure of CMHT work is vast so even with the best will in the world it's hard.

The fact that direct payments are a relatively new procedure meant that it required additional effort and time to find out about the process, to do the paperwork, to think it through thoroughly with a client, to set it up and to monitor progress. This was seen as an additional pressure for care co-ordinators who already felt overburdened. By implication, this made it hard for care co-ordinators to fit direct payments in with other priorities and demands on their time and to incorporate it into their daily practices.

It's just not something we've considered in mental health up until now, and because people are overstretched, there's not the energy or the time for people to get their heads round it at the moment. It's something I would like to use, but it's difficult getting to grips with something new, when you have got those other pressures.

Care co-ordinators had a range of experiences in relation to the actual process of direct payments. However, all found that in practice, at least initially, it required more energy and input from them to set up.

PAPERWORK

Most care co-ordinators already felt that there was too much bureaucracy and paperwork in their job. Whilst paperwork is required for any commissioning of services, in practice accessing direct payments for clients did require a fair deal of additional paperwork⁶⁴. However, whilst co-ordinators found it reasonably straightforward and smooth, others found it an extremely complex and difficult process to work through. A few described the paperwork involved as an 'absolute nightmare'.

There are so many processes people get tired. We recently worked out that when we first meet a new client we have to fill out 14 forms! People get really bogged down with all this and direct payments can seem like more.

I have thought about 2/3 other people...But I have not pursued it, selfishly I suppose because of the amount of time and energy I would have to put into setting it up. I know it would require a lot of input from myself.

Some found the paperwork was unclear, lengthy and full of jargon.

It was hard to get the info I needed and more information was not really available. I could not find anyone who knew about the system and those who should have known more did not. My team manager did not really have the information. They found out what they could but it was down to me really. So I had to just find out the info as I went along.

Those who found the process complex and overly time-consuming recognised that this significantly held up the process. However a number also recognised that if they regularly reviewed clients' care packages anyway it should not necessarily be an additional work burden:

There seems to be lots of additional work panels, writing reports etc. But then I suppose you have to do this anyway and if it is part of everyday practice and if you start every time at the beginning with people and do this as a matter of course then I guess it should not really be too much more work.

PREPARATION

Care co-ordinators also recognised that there was often insufficient time available to fully involve the client and prepare them for the task of receiving and using direct payments, particularly if it involved employing their own PA. Thus just 'ticking a little box' at the end of a CPA form or needs assessment was not seen to do justice to the often lengthy process of developing a direct payment.

Although most direct payments had only been in operation for less than a year, the majority of co-ordinators spent as much time, if not more time with their client as they had done before the direct payment. However, care co-ordinators reflected that the quality of time spent with their client often increased as they were more able to work specifically in their role as care co-ordinators especially if the direct payment had alleviated some of the extra support needs that clients had.

It's one of those things you've got to put the work into at the beginning initially, to get it up and running. Once it's done you can see the benefits, so there's not been any disadvantages at all, apart from just taking a bit more time to set it up. Yeah, it's all been beneficial really, definitely.

However, the increased support that care co-ordinators offered clients to help them access direct payments may result in limitations in terms of how many clients they could refer and support.

It's been really time consuming and a lot of hassle... It's off-putting 'cos it's more work. Our work is based on client load not the amount of input therefore the quality of support we can offer may suffer. Ultimately it could deter you from doing it – it comes to a point when you just can't take any more on. If things don't change we could not physically take on any more.

CRISIS WORK

Care co-ordinators do not seem to treat it with any priority, they're too tied up with responding to emergency cases that the direct payment referrals go to the bottom of the pile and stay there, until a problem arises and then they might respond to it. (Direct payment support worker)

A specific pressure that care co-ordinators experienced was in relation to the crisis response aspect of their work. Care co-ordinators experienced an acute tension in responding to short-term crises as opposed to developing planned and longer-term work. This often meant that 'good ideas' which were not seen as urgent, such as direct payments, were often sidelined and not prioritised. Because it was generally felt that direct payments would be most suitable to those clients who are relatively 'stable' in terms of their mental health needs, these clients were frequently not those experiencing a crisis and therefore taking up the care co-ordinator's time:

In reality, when you're working with thirty/forty clients and you need money here and now obviously it's great if you have got the time and the capacity to pursue it. Obviously we try and work holistically and look at people as a whole. But often we need money now, we're dealing with a crisis, the very nature of our clients are very severe and enduring... people do not see it as a priority, because we rarely get to the point where we can sit back and everything is hunky-dory and everything is ticking along, it's usually crisis, it's been fire-fighting a lot of the time. You need that level of stability in a way to even approach the subject of direct payments.

STAFF CHANGES

Against this background, sites experienced a high level of staff changes and sickness at the individual care co-ordinator, direct payment support agency and management levels. In one Local Authority, the direct payments support worker reported that in 80% of referrals to direct payments, the client's care co-ordinator had changed during the time it took to process the application. This often meant that the application process could be delayed, that clients could be left without a care co-ordinator or that when a new care co-ordinator was appointed, direct payments were no longer considered a priority.

*There has not been one case that I have worked alongside that has actually gone through the process from initial referral to actually somebody getting a direct payment, that there has not been a fluctuation of care co-ordinators that have been involved.
(Direct payments support worker)*

SERVICE-DRIVEN ASSESSMENTS

Care co-ordinators often had very limited conceptions about the potential use of direct payments. Assessments were still often dominated by a 'service-driven response' with implications for services being tied to care co-ordinators' perceptions of what was available rather than what the client needed or wanted to meet their needs.

Actually I do not think we're utilising direct payments as best as we could be...that's because people have resorted to the same old procedure, because that's what they know.

Tensions emerged between the care co-ordinator's role in developing a client's care plan based on a needs-led assessment and imperatives to gatekeep resources through the application of eligibility criteria (see Dowson 2002; Salisbury 1998). This tension has often resulted in what Dowson (2002) has referred to the way in which care managers 'talk down' clients' expectations to enforce a 'fit' between what the service user needs and what is actually available. This practice still frames the way that assessments are carried out in terms of culture, mindset and imagined possibilities.

It's all about keeping costs down – the cheaper it is the more likely it is to be agreed. It's the hard sell really. We have to leave our social work hats behind and basically become a lawyer, and an accountant, you have to have a business head on 'sell sell sell'.

Therefore, when resources are limited, care co-ordinators have to make difficult decisions about priorities (see Lipsky 1980). What service users may request via direct payments may seem to be 'fanciful' in relation to other seemingly more urgent needs. This was most clearly illustrated when care co-ordinators questioned how a client would want to use a direct payment to meet their assessed need:

*We have had difficulties at the care co-ordinator level, where they thought a package would be a good idea and they could see that direct payments might be a way of using and empowering the client, but because of priorities and pressures on budgets and resources and so on, they felt that that person was not actually eligible when it's come to what the person is going to use it for. It's been 'well that does not meet our eligibility criteria, so although you as a person do, because you have needs, the way that you want to use it to meet your needs, does not'. So sometimes it's actually stopped at care co-ordinator level because they have somehow decided that it's not very suitable.
(Mental health service manager)*

Where most successful, care co-ordinators were thinking more creatively and moving away from service driven assessments and were committed to facilitating more person-centred and needs-led and self assessment tools:

It was an opportunity to just basically look at her needs rather than trying to fit that in to some kind of service.

I see the assessment as being really important to get clients to describe their difficulties in their own words and try to capture their understanding and help them to do this. Direct payments fits in well with this 'how I see my needs' form.

7.5 Discussion

A wide range of factors has been identified which mediated care co-ordinators' pursuit of direct payments as an option for clients. This discussion highlights some key issues for further consideration. The findings here build on previous research which has reported that care co-ordinators' concerns about eligibility and their lack of awareness that as much support as needed to manage a payment can be offered, has an influence over whether direct payments are even considered, let alone offered to mental health service users (Ridley and Jones 2002). Ridley and Jones (2002) maintain that one of the most effective ways of promoting direct payments was through word of mouth and through involving recipients of direct payments speaking to other users about their experiences. It was too early to report on whether this had started to happen in the pilot sites although in a small number of cases recipients' satisfaction with direct payments has generated a few referrals.

Ultimately, the impetus for direct payments needs to come from service users. Without the knowledge, awareness of and demand for direct payments coming from clients, access will be dependent on care co-ordinators' discretion about who they think would be suitable for direct payments.

It's so much work but if the user asks for it, it's harder to ignore, we'd have to do something, we'd be more likely to pursue it.

In the absence of this shift, the ongoing confusion care co-ordinators have about direct payments and the selective criteria they apply, raise questions about training and supervision strategies to ensure that care co-ordinators are conversant with the principles, practicalities and processes of direct payments. The evidence presented here suggests that there is often insufficient opportunity for sharing and learning within mental health teams which might facilitate greater consideration of direct payments. This suggests that effective implementation requires greater attention to development at the practice level in relation to:

- Creating more spaces for reflective learning and practice and the importance of ongoing supervision in relation to creating new ways of supporting care co-ordinators to develop creative care packages. Encouraging dialogue and debate through peer-mentoring supervision, action learning groups, clinical supervision, co-working etc. (Clark and Spafford 2002).
- Moving away from service-driven responses and developing practices to support this (for example, self assessment tools).
- Approaches which embrace risk-taking, person-centred planning and creative thinking.
- Developing shared objectives within teams which relate to maximising clients' choice and control.
- A positive and open-minded attitude focusing on the potential of direct payments and longer-term benefits.

These practices are necessary in order to counteract the barrier of care co-ordinators talking down clients' aspirations in relation to a more pervasive service and resource-driven response. In turn, this relates to the tension identified for care co-ordinators linked to their gatekeeping responsibilities (see Salisbury 1998; Dowson 2002). Individual care co-ordinators did extend their practice beyond the limitations of their conflicting role in order to offer additional preparatory support to individual clients. However, it was unclear how much this was considered part of their role. Thus, the reflection that care co-ordinators need to be willing to 'go the extra mile' implies that more generally care co-ordinators saw direct payments as something that was outside their remit. However, if care co-ordinators are to continue to have this gatekeeping function, this is problematic in terms of widening accessibility.

As time for independent planning⁶⁵ is not 'built in' to the way needs assessments are carried out, it depends on the will of individual care co-ordinators to be prepared to develop their role in this way. The evaluation strongly suggests that a crucial element in the increased take-up of direct payments was the assertiveness and persistence of local care co-ordinators in enabling clients to take up the option of using direct payments. However, more generally, limited local resources will make these decisions increasingly difficult. In part, the ability of other local agencies to offer support to clients in accessing direct payments will also determine the extent of progress.

This discussion raises the need to clarify the role, function and contribution of direct payment support services in providing this support. It also specifically raises key questions about the allocation of roles and responsibilities in relation to assessment and promotion. It may be that mental health direct payment implementation will be more successful if direct payment support agencies were explicitly assigned and adequately supported to provide these functions, such as support with assessment and individual planning. As previously highlighted, the varying extent to which the direct payment support services acted across different sites in relation to their pro-activeness, independence and early intervention suggests that their roles and function are not necessarily clear and adequately defined in relation to care co-ordinators.

It has been suggested that assessment for direct payments requires a new relationship with users, a new approach to allocating community care resources, including provision for self-assessments (Hasler et al 1999), and community care assessments that are dynamic and person-centred (Ridley and Jones 2002). It is significant that this analysis outlines the positive contribution of the direct payments support workers in this regard, especially in assisting clients with assessments and planning packages. It implies that the role of direct payments support workers may be more conducive to working in a person-centred/ needs-led way than care co-ordinators who would otherwise perform this task. This may relate to the tensions and conflicts experienced by care co-ordinators in their role in that they are often gatekeepers to resources, service providers as well as responsible for individual needs assessments. The pro-activity and independence of the local direct payment support services, their early intervention and assistance in supporting needs-led and self-assessments can go some way to addressing these difficulties and would bring us closer to the independent planning model advocated by Dowson (2002).

Having considered the mediating role of care co-ordinators in facilitating access to direct payments, the next chapter explores in greater depth the concerns and issues care co-ordinators raised about implementing direct payments for people with mental health needs.

⁶² In particular, work experience in the caring professions or in business. For example, one client had been an accountant.

⁶³ For example, those without a 'significant other'.

⁶⁴ For instance, additional paperwork to complete financial assessments, written agreements and as part of recording regular reviews.

⁶⁵ 'Independent planning' is a process whereby clients have an opportunity to develop a proposal for their own care package with the support of a trained broker, someone who is independent from the funders and providers of community care services. The package is then presented to social services for funding agreement. This prevents care managers/care co-ordinators gatekeeping resources and access to direct payments and reduces conflict inherent in the role of care managers being both assessors and service providers.

CHAPTER 8

Implementing Direct Payments in Mental Health Issues Raised by Care Co-ordinators

Previous research has indicated that care managers have a number of specific and general anxieties and concerns about direct payments, particularly about their clients' ability to manage direct payments. Carmichael and Brown (2002), for example, reported a huge fear factor on the part of care managers. These concerns can be particularly acute in mental health (Witcher et al 2000; Ridley and Jones 2002). Despite training, support and information these anxieties and concerns are not easily alleviated.

It has been argued that professionals with no direct payments users on their caseloads are more likely to be under-confident and reluctant to pursue direct payments due to a lack of experience in setting up direct payments (Witcher et al 2000; Stainton 2002). As indicated, the evaluation concentrated on care co-ordinators who were working with clients who had used direct payments. Whilst their concerns were lessened by this experience, they still expressed a number of key considerations in relation to widening implementation. This chapter highlights some key issues that professionals, predominantly care co-ordinators, thought hindered implementation.

Overwhelmingly, care co-ordinators who referred clients onto direct payments expressed a range of concerns about how direct payments would work in relation to their clients, the majority of whom were people with severe and enduring mental health needs. Most thought that these concerns would make take-up extremely difficult and were often very pessimistic about the possibility. To a large degree their concerns echoed those raised across care groups (Dawson; 2000; Hasler et al 1999; Witcher et al 2000). However, analysis of the data suggests that these concerns, whilst not necessarily being more pronounced, certainly raise specific mental health issues and concerns that require careful consideration. These concerns need to be addressed because they often result in negativity, scepticism and an unwillingness to consider direct payments as an option.

Many mental health professionals have been very tentative in approaching direct payments in part because it is seen as 'uncharted territory'. Direct payments were described as requiring a 'massive leap of faith' and the difficulties discussed here often resulted in care co-ordinators not being prepared, able or willing to pursue this option.

A lot of it is about the care co-ordinator having the confidence to actually take that step to a direct payment. (Direct payments support worker)

Therefore, in view of the significance of these issues in relation to care co-ordinators' consideration of direct payments, this chapter presents and discusses the implications of these dilemmas for the implementation process. It is important to note that these were concerns raised by care co-ordinators who had referred onto direct payments and were therefore engaged in the process.

Section 8.1 looks at general concerns in relation to clients' mental health issues. Section 8.2 considers the dilemmas for care co-ordinators associated with managing their responsibilities towards their clients in relation to their mental health needs. Section 8.3 highlights concerns which were expressed about the support that clients may require for them to be able to manage direct payments. Section 8.4 summarises the issues participants raised in relation to clients employing their own PAs. Unless otherwise stated, all interview extracts are taken from interviews with care co-ordinators.

8.1 Mental Health Specific Issues

Care co-ordinators and other participants frequently raised questions about the existence of more complex tensions and dynamics in relation to setting up a direct payment in mental health including more considerations in relation to 'therapeutic' concerns and perceived benefits. In physical disabilities, for example, professionals felt it was clearer what support and assistance someone needed in order to gain greater independence. This was because the independence disabled clients needed could be more easily distinguished from mainstream services which may not be able to offer the flexibility needed to accomplish such objectives as going to work, college or take part in leisure activities. Whereas clients' mental health needs were seen as more nebulous, changeable and harder to define. By way of illustrating this point, one care co-ordinator relayed her concerns about how this may affect employing PAs:

The main problem is that it's very hard to sort of clearly define the role [of a PA]. You can with physical problems, where someone might need help getting up on her feet and I mean that is relatively easy...but it's very difficult to define exactly [how a mental health problem] is affecting somebody and exactly what level of support that they need and so I think the sort of selection, the training, and the support of that personal assistant I think is difficult, and I think it's difficult also to try to be fully aware of what those difficulties are.

Many staff members expressed concerns about how users would be able to manage and benefit from it, particularly when they are 'unwell'. This would be when they would be at most in need of a service and yet they may not necessarily, at that time, be able to control and direct it in ways that would be most beneficial to them because of their mental ill health. The possibility of using tools such as advanced directives, whilst helpful, did not necessarily allay these fears.

CAPABILITY AND CAPACITY

Care co-ordinators expressed specific concerns about the perceived compliance, capacity and competence of mental health service users to set up, manage and benefit from a direct payment.

A lot of our clients lack capacity. So to even introduce an idea like that especially with clients that are quite paranoid and delusional, the whole idea, well you just would not even approach it, to be honest you know, even though there may be a need, it would be just impossible.

8.2 Responsibility for Client Care

Clients' perceived lack of capacity was related to a number of factors, namely:

- **Emotions** such as fear, anxiety, paranoia, panic may make engaging with the complexities and responsibility of direct payments difficult. Whilst emotional difficulties may be expressed across all care groups, care co-ordinators considered that the severity and intensity that these are often experienced by mental health service users made this issue particularly acute.
- **Social isolation.** Care co-ordinators reported that the majority of their clients were particularly socially isolated and did not necessarily have 'significant others' who may be drawn upon to support them to set up and run a direct payment.
- The **experience of long term mental health difficulties** as well as the **side-effects of psychiatric medication** was seen as contributing to difficulties with concentration, memory and motivation as well as to vulnerability, a lack of confidence, self-esteem and assertiveness.
- Participants made reference to the **fluctuating and unpredictable nature of many mental health difficulties**, in particular the onset of acute crises, as making organising direct payments difficult.
- **Awareness and insight.** Once in the middle of a mental health crisis, clients may not necessarily be aware of the support they require and may turn down the support they might need.
- Care co-ordinators thought that **inappropriate behaviour, potential risk of suicide and dangerous behaviour** made consideration of direct payments less likely.

These factors made many care co-ordinators feel that clients would be ill-equipped to manage the money and the paperwork and/or to employ a PA, to decide and direct the support they needed. In practice there are various ways in which clients could be supported to manage the payments e.g. some recipients used their PA to help them with the paperwork.

As we have seen, the option of direct payments threw up many concerns about the question of ongoing responsibility for clients' care. Some care co-ordinators felt that the lack of structures and controls over how clients use their payments made their duty of care difficult to resolve. For example, this was raised in relation to the possibility of the user being left 'without a service' if their own support arrangements broke down or if a difficult incident occurred.

Other professionals also raised questions about the equity of direct payments, in that it may enable a minority of users to gain greater levels of services, flexibility and choice whilst the majority would be stuck with inadequate and under-funded services. This concern has not just been raised in mental health and not just about direct payments but has also been raised in relation to other developments such as Person Centred Planning in the learning disabilities field. More generally, this suggests that issues of equity need to be set within a wider context of a cultural shift in and challenge to traditional models of 'care' and 'responsibility'.

DEPENDENCY

One specific concern raised was about the potential of fostering dependency. Paradoxically, although direct payments are ostensibly about facilitating 'independent living', some participants worried that direct payments might inadvertently create or reinforce clients' dependency on needing support. During the pilot, a small number of direct payments packages were actually turned down partly because it was felt that a direct payment would encourage the client's 'institutionalisation in the community'. Unlike in some other adult care groups, care co-ordinators sometimes thought that a service user's mental health could and should improve such that they would no longer require mental health services, in whatever form. Thus, the aim of services should be to help the client 'move on' when they are well enough and not become trapped in a dependent 'mental health career' where they feel like they 'need' help and assistance, rather than having the confidence and self-belief to move away from services. These are reasonable concerns and goals, and the tension between dependence and independence needs to be kept in mind. However, it is also worth noting evidence from literature on Assertive Outreach which suggests that, at least with people with profound and complex mental health needs, longer-term and ongoing support may be essential to prevent 'relapse' (Stein and Santos 1998).

In addition, although direct payments are often conceived of in terms of promoting greater social inclusion and participation in 'normal' community and social networks, some professionals felt that service users may become more socially isolated through direct payments. They expressed concerns that direct payments would only facilitate an unreal sense of social life because they may then be dependent upon the provision of a paid PA.

NON-COMPLIANCE

Another concern related to the possibility of users disengaging from services, and from support set up via direct payments. This is perhaps the 'flip' side to the concern about dependency. It is related to professionals' concerns about users 'non-compliance' with services and was linked to clients' 'denial' of their mental health difficulties, particularly during periods of heightened mental health conflict. For example, some care co-ordinators reported that clients were not receptive to direct payments because they did not accept that they needed any support. Ironically, a number of professionals wondered whether those most in need of services would be viewed as least likely to be able to manage a direct payment precisely because the client was not aware of the support they needed:

They may actually be more eligible for direct payments if or when they are most resistant to it and yet if they are receptive to it, do they really need it? (Mental health service manager)

8.3 Support to Manage Direct Payments

Responsibility and managing the paperwork was a specific worry that many care co-ordinators identified in relation to clients' difficulties with accessing direct payments.

You are talking about somebody's ability or their inability to manage money. Because they are so debilitated by their illness they can't actually look after themselves and they often can't manage money, so that is a major stumbling block. Also service users' inability to control the process - whether that's because of the side-effects of their medication or the very nature of their illness - they will not be able to control the money used for direct payments and they're often scared of the paperwork.

As indicated in the previous chapter, care co-ordinators were more likely to consider clients suitable for direct payments if they perceived clients as having a relevant support network. The direct payments legislation states that clients must be considered willing and able alone or with assistance. This often means in practice that clients' carers and/or partners or family/relatives provide the assistance necessary to enable clients to use direct payments. Echoing a previous point, care co-ordinators often identified their clients as lacking the social networks that could be drawn on in this way.

It may be hard to clients to access direct payments without a lot of support, especially if they are isolated. If they had a carer or something in the wings perhaps they could manage but many of them have not got that. Many people live alone. The only way this could be achieved is with a lot of help. Without the positive input from immediate carers, they would need someone on a day-to-day basis to do this.

8.4 Employing PAs

KNOWLEDGE, EXPERIENCE AND SUITABILITY OF PAS

One of the most frequently voiced concerns by care co-ordinators who participated in the evaluation related to how their clients would be able to employ their own PAs via direct payments. Some expressed concerns over whether PAs would receive any training or external supervision. In particular, this was associated with the often 'emotionally draining' aspect of mental health work. In addition, some questioned how feasible it was that the PA would not share any information about clients with others given the perceived risk element in much of their work. Some workers also expressed anxieties that their clients were often very vulnerable and may suffer abuse from potential unscrupulous PAs or vice versa. Indeed, one care co-ordinator admitted that she 'sabotaged' the direct payments because she was worried about risk issues for the worker going in. As a consequence, many felt that they would need to monitor and supervise this process.

This potential difficulty was one contributing factor to care co-ordinators not exploring direct payments as an option because they did not feel they could trust the quality and expertise of any PAs that the client would be able to recruit.

The key seems to be choosing the right PA. However, our clients are very vulnerable. Ideally they would employ someone who they already know are responsible and trustworthy, but many people do not know that many people. The usual practice in ILCs seems to be to put an advert in a local shop – which does not seem sufficient really for complex mental health needs. I would need to get really involved in that as clients would not be able to process this themselves so it would be time-consuming. Quite honestly this has often held it up a bit. I'm sure there's an element of overprotectiveness here but...if there were any risk I would not go down that road e.g. if it was a case of employing someone who I did not know then I'd would be very cautious.

The reluctance of care co-ordinators to pursue direct payments was particularly the case when clients had very complex mental health needs which raised concerns about 'risk' and confidentiality in relation to the client themselves or the possibility of inappropriate behaviour in relation to others. These scenarios meant that care co-ordinators felt that to hand over such responsibility might put into question their duty of care and may constitute negligence. Given a prevailing culture of risk aversion within mental health services, this was seen as even more acute.

A new document framework issued by the Department of Health provides a legal framework for local agencies to use when developing multi-agency codes of practice for preventing and tackling the abuse of vulnerable adults (Department of Health 2000b). This may provide some guidance in such cases but there may need to be consideration given to how this framework fits in with new developments such as direct payments.

However, in practice these concerns led many care co-ordinators to want to oversee the relationship between the client and the PA. Some indicated that they were unlikely to pursue a direct payment if they did not feel that the client would employ a PA that the care co-ordinator felt was appropriate. A few even thought that PAs should be supervised by the care co-ordinators. This close supervision may compromise the ethos of user control and independent living through direct payments.

Doing the care management, we're used to having a lot of control and overseeing it. We know the people, we oversee it, but they could lose a lot of that. They could just get any 'Tom Dick or Harry'. S/he recruited from [an agency] but if she had not I might have been more worried and questioned it. As it was I approved of it cos I knew the agency cos it's one we use anyway. They vet people so that's like a safeguard. They need more help in choosing PAs, we need to make sure people get vetted and people get the right help to do that for perhaps the ILC could vet people, not the client. I'm not keen on individuals being able to choose.

One of the things that concerned me initially in the change-over was whether the liaison between the two services would... work as efficiently as it does with services that are already existing was that we had had very clear liaison structure with, obviously with our own support workers.

However, at the same time, some care co-ordinators did recognise that the lack of official mental health training, professional status and approach might be precisely what clients want:

However, interestingly it is precisely our caution around PAs that can actually be a benefit – the positive aspect of this is the PA actually not having a professional background, it being a more normal environment etc.

Some workers also questioned whether there would be adequate availability of PAs to serve the needs of their clients. This was particularly the case in view of the wages that PAs would be offered, the lack of job security or potential career opportunities.

It is unrealistic to expect that there is a ready pool of people willing to do the kind of complex and intensive work for the amount of money paid. (Mental health service manager)

The Government needs to think about pay structure for PAs if direct payments is to be extended to people with such complex needs.

This was also made more problematic given the often complex needs of many clients where care co-ordinators often felt that it might be impossible to recruit and retain PAs with enough experience or knowledge.

ROLES AND RELATIONSHIPS

In terms of the actual work a PA could perform, there was a concern over their role in supporting clients, given the specific role that mental health professionals are expected to perform for their clients. This often resulted in professionals questioning the training, supervision and direction a mental health worker would receive, that a PA might not. In particular, the complex nature of mental health difficulties made many question how a PA could take on an 'assertive' role in relation to their clients and, in particular, deal with conflicting demands that might arise during difficult periods of crisis. Some staff felt that making the clients the direct employer of the PAs could make their employment relationship difficult, if not untenable.

Usually it was argued that workers would weigh up the needs of the user with guidance from their organisation and their own mental health expertise so as to ensure an adequate 'balance':

You may not get a good balance if they were only employed by the user. There is a big issue about the level of 'friendly persuasion', 'firmness' and 'toughness' that might be possible through a PA employed by a user directly. On a day-to-day basis it may be difficult to do this if employed by the user, particularly if the PA is not very experienced. This might make it difficult to be 'tougher' even if it is in the best interests of the user and they would probably agree that it was in their 'better moments'. (Mental health service manager)

Similarly, Ridley and Jones (2002) report that professionals, particularly managers, worried that the employer/employee relationship could be compromised particularly in situations where, to be effective, an individual needs a worker to be directive and authoritative.

Over and above this, workers were concerned about appropriate boundaries being maintained between the client and the PA with regards to preserving a supportive relationship and not overstepping the boundaries between friendship, a helping relationship and maintaining confidentiality. Some care co-ordinators worried about clients getting off on a 'power trip' in relation to having the power to hire and fire someone 'if people have such a deficit in their lives and low self-esteem, you have to worry about how they might use that power'.

8.5 Discussion

Concerns about risk and safety can hinder the wider uptake of direct payments. Such concerns can too readily drive assessments resulting in a neglect of the potential benefits of risk-taking strategies such as direct payments (Clark and Spafford 2002). In this evaluation, many participants identified a dominant risk averse culture present in mental health services. This was attributed to a heightened political emphasis on risk particularly within the contexts of the proposed revisions to the mental health legislation and the dominant media agenda, resulting in a heightened focus on risk assessments. In practice, it is often care co-ordinators who bear the brunt of this risk averse climate. This focus has set the practice agenda and often results in a tendency to 'play safe' which can contribute to a reluctance to pursue direct payments as an option.

In addition, care co-ordinators may find it hard to move beyond their clinical role with clients and allow them to make their own decisions whether they agree with them or not. Furthermore, there may be a lack of belief or trust in clients' abilities, resources and experience. Care co-ordinators could too readily assume that direct payments would not be suitable for any of their clients because of their mental health difficulties and ideas about their 'competence' and experience. Care co-ordinators could look upon their role more as about developing clients' capacity to become more able to exercise greater levels of choice and control.

Therefore, some care co-ordinators were finding it difficult to relinquish their professional knowledge and control and hand over decisions to the service user. The idea that professionals still hold onto paternalistic ideas and practices and are not fully embracing the need to relinquish their control has been highlighted across care groups (Stainton 2002, Holman and Bewley 1999; Holman and Collins (1997). This tendency may be particularly acute in mental health services because of specific concerns about clients' abilities to make decisions in their best interests and their perceived need for professional intervention and support. Thus, whilst Stainton (2002) found no evidence that social workers were discouraging people from direct payments in general, he reported that social workers working in the mental health and learning difficulties fields were often more sceptical about the practicality of direct payments for their clients.

However, while it has been argued that the willingness and ability of care co-ordinators to support the possibility of direct payments is crucial, it is not only their reluctance to pursue direct payments that has held up implementation. A number of care co-ordinators have offered direct payments and clients have subsequently felt unable to take up the opportunity.

It's about changing into a different way of thinking and that's not just for the care co-ordinators, that's the clients too. Quite often it can be as high as you like on the care co-ordinators agenda, but it's adjusting to that shift in the way that clients are thinking... Some people have been approached and said 'no, no, it's too risky, it would involve too much'... So you have lost clients - even though the care co-ordinators are fully engaged with the process. (Direct payments support worker)

Therefore, whilst these concerns may be related to overprotectiveness in relation to the abilities of mental health service users, they may also reflect real concerns that are shared by users themselves. Worries that these concerns may only be about prejudicial attitudes and assumptions may mean that such concerns were not discussed openly and honestly so they can be addressed, without reinforcing misconceptions about mental health.

Care co-ordinators were often unclear about how much support could be offered to clients and the possibility of utilising a number of innovative and flexible ways of widening access to direct payments, whilst still enabling the user to delegate control and responsibility, for example through third party payments, user-controlled trusts and advanced directives. Therefore, it is important to generate greater knowledge about the support that can be made available to service users to help individuals plan and manage their own support arrangements. Overall, this suggests the need for ongoing training opportunities to address the concerns of users and staff (Murray-Neill 2000). It also requires more practical ideas about addressing potential difficulties in selecting and recruiting workers and development and roles. More generally, it raises questions about who is able to provide access to direct payments and whether it should necessarily be care co-ordinators.

This chapter has presented the findings in relation to the key issues of concerns raised by care co-ordinators. Some of these, recipients themselves shared. The next two chapters explore the experiences and views of people with mental health needs themselves. Chapter nine looks at their views of accessing direct payments and Chapter ten considers their experience of managing direct payments.

CHAPTER 9

Experiences of Getting on Direct Payments

This chapter is based on interviews with 27 service users and focuses on their experiences of getting onto direct payments. All quotes are from direct payments recipients unless indicated otherwise. Most people who were offered direct payments found out about the option of using direct payments from their care co-ordinator. As we have seen from interviews with care co-ordinators, it seems to be the case that care co-ordinators specifically talked to clients about direct payments if they had identified a specific need was not currently being met within mainstream service⁶⁶. As one client recalled:

I was talking to my social worker and saying that I wanted someone to befriend me and go out with me, and I think that's when she brought this [direct payments] up.

However, there were a variety of other ways in which clients heard about the option of direct payments:

- Three people heard about it via a day centre they attended and subsequently approached their care co-ordinator about it.
- A number of people had heard about direct payments from other local user organisations. For instance, two people heard about direct payments from a user involvement worker and one person from a local black and minority ethnic advocacy project.
- One person heard about it from their clinical psychologist and another from an employment officer – both of whom were helping to support the client get back into voluntary or paid work.
- Two people heard about direct payments through a close relative or 'carer' who had heard about direct payments through other settings. For instance, one worked as a PA for a disabled person and the other worked within social services.
- Another person heard about direct payments through the local pilot site co-ordinator.

9.1 Assessments

Although the sample size is extremely small, there was a difference between the outcomes of people who had heard about direct payments from their care co-ordinators and those who had heard about it from other sources. Thus, the two people in the sample who had their direct payments turned down had heard about direct payments from a local user/advocacy projects. Other evaluation data indicated that some clients are less likely to access statutory services, particularly for example people from black and minority ethnic (BME) communities. This may mean that, although they may be eligible for community services, they tend to avoid statutory services and may use for example local black and minority ethnic projects in the voluntary sector. The local BME workers that were interviewed as part of the evaluation specifically raised this issue of how their clients could access direct payments if they did not regularly see a statutory mental health professional. Many mental health service users avoided using statutory services because of difficult past experiences of services and because of the compulsory nature of some mental health interventions. This seemed to be the case particularly with service users who had young children and who were worried about statutory involvement in relation to their children. One suggestion made was for other local organisations to be involved in doing assessments for direct payments rather than them having to be done by a care co-ordinator, particularly if there are language/cultural needs and other workers knew the client well.

Accounts from recipients support previous assertions that the persistence and pro-activity of individual workers, especially care co-ordinators, direct payments support workers and advocacy organisations, were key to facilitating access to direct payments. As one recipient commented:

Although we had a CPN they did not really know anything about direct payments. It was hard to get a social worker, but we eventually got one and he took it up for us. He was great, he did not let it go, he kept doing all the forms and sending off the stuff and everything. It definitely was not straightforward but he did a fantastic job and sorted it all out for us. He was really persistent. I know that many people would have just given up.

Referrals leading to an agreed direct payment package were often where the support of the direct payments support worker was enlisted early on in the process. The direct payments worker then worked alongside the service user (and the care co-ordinator) to develop an assessment which more closely resembled a self-assessment based on a needs-led approach. This could then be taken up by the care co-ordinator and considered in relation to their eligibility and assessment criteria. However, in a small number of cases where the direct payments package was developed just to meet a specifically agreed need⁶⁷, the direct payment support services did not necessarily get involved and the service user was pleased to be able to access a service.

In addition, in some cases, the care co-ordinator took on this role and helped the client to develop their own self-assessments:

Yeah it was [the CPN] he said to us, 'make a list of all the things you'd like to do if you had the money and put down the amount of hours needed', so once we had done that we could give it back to [the CPN] s/he did the assessment, s/he typed it all out and went back to social services to see if we could get those hours for those things and it worked out fine.

Approximately half of the people interviewed did not remember having had a community care assessment for direct payments as such. This was particularly pronounced when their care co-ordinator was involved in developing the assessment. When the direct payments support workers worked with the service user to help prepare a needs assessment for direct payments, clients were more likely to identify this as an assessment because it was more focused⁶⁸. It seems that because care co-ordinators knew their clients quite well, they were more likely to just write up their own request for direct payments without necessarily seeming to involve the client formally in the process. As one client put it:

Yeah [my social worker] just went off and got on with it and did it all for me.

Service users did not necessarily view this as a negative process, especially if they trusted their worker. Moreover, service users seemed content if the package that the worker was putting in for had genuinely arisen out of a shared discussion and if the direct payments support worker had been involved in the process.

It was reasonably straightforward, because it was [the CPN] who did it and then he submitted it to social services, so I mean he had already gone through it with me and the direct payments support worker who dealt with my case, she had been through it with me beforehand, [about] what to expect. Then I thought it was going to be somebody from social services, but it was [my CPN] so, and you know I trust him implicitly.

However, sometimes this could cause difficulties later if the client did not feel that they were sufficiently prepared for developing their support arrangements through direct payments, if they wanted to change how they were used or if they wanted to use them more flexibly.

In some ways they needed to have involved me more in the beginning to help me think about it more... I feel like I was pushed into it a bit, not that I did not want it, but it all happened so quickly.

It was striking how little recipients seemed to know about direct payments and about how flexible they could potentially be. This was in part because care co-ordinators and to some extent even direct payments support workers tended to agree what direct payments would be used for at the outset. Care co-ordinators often influenced a client's choice of direct payments package. Sometimes it was hard for both clients and care co-ordinators to consider alternatives to what has traditionally been provided by social services.

I did not really understand what direct payments was. No-one has yet told me what I can use it for! So I did not know that I could ask for anything. I thought it was just like a grant you know another route, another secret door to get something that they had somewhere, like in the past they've had pots of money to pay for fees for college and things.

Often direct payments were used merely as a means to use what was currently available⁶⁹ as opposed to agreeing a certain number of hours based on assessed need and outcome, which could then be used however the individual service user saw fit. The latter moves further away from a service-led assessment towards a needs-led assessment and is more in line with direct payments guidance and policy:

As a general principle, local councils should aim to leave choice in the hands of the individual by allowing people to address their own needs as they consider best, whilst satisfying themselves that the agreed outcomes are being achieved (Department of Health 2003: 6).

Recipients often experienced quite tight constraints placed on what direct payments could and could not be used for⁷⁰. In addition, whilst the support of direct payments support workers was invariably experienced as positive, they could often too readily assume what clients would want to use direct payments for. Often, this was based on their experience of working with disabled people where, for example, employing PAs predominates.

However, the majority of clients who took up direct payments reported being reasonably happy with the assessment process. Therefore, it may be that at least initially, many service users (as well as, and especially, care co-ordinators) are more comfortable with this process and that it can be a gentler way of introducing the idea of greater independence, choice and control through direct payments. However, any such 'graduated' process needs to be checked in order that it is not overly paternalistic and cautious and ensures that it allows for greater flexibility over time.

Many recipients became increasingly aware of how much independence and control they could potentially exercise through using direct payments, even if they were initially used as a way to get a particular service:

It's been a long learning curve. I now know that it's about what I want. I did not grasp the fact that this was about me – me to choose – I did not have any concept of it at all. It's taken me all these months to grasp that I needed to know what I wanted.

9.2 Difficulties Getting Direct Payments

In order for clients to be able to fully engage with the option of direct payments and to be able to take it up, the timing and pace of the process was crucial. Recipients' comments suggested that it was important that it was done at the users own pace such that it was client-led. If the process seemed to happen too quickly, clients could feel daunted and put off by the amount of work and responsibility involved. However, if the process went too slow it could be frustrating and the initial impetus could be lost. In this way, support and/or training offered to potential recipients needed to be tailor-made to suit the individual's own needs and done at a pace with which they felt comfortable. It may be important that there is someone who can hold onto the idea of direct payments for the client, or the actual package if it has been agreed, so the client can take it up at the point at which they feel ready.

Clients highlighted a number of problems with accessing direct payments. Firstly, care co-ordinators' lack of knowledge about the process of direct payments could make access difficult and time-consuming:

The CPN took forever to do the forms. She did not know what to do and kept asking me stuff which I could not answer about it all. It's like they were just bluffing their way though it...Neither the housing association, my CPN or the psychiatrists knew much about it.

Secondly, there were a number of instances where there was a conflict between what the client said they wanted and needed and professionals' interpretation about the appropriateness of direct payments to fund these. Thus, in two cases, clients had difficulties accessing direct payments due to the support that was offered in their supported housing. One of these clients had their initial application turned down because the housing association where she lived claimed that they provided the support that she was asking for through direct payments. Although as far as she was concerned, they did not provide this support.

In another example, a client had a direct payments package agreed but whilst she was waiting for it to be processed, had a serious mental health crisis resulting in hospitalisation. By the time she left hospital, a direct payment was no longer seen as appropriate. A year later she was left with very little support and the direct payments application had been forgotten:

Everything was agreed. However, I was sectioned for four weeks. The hospital social worker was different from my previous social worker and they knew nothing about it and just said it was not suitable in my condition and so it was dropped. My own social worker did not visit me in hospital. They said it was not their role so I just saw the hospital social worker. She just said that my situation had changed and I was no longer suitable and should forget about it. That I was too ill and could not manage it. She said once I was more stable maybe we could approach it again, but it never was. It all just fell by the wayside. They did not really explain why and I did not really understand why cos I was actually much worse and needed more help. I do not see any reason why I could not have had it. I think I could have managed it.

This points to the potential benefits of continuity of contact and communication on the part of care co-ordinators in relation to direct payments to ensure that applications that have been placed in abeyance can be reactivated. Furthermore, care co-ordinators need to be able to explain very clearly to the service user what will happen if they go into hospital.

Other clients also experienced problems if their care co-ordinator changed, was on leave or went on long-term sick. Recipients indicated that this could frequently hold up the direct payments application. Situations were related in which one care co-ordinator may be pursuing a direct payment while the next one differed in their assessment of need and eligibility. This was especially pronounced when a client had a difficult relationship with their care co-ordinator. In such circumstances, it seemed that the care co-ordinator was less likely to support the client in pursuing a direct payments application. Difficulties around the key working system has been emphasised where alternative and more team and community-based approaches have been advocated as a way round these (see Navarro 1998).

Recipients reported a variety of administrative difficulties that often held up the process of getting on direct payments. They indicated that it could take a long time to process the application, particularly when clients were the first in an area to use direct payments.

It took a long time, because it was all new. [The CPN] was having to find out how the process worked himself, like who to contact, what forms to fill in... I think a couple of times, the wrong forms were filled in or they went to the wrong address, that sort of thing... So it took a while to set up... I think I had to contact social services and even when I contacted them, the finance department, even they were confused, because they were so used to physical problems, that they did not know what to do with mental health... So there were quite a few hitches at the beginning, but we got through it.

Even when a package had been agreed, it could take a while before clients started receiving the payments. Several recipients commented that paperwork was 'put to the bottom of the pile and forgotten' because of an administrative error or people who were dealing with the money being off sick. A small handful of clients had actually started to pay for their own support arrangements in the meantime and some had to use their own money or borrow money. A number of recipients also reported that the money continued to be late arriving. A common complaint was that when the money did arrive, it was unclear what the money was for and what time period it was meant to cover which often caused undue anxiety.

The first payment did not have a date on it so I did not know what timespan it was to be used in... it was just a blank statement, it could have been anything! It's very difficult to do financial returns without this.

In addition, a number of clients also had difficulties getting a bank account because of previous debts they had incurred. The direct payments support services reported that this was a problem that was getting more pronounced as banks were becoming stricter about credit checks.

Having highlighted some of the difficulties recipients encountered in accessing direct payments, the next chapter looks in greater detail at how recipients managed their payments.

⁶⁶ For example, a befriending service.

⁶⁷ Such as gym membership or transport.

⁶⁸ For example, on what activities they wanted to do and how many hours were required etc.

⁶⁹ For example, transport.

⁷⁰ e.g. to employ PA rather than agreed hours which the client decides how to meet needs.

CHAPTER 10

Experiences of Managing Direct Payment

There are three stages during which direct payment recipients may require assistance with setting up and managing direct payments:

1. **Pre-assessment:** preparing ideas in relation to what support is required.
2. **Start-up:** setting up once direct payments has been agreed (e.g. recruiting PAs).
3. **Ongoing support:** Continuing support when a direct payment is up and running.

The last chapter considered direct payment recipients' experiences of the first stage (the assessment process). This chapter outlines issues that direct payment recipients have identified as being important in the following two stages in managing a direct payment once it has been agreed. Key issues that recipients identified are considered under the headings of 'managing the money and the paperwork', 'additional support with paperwork and 'employing PAs'. Again, all quotes are from direct payments recipients unless indicated.

10.1 Managing the Money & Paperwork

In part, clients' experiences of managing the money and doing the paperwork associated with direct payments were related to what they were using the direct payments for. Thus, when clients used their direct payments to employ PAs, the paperwork was more complex compared with things like gym membership or transport.

Of the 20 clients interviewed who were in receipt of and actually using direct payments, nearly all had had initial help from the direct payments support service in explaining what was needed in order to manage the payments. In terms of actually running the payments, a substantial proportion (8 people) had a close relative managing the paperwork for them⁷¹. Six people managed the payments themselves. Another client, who used to work in accountancy, found doing the paperwork to employ a PA relatively easy:

Well I suppose I have to say it's probably quite easy for me, because I am used to keeping financial records, so I have actually written a spreadsheet program that I put the hours in and everything else gets done, but of course not everybody has that experience.

Two people enlisted their PA to do the paperwork for or with them. In both of these cases, the recipients' PAs got support from the direct payment support agency in running the paperwork aspect of the direct payment on behalf of the client.

Managing the money is OK...I did bookkeeping before in work/school. The PA helps me. She goes to the [direct payments support agency] training course with me and helped me with the money and paperwork initially.

The only difficult thing I think is the paperwork, but I don't do that because I can't read properly and I can't spell, I find it really stressful. The direct payments support worker come out and showed me what to do, went through it one afternoon, but it didn't go anywhere. I didn't take it all in...Then she come out and showed my friend, my personal assistant and now she is all right with it.

Two people actually had their care co-ordinators doing the paperwork for them. As one of them explained:

My CPN gives me all the support and helps sort out any problems with it. It was frightening to start with – keeping separate money that's not mine, keeping receipts etc. But now I feel better about it, more independent. I've got into a routine now with it. I work out how much I need and give the receipts to my CPN and she tallies it all up. She does it all for me. She just said that now it's happening there was no question about it. I wouldn't have taken it up if I had to do it myself. I wanted her to do it. She dreads it!

Another recipient, who used direct payments for going to the gym, had help from their care co-ordinator in doing the paperwork:

My social worker does it and I give them receipts when they ask for it. I just pay the money and keep the receipts... They do all the paperwork. I definitely wouldn't want to do any of the paperwork... It's fine. I don't worry about it.

One person had ongoing help from the direct payments support worker in doing the paperwork.

If I phone up and need her, she will come out; she'll phone up ever so often to see if everything is going OK.

Another had help from their housing support worker:

It's OK I just use the [bank] card. I was worried about this first but it's OK now. I just get the amount I need and any left over I put in an envelope and keep all the receipts. I just give all the receipts to the office upstairs here and they deal with it. [The housing support workers] keep the receipts and everything. That's fine.

Therefore, whilst a number of recipients were managing the paperwork by themselves, others felt that they were only able to use direct payments if someone else handled the paperwork for them. One client memorably reported that whilst she really appreciated the help she was able to get via direct payments in employing a PA she did not see why she should have to do the paperwork. She could not understand why social services or the direct payment support agency could not pay her PA directly:

I would like somebody else to do the payments. I don't want any control over it. All I want is to know that I have got somebody to care for me and I don't really want any control of the money. It frightens me, particularly with the mental health issue. Certainly with bipolar because there is fine edge and usually a financial side with it, I don't really want to be involved with the money side of things. It's the legality of it, the responsibility, what if I do it wrong and what will happen. I really think, although I am the employer, the City Council are truly the employer and I think they should do that or [the direct payments support service] should be the ones responsible for it. I don't want any involvement with the finance you see, because it causes a pressure to me.

Other clients felt that it should be their choice about who gives them the support to run the direct payment:

It should be the client's choice to ask their social worker or CPN if they could do the paperwork until we're ready to do it ourselves... They could set up a contract to do that... We should have more power to do that.

10.2 Additional Support

The number of recipients who had enlisted the help of a close relative to assist them with the paperwork raises an important issue in relation to access. We have already discussed in Chapter seven how care co-ordinators may be more willing to offer direct payments to clients who have a 'significant other' in their life who is willing to help them manage it. Furthermore, the recipients who did have help from a close relative felt that they would be unable to use direct payments without this support.

[My husband] does that.. I haven't had nothing to do with it in that sense, but I still worry about it. If he hadn't have been doing that, I said I wouldn't want to go on this payment, because it's too hard for me to do it.

One client who was offered direct payments did not take it up in part because she did not feel she had sufficient support to manage it:

I couldn't cope with it all on my own. I needed someone to help me with it. My husband works full-time and didn't have the time to help me with it. It all seemed too much. At the time I wasn't even able to make the beds. I just found it too much – It sounded easy and straightforward but it felt like a mountain to climb. The hardest bits, yeah well, I had to find a person, then sort out all the tax and write out the cheques and sort all that out... I don't deal with the money in the house you see. It was too much for my little brain to handle!

Given that many mental health clients can be socially isolated and do not have a close relative or friend able to offer this level of support suggests that additional assistance may be required to ensure that more clients have the option of using direct payments. Thus one client who did the paperwork herself recalled that:

[The direct payment support worker] went through the paperwork with me very slowly but I have still found this very difficult since. I dread the time of the month when the paperwork needs to be done. I just feel out of control and vulnerable with all the forms... This is quite an issue for me. I still need more help with this. I'm OK when they go through it with you, but when I'm on my own I lose confidence. You don't know what the penalty might be if you get it wrong. This hasn't helped my anxiety really.

In those pilot sites where recipients were able to access a payroll service⁷², this often supported people in being able to use direct payments. However, this usually had to be paid for out of the direct payment package itself.

They pay the tax and National Insurance and tell you at end of the month how much you need to pay. If I get stuck I can just phone them up.

Many direct payment packages in mental health were for relatively small amounts⁷³ and do not include such additional costs. Therefore there is often little additional funding available to help with the actual setting up of direct payments and the paperwork. In the case of larger packages, additional help may be provided by the PA or a payroll service. However, this support may be necessary regardless of the size of the package. Relevant here, a close relative of a recipient who managed the paperwork stated:

It'd be better if his PA could just complete the time sheets and we could check them and then send them off to be paid. Then he could probably do it himself.

Where the individual is assessed as needing additional support and if they want this support provided by the PA or from another agency, this additional support could be costed in. A standard minimum level of additional setting up costs could be given, regardless of the package size and this could increase proportionally depending on the complexity of the package and the number of hours allocated. It is worthy of note that another area outside the pilot (Essex) has a Personal Assistance Support Service (PASS) and subsequently they have a significantly greater take-up of direct payments than in areas without this service.

Recipients made a number of suggestions which may make the paperwork aspect of direct payments more manageable for them.

REPEATING INFORMATION

Firstly, many recipients reported that they needed information to be repeated a number of times and in different ways before they were able to take it in. Various recipients said that they were not very good at retaining information, in part due to their mental health difficulties and the medication they took which affected their ability to concentrate.

[The direct payments support worker] went through it too quickly. I needed for him to go through it several times. They give you everything at once – it'd be better if they did it bit by bit. You get a barrage of info.

For this reason, one recipient argued that an audio or videotape might enable people to retain information better because it could be re-visited:

Sometimes it might be appropriate to offer a cassette to somebody with a mental health problem, because I can achieve more by listening than reading... Reading something if your mind is muddled and you can't think straight, it's very, very difficult to concentrate and it's very tiring. Whereas with something like audio, you can play bits of it at a time, and you can keep playing that bit until you understand, or a video, and then they'd get the visual as well as the audio.

REASSURANCE

A number of recipients stated that it would be helpful to have mock-up forms to fill in so they could see how it should be done. Furthermore, recipients often seemed to want reassurance that they were completing the forms correctly. Some also worried about what might happen if they filled in financial returns wrongly, and whether there was any 'penalty'.

PLACE TO CONTACT

Another suggestion related to having a central place to contact⁷⁴ where they could raise queries about the paperwork, the financial returns and could check they were filling out forms correctly to help alleviate anxiety.

I'd like a name and number to be able to phone up if for example if something's changed or whatever, like a 0800 number, something local would be best. Otherwise my CPN has to do it and it's really long-winded cos then she has to ask someone else. Anyway, she's a CPN and hasn't got time to do all this.

As one recipient suggested, this service could provide additional assistance in relation to questions regarding the flexibility of the payments and what it can and cannot be used for:

It's all very mysterious this direct payments – you don't really know who does what, who to ask about what etc. and what happens to the info you send back, the financial returns etc. and I don't know what I'm allowed to spend it on.

Whilst the majority of recipients did worry about doing the accounts, a number reflected that the biggest worry for them was actually in recruiting a PA (if they were using direct payments to employ PAs).

10.3 Personal Assistants

Whilst employing PAs was not the only way in which mental health service users were using direct payments, issues relating to identifying, recruiting and managing PAs were important for recipients. As we saw earlier, issues around employing PAs was also something that concerned care co-ordinators and could affect both their willingness to pursue direct payments for their clients as well as clients feeling unable to pursue this themselves. On this point, one care co-ordinator recalled referring two clients for direct payments. Neither decided to pursue it because of worries in relation to employing people:

The first client said she was a bit blown away by all the paperwork and ‘what do you mean I have to pay for someone, find someone and pay for them, can’t you just pay for them, can’t you just pay for it, can’t you take that away from me, I can’t deal with it’. Then she didn’t want to take it up. She found it too complicated and too much of a responsibility...I think this was just too much, even though she could see the benefit in the long run, the initial stages and the set-up of it, she just thought, ‘no way I can’t, I don’t want to do that’. The second client we referred was very similar, she was like ‘oh my god, I can’t deal with that, I’ve got enough on my plate. Will I have to advertise and find someone? Oh I can’t do that, I don’t want to’. I think there was a lot of apprehension about sort of strangers and someone coming into their home environment. (Care co-ordinator)

It is widely argued in the Independent Living Movement that employing a PA is the most empowering way in which a direct payment recipient can direct their support arrangements (Zarb and Naidash, 1994; Campbell, 1998; Glasby and Littlechild, 2002). It is also recognised across care groups that the success of a direct payment package relies heavily on the ‘match’ or suitability of the PA and the service user. Therefore, careful attention needs to be paid to these issues and this section concentrates on recipients’ experiences of this process.

IDENTIFYING QUALITIES OF PERSONAL ASSISTANTS

When thinking about employing PAs, clients identified a variety of qualities that they wanted their workers to have. Most important for recipients were the PA’s personality and that it was somebody with whom they would feel comfortable. Qualities that were often mentioned included someone with a sense of humour, who was easygoing, outgoing, with a ‘cheerful bright’ personality but also someone they were able to talk to if feeling low. It was very important that the client felt that they could trust their PA. These qualities are often related to the ‘befriending’ nature of the relationships required. It was also often important that the PA could gently motivate the recipient into doing things without being too pushy. In addition, it was often important that the PA shared similar interests, had a similar outlook on life and, to some extent, a similar educational background.

It was often important that the PA could drive and had their own car if the clients wanted to be able to go places. A number of recipients also had pets, and if they did, it was important that their PA liked animals. Also because of a number of recipients interviewed who smoked, it was important to them that their PA did not mind them smoking.

In addition, whilst recipients varied as to how much awareness and understanding they wanted their PAs to have about mental health issues, all felt it equally important that they had sensitivity to their personal mental health difficulties and needs. Thus, a number of clients who self-harmed felt that it was important that their PA understood why they might harm themselves and was prepared to talk to them about it if necessary without being patronising or negative:

It’s important that she understands stuff about self-harm, like why I do it, the reasons behind it, and she’s not patronising and she’ll talk to me about it afterwards. She doesn’t say silly things like some people do like ‘don’t do it’ or ‘why do you do it?’ or ‘that was a silly thing to do’.

CULTURAL APPROPRIATENESS

Most recipients felt it was important to have a PA who was the same sex as them. This was especially the case for women who often felt more comfortable with another woman. It was also often important that the PA was of a similar age, although their general personality was more important.

As stated previously, clients from black and minority ethnic communities often wanted PAs who shared a similar cultural background. An African Caribbean woman wanted a PA who had an understanding of her cultural needs and could, for example, help her cook Caribbean meals and understand how to fix her hair as she was unable to do this by herself. She did not mind if the PA was black or white, male or female as long as they had the qualities she required. These also included sharing particular religious beliefs and being willing to work on Sundays because she wanted her PA to go to church with her.

RECRUITMENT

Many recipients who used their direct payments to employ PAs felt that they preferred to employ someone whom they already knew. This was largely due to the need to have someone they trusted and who knew them and their difficulties. If they were able to employ someone they already knew, they tended to have fewer difficulties with recruitment and it usually worked out well. Such people were often friends who usually also worked in the caring profession.

I employ a friend – she has been a friend for years and is in the caring business. I thought it'd be better if I knew someone cos I find it hard to build up a relationship with someone new, it'd take me ages.

In addition, one client employed their mother whom she was close to and felt that she trusted:

It is important that you have somebody you know, in my case, a member of the family who you trust implicitly with the finances and everything else. It was very important to me cos I knew I could trust her. I'd had bad experiences with carers in the past. I trust my mother implicitly.

What was often important in these examples was that the PA knew enough about the person's mental health difficulties to be able to offer appropriate support at the right time:

She knows me and know the signs when I'm going down – if she told me I was, I'd believe her because she knows me well enough.

Moreover, a small number of clients already employed someone⁷⁵ initially and because they got on well decided to employ them as their PA as well. One local direct payments support agency had a generic PA pool⁷⁶. In this area, a number of recipients were able to recruit a PA from this pool. The direct payments support agency would circulate a list of potential PAs and their availability, interests and skills and the recipient would choose people from the list to interview. In addition, if the support agency had a direct payments customer/recipient support group, this provided a useful opportunity for recipients to share PAs.

Some recipients successfully recruited PAs from other care agencies. Interestingly, these agencies did not often have mental health specialists. Thus, one client who had a sizable package employed six PAs from a local agency that worked with people with learning difficulties. Another recipient recruited a PA from a local charity working with elderly people. In such cases, the agency would tell the recipient what workers they had available and the recipient would interview them if they were interested.

One person recruited a PA from putting an advert in the local paper. Another client recruited the three PAs they needed from answering adverts that workers had put in the local newspapers and through word of mouth. A few people had initial difficulties with getting someone they felt comfortable with but felt OK about changing them where necessary.

However, difficulty in recruiting PAs was amongst the most common reason for not taking up direct payments once they had been agreed. Thus one client was unable to find someone suitable and decided not to use their direct payments:

I couldn't find anyone. I put adverts in the local papers and job centres but only got two replies and they weren't suitable and the hours weren't enough for people. If there were people available to do this kind of work it might have been OK. In the end I just gave up I suppose. It made me feel a bit despondent after all that.

Another client was offered direct payments but decided not to take it up because she felt she would be unable to employ someone with enough understanding about mental health:

They might not have the proper knowledge, training and experience. When I'm unwell I tell people I don't want to see them, whereas [a directly provided service] would just come round anyway – they understand this and know how to handle it. It would be far too easy for me to say you know 'don't bother with it today'.

Other clients experienced major difficulties with recruiting someone which led to significant delays in them arranging their support. Whilst the considerable help with advertising offered by the direct payment support agency was sufficient for some people, for others it was not.

[The direct payments support worker] put the advertisements around, but in hindsight I feel that maybe the first advertisements could have been better placed. ... S/he just used the shops and things. I think it would have been better to advertise in the newspaper because it didn't actually attract a lot of people.

[The direct payments support worker] told me that I had to find someone myself and I didn't think it meant just putting up a message on a pin board in [the local newsagents]! It totally freaked me out and I felt really uncomfortable about it all. Even though s/he said he would sit in with me through the interview it wasn't enough. I didn't feel safe enough, I still don't.

The difficulties in finding suitable PAs were related to a number of factors. Firstly, recipients expressed concerns about not knowing people, about having 'total strangers' involved, about not getting on with them and about PAs not being able to handle it and leaving, about feeling rejected, exposed, unsafe or uncomfortable. They also worried about PAs respecting confidentiality or not understanding enough about mental health. In particular, they were often unhappy about putting adverts in the local paper or in a newsagent (the common practice in other care groups).

Secondly, some recipients experienced difficulties actually finding suitable PA(s). These respondents found that the few hours they could offer PAs could make it difficult to recruit someone who was willing to work such few hours and who was sufficiently available and flexible⁷⁷. In a few instances, a recipient had identified a suitable PA but could not offer them enough hours for them to be willing or able to accept. The flexibility and unpredictability of some mental health difficulties could make employment difficult to negotiate which, in turn, could raise anxieties.

In addition some recipients found that potential PAs were reluctant to give out their Tax and National Insurance details for fear of losing out financially. In addition, the low rate of pay they were offering could also be prohibitive to recruitment. The seeming lack of formal guidance about paying higher rates to workers with particular skills acted as a barrier. This was even more problematic if a client had multiple difficulties⁷⁸ or if they had specific needs in relation to language and culture or other specialised knowledge.

However, during the pilot there were certain examples of PA rates being agreed on a higher rate where the person's needs were more complex. Furthermore, some recipients found that if they tried to use agencies, the agency would charge more than the direct payment hourly rate. Effectively, this meant that they would have to employ someone for fewer hours. These difficulties relate to the hourly rate being set in accordance with contracts between the Local Authority and private care agencies. These are effectively low (due in part to agencies taking a proportion of the amount) and this makes it hard to be flexible in relation to alternative support arrangements thus reproducing a vicious circle whereby it becomes difficult to recruit workers with sufficient experience and expertise.

It is recognised that in many cases PAs in mental health may need to engage in a variety of more complex tasks and have to negotiate more complex needs and relationships. Yet most PA rates are based on fixed domiciliary care rates despite the range of tasks that PAs may be required to do. The resulting difficulties with recruiting suitable PAs have been identified in previous research by the both staff and users as an important barrier (Witcher et al 2000; Zarb and Naidash 1994).

10.4 Employing PAs in Practice

With the exception of their care co-ordinators, a number of clients had not had input from any other support worker before they took up direct payments. However, when they had had previous support, various clients commented on the differences⁷⁹. Invariably, recipients drew a positive comparison between the support they were able to arrange through direct payments and the previous support they had. The issues they raised are considered in relation to assertiveness, mental health, befriending, reliability and flexibility.

ASSERTIVENESS

The majority of recipients interviewed who used PAs reported being able to assert what they needed their PA to do. Although they often did not elaborate about how this happened nor about the process of negotiation with their workers, it seemed to happen without much problem:

Yeah, it's absolutely fine. I am able to say what I need her to do. No, it's not a problem.

They [PAs] get me to decide what I want...If I'm unwell then sometimes they'll do it for me. It's not been agreed like that it's just how it happens, it's working out great.

However, in a small number of examples, recipients reported finding it difficult to be assertive with PAs. In these instances they found it hard to know what they wanted and needed and then to ask for it:

Because I am in charge, I have got to make the arrangements myself, and it's just a bit hard for me at the moment because I am not, I think I just find it a bit difficult to talk to people being the boss. I think I do have problems asking people to do what I want. I suppose I am a sort of a follower, I am more used to following people, not telling them what to do. My problem is I don't think I am worthy of anything, so nothing is going to make me think 'oh yes, I should be able to tell people what to do' and all that.

Difficulties in being assertive may be a common issue among people with mental health difficulties, especially women. This may be particularly acute if people have been used to being told what they need by others. This may also be related to long-term use of mental health services which may erode people's sense of autonomy and independence. Significantly, many recipients who employed people they already knew, reported having fewer difficulties with being assertive. On the other hand, a number of recipients who employed people they did not already know, also did not experience any difficulties with this process. Likely as not, recipients' ability to be assertive may develop over time. However, it is worth noting that clients who find it difficult to assert themselves and have particularly low self-esteem may require additional support and assistance. Indeed, it may be the task of the direct payments support agency to help the individual to be able to give instructions and then to recruit workers who are sensitive to this and able to take instruction.

MENTAL HEALTH SUPPORT

A significant number of recipients felt that they were able to get some emotional support from their PAs. As previously stated, the befriending aspect of this seemed most important. Where recipients reported their PA arrangements working well, they often referred to their PAs as being 'like friends', whether or not they were actually friends to start off with. In particular some of the benefits of these relationships appeared to be related to the 'ordinariness' of their PAs in that they were not necessarily mental health professionals:

It's kind of good they're not mental health trained cos they don't look into the mental health aspect all the time.

It works well. I can be more open with [my PA]. Sometimes they just see the illness these carers, and they are not bothered about your emotions, but with [my PA], it's much better.

Thus one husband of a direct payment recipient who employed three PAs argued that the recipient/worker relationship seemed to be more equal than in the past:

As an equal, as a friend as just someone else in the public who has got a problem...Previous support workers were more like a nurse/patient relationship...With direct payments, these people, they don't have any experience of mental health, so you are telling them you know.

In particular, a number of recipients felt that because they were in charge, they were in a sense the expert on mental health issues, not the PA. Therefore, they were more able to define how and at what pace they wanted to approach tasks, as well as allocate the amount of time available to complete them. These recipients felt that previous workers were 'too pushy' partly because their time was limited and partly because it seemed that they knew best.

However, in a small number of cases recipients found it hard to get any emotional support from their PAs. Some found that they had employed PAs who were used to working for people with physical disabilities and did not necessarily grasp the complexity and subtlety of their emotional and mental health difficulties.

I mean, half the time I feel like I am supporting them, rather than them supporting me. She'll come in and she'll say, 'are you alright, I'll say yes or no, or whatever', and then that's really the last we talk about it... She came from the PA pool and has worked as a PA with direct payments in physical disabilities before. I think that's the trouble with a lot of them there, it's more the physical side.

Although recipients found they could call on their PA for support with what many regarded as 'everyday-related problems such as hospital appointments, paying bills, getting out etc.', most indicated that they would turn to people other than their PA for support with serious mental health difficulties, such as experiencing difficult symptoms, a relapse or crisis.

RELIABILITY AND FLEXIBILITY

Most clients who had transferred from directly provided support workers to employing PAs through direct payments, reported that previous support was often inconsistent, involved too many different people, was too restrictive in the times available and the tasks they were able to do. In addition they often felt that they were kept waiting because the workers turned up late or sometimes didn't turn up at all. These factors could increase their anxiety. However, when they used PAs they were, on the whole, more able to organise the times and days when they wanted support and control what they wanted to do and how they wanted to do it.

Recipients thought it was beneficial that they were able to get to know the person who was coming to support them and when they were coming:

Yeah it's much better because I have got the same person now. With [the support agency] they were sending different people and people that I didn't know and I wouldn't talk [to them] and it just got, they were letting me down and things like that.

You get to know them, you are certain of who is going to come and when they're coming so you're not hanging about waiting.

In addition, employing workers enabled them to be more flexible in the way their support was organised to fit in with their lives and changing circumstances:

It can be a lot more flexible...If I'm bad we can put in extra hours or if there's something I need to do I can switch the times to accommodate it, like going to the doctors or whatever.

In a way, when I had a support worker from the mental health team, if it was in my care plan that I've got to do this, this and this, then that's kind of what we did, whether I wanted to or not. [Now] I can switch it to something else and there's no come-back from the mental health team. It's like if the worker was coming and the weather was really nice and it was meant to be a shopping day, we could say go for a walk instead...It's much more flexible.

By comparison, previous support was often experienced as too restrictive in terms of what the workers were able to do with clients and what tasks they were able to perform. Personal assistants enabled clients to have more choice over exactly what they did with the time they were allocated via direct payments:

I just think it's a lot better, because ... I have got a voice and I can say, 'can I do this today?' and she will say 'of course you can'. Before [the support worker] used to tell me what to do and it was like I had no control over my life.

In particular, recipients employing PAs meant that they could decide how much time they wanted to spend on tasks or events. Thus previous support workers tended to visit or arrange tasks in one-hour slots and in practice this was often less. With direct payments, clients often pooled the hours allocated to allow them to spend more time with PAs. This enabled them to do more things and go to more places. Furthermore, it also meant they felt less pressurised:

Now I have all the hours in one day it's much better cos I don't feel so pressured into doing things quickly and getting myself more anxious about it. Now I actually get more time cos they used to split it up in the week.

However, some people found the flexibility and responsibility was often difficult to manage and negotiate. This was particularly difficult for people who felt unassertive and unsure of their needs especially when they were aware that they could change at short notice.

The problem is I never know for one day to the next what I want and how to organise it.

In addition, one client experienced employing her own PA as less reliable than directly provided support. This was because if her PA was unwell, or she wanted to change the day, she often couldn't replace them at short notice. However, the agency she used before would ensure that someone would visit:

I keep changing my mind about what days I want. I found out that you can't keep swapping your days. With creative support you could, you know what I mean and they'd just send somebody else. If [my PA] rings up in the morning and can't come then I'm stuck for the day... it's too late to find somebody else. With [the support agency] they'd have sent someone else, they are all getting paid anyhow, so the people are there. With this you are hiring these people and they have got other commitments, so, like I say, it isn't always as good as you think. It's not always very reliable.

In this way, it may be that PA users are dependent on the ability of their PAs to be as flexible as they need them to be. This may be hard to achieve, especially if the PAs are balancing other work commitments. In such cases, they may be more like support workers who find themselves juggling a heavy caseload and not being particularly flexible and reliable. This might suggest the reason employing someone already known often works better is because they already have some sense of commitment over and above that in relation to paid work.

CRISIS

Recipients were developing a variety of ways of dealing with direct payments if they were unwell or experiencing a mental health crisis. If they were employing PAs this depended on what the PA did for them. For one recipient if they were in hospital for a short length of time⁸⁰ direct payments carried on and PAs were able to visit and still be paid. Alternatively, it was put on hold but the hours could be saved up and used for when they got out of hospital.

I have been in hospital voluntarily for a few weeks. [My PA] comes to see me on the ward, she phoned a lot and kept in contact on the phone, she kept in contact with me, so the night I came home, she came that night.

However, some recipients argued that their payments were often not flexible enough to enable them to provide additional support during a crisis⁸¹. One client had a package which included money for respite if needed and another had ten extra hours banked which could be drawn upon in an emergency. However, contingency funds like this were rarely put in place. If a client didn't have a contingency fund or if their payment wasn't flexible enough to allow for changing circumstances and crises, they often had to rely on the goodwill of their PA to continue to support them⁸². Thus, when one client spent a short time in hospital, their PA continued to visit in her own time because the payments only covered night sits.

10.5 Additional Support with Employing PAs

ADVANCED DIRECTIVES

Advanced directives enable people who receive services⁸³ to direct how they would (or would not) like particular things done, at a time when they might be experiencing a mental health crisis, are feeling unable to cope or manage their support themselves. They are designed in advance of such times when the individual is able to reflect upon their support needs. They can be developed alone or alongside significant other(s)⁸⁴ whom they trust.

Despite the National Pilot promoting the idea of advanced directives in local sites, care co-ordinators, direct payment support workers and service users appeared to know little about their use. Whilst in practice some professionals may have used advanced agreements or statements, they were rarely seen as such or developed as part of the direct payment package. Furthermore, many service users seemed to depend on the fact that if they employed a PA with their direct payments that their PA would 'know them well enough' to know how best to respond in a crisis. This was particularly the case, and often worked well if a client employed somebody they already knew and trusted. However, this would not necessarily ensure that their wishes would be adhered to and seemed to be leaving it to chance and goodwill. One recipient reflected that it would have been useful to have had support to develop this:

No one said to me 'what would you want to happen if you're having a bad day?' like an advanced directive. How the person would like to be treated by their PA. No one said this, it would have been really useful to have been asked this. It was in the information but to be honest I didn't read it all. It's really important to check this out I think. That's where it's different from physical disability. What not to do in a crisis is often more important than what to do e.g. for me it'd be to stay with me until my daughter comes home. Some people might want to be left alone or whatever. It's difficult for a PA if they're not given advanced directives cos they may not know what to. I've got a friend who knows me really well so in a way I don't need to do this, but I might have done. Having a PA has been really positive for me but it might not have been.

The direct payment support agencies offered valuable support and assistance to recipients using direct payments to employ PAs⁸⁵. This support given by the direct payment support agencies was greatly appreciated. However, it was sometimes felt that more support and prompting could have been given in preparing recipients for employing somebody, including recruitment. Additional support was often necessary in helping recipients think about what they wanted PAs to do, how to organise their time and what questions to ask them in an interview.

Nobody got me to think about what I needed to ask them [in the interview]. I should have been forewarned that I'd have to ask them questions. Way back I needed to be encouraged to think about what I needed and wanted. Reading everything I have now and understanding what direct payments is, it's ironic really that I wasn't encouraged to think about what I wanted.

The assessment process and all that was OK and there weren't really any problems with getting the money or anything like that but then it was just like left up to me – 'right it's up to you to sort it out now' and I couldn't cope with it. It's really hard when it's a mental thing I mean if you've got a physical disability well, you know, fair enough but I started thinking you know 'do I really need this?'

Participants indicated that it was important that the support was given in the right way and was not too controlling. A number of direct payment support workers gave recipients a standard job advert and job description as well as standard questions that might be asked. Thus two recipients in particular recalled that they had designed their own job advert and job description but reported that the standard one was sent out from the support agency. As one of them explained:

I designed an advert and put stuff in for the job description but they didn't actually use it – they just used the standard one which was similar but a bit different.

In addition, recipients sometimes felt that they had been given insufficient time to think this through themselves:

The [direct payments support worker] brought a list of questions with her, but I sort of had some of my own... I think that's something the support worker should go through with the client... you know what is important to you like 'here's some ideas, you know, that might be useful and what do you think?'

No I didn't write [the job description], the direct payment support worker did. They wrote it and then showed it to me, and it seemed OK...but I think in hindsight I would word it differently or encourage people to word it differently, get a few ideas from them, so I mean I have learnt from that.

It may be that direct payment support workers did not have the time needed to offer this additional level of support and encouragement or it might be assumed that people would be able to think this through for themselves. However, in a small number of cases recipients found that they needed additional support with this.

One recipient made the suggestion that other direct payment recipients (not necessarily mental health) could offer one-to-one support to people just setting up their direct payments.

I can't do it and I can't get the help I need. I am not asking for anything difficult, I just want somebody that's using direct payments to talk to me, that's what I would like so that I can say, 'how would you do it?'. Then I can help people when it's up and running for me...I can help people with the payroll and things, because I understand that, and I wouldn't mind doing that.

Direct payments support workers were keen to reassure clients that they would be able to manage direct payments. This meant that they often emphasised the support they offered with the paperwork, but neglected the subtle but crucial support needs relating to deciding and preparing what recipients wanted to do with direct payments and how they might go about doing it. This could set a precedent that they would be able to continue to support the process. If ongoing support was not available, recipients could often struggle later:

The [direct payment support worker] said that I didn't have to worry, that they'd help me with everything so I didn't really think about it. People like me need to be encouraged to think about these things earlier. Most people like myself need a bit more guidance to think of things other people might think of naturally, like when the person comes, you will then have to be telling them what to do, so think what you would like them to be doing.

Thus another recipient noted:

I got support in preparing for the assessment, but after that less. The [direct payment support agency] are sort of very involved at first. After agreeing package they tended to take over a bit, which was OK, but then there wasn't much follow-up, they didn't really offer support over problems, or I didn't feel there was enough support over problems.

Most recipients had only been on direct payments a short while and therefore it was difficult to record what ongoing support people may need. However, it was clear that ongoing support and reassurance may be necessary over time and should, where possible, be offered. Furthermore, as this recipient pointed out, people should be offered the option of how much and how they would like ongoing support to be offered and this should be negotiated:

I think you have to offer support as much or as little as somebody wants, but I think there should also be like an ongoing support, if they want it... you could say to somebody 'would you like me to give you a ring once a month to see how it's all going?'... and you could say yes or no. Yeah, or have a sort of agreement with the client, say like 'how would you want us to proceed from here, do you want to just contact us when you need it?' [The direct payment support agency] has never contacted me to ask how it's going. I have always been the one to contact them...so to a degree I have felt isolated there, particularly when all the problems arose with the PA.

10.6 Discussion

In addition, in one example a recipient was worried about employing a PA and phoned up a local agency for some advice about employing someone and whether they knew somebody reputable. However, she described how they misunderstood her request and ended up providing her with agency workers which did not work out.

During the pilot, direct payments support agencies had developed a number of ways of addressing difficulties in relation to employing PAs. These included using a 'pool' of PAs⁸⁶, developing a care plan involving the care co-ordinator, service user and the PA(s) which would address and negotiate roles and responsibilities, providing training courses and support to both services users and PAs.

This chapter has explored recipients' experiences of using and managing direct payments. It has subsequently highlighted a number of key issues that need addressing in order to support mental health service users' access to and use of direct payments.

At the local level, it is clear this support needs to be offered if the person requires it and that this support is offered at a pace that is acceptable to the recipient. Moreover, it needs to be offered with enough flexibility and sensitivity to ensure that recipients are able to use direct payments effectively. Where possible, clients could be given a choice as to who is able to offer them this support but such support needs to be adequately resourced. Relevant here, the local site with the most mental health recipients were experiencing difficulties in being able to offer the amount of support and assistance that many recipients needed. In addition, if PAs were to provide this additional support this would need to be costed into the recipient's package. In some cases, care co-ordinators were able to offer additional support but this relied on their willingness and ability within the context of their wider role and workload.

Where recipients experienced the process as difficult they often suggested practical ways in which these could be addressed, for example by having more contact with other recipients and for example 'shadowing' them in the early stages to see how they manage. If recipients were fortunate enough to have a close friend or family member who could offer support, then this could enable them to take up and use direct payments. However, in order for access to be more equitable, support and assistance to enable management of direct payments should not be left to luck, chance or goodwill.

The following and final chapter outlines a number of key areas that have arisen during the evaluation that require further consideration, development and research. Finally, it makes a series of recommendations for the development of the implementation of direct payments in mental health.

⁷¹ This included husbands, mothers and daughters.

⁷² This was often attached to the direct payments support service.

⁷³ In comparison with the cost of packages for people with a physical disability.

⁷⁴ Either within social services or an independent payroll/administrative service.

⁷⁵ For example, as a cleaner.

⁷⁶ A list of PAs who had been trained in basic care and were available to work.

⁷⁷ For instance, evening and weekend working.

⁷⁸ e.g. physical and mental health problems.

⁷⁹ For example, in one site it was a direct change-over from support agency to direct payments.

⁸⁰ Usually less than 4 weeks.

⁸¹ e.g. if in hospital when they felt they required more support and/or a continuation of their support.

⁸² For example with visiting in hospital.

⁸³ Via direct payments or otherwise.

⁸⁴ This may include carers, family, friends, care co-ordinator, direct payments support worker and the person's PA(s).

⁸⁵ For example through providing advice about tax and NI, helping with advertising for and sitting in with interviews.

⁸⁶ Held by the direct payments support agency.

CHAPTER II

Conclusions and Recommendations

11.1 Impact of National Pilot

This report has covered a wide range of issues relating to the implementation of direct payments in mental health. Using the National Pilot as a context, this report has outlined the most important organisational, practical and ideological factors which have helped and hindered the implementation process. In addition, and most importantly, it has identified issues that mental health service users thought were crucial to them in accessing and using direct payments.

Overall, the National Pilot to implement direct payments for people with mental health needs was experienced as a positive, interesting and useful learning experience for the five local sites that participated. It provided a framework for focusing on direct payments, sharing information and experiences and achieving significant steps towards progressing direct payments in mental health. It was widely viewed as a 'catalyst' for the process of implementing direct payments in mental health and as providing an additional impetus for organisations to engage with the issue of direct payments. Being part of a National Pilot provided external attention for the Local Authorities and this acted as an incentive and helped focus development and priorities.

In general, the National Pilot highlighted the low take-up of direct payments in mental health, raised awareness and promoted the idea of direct payments. It drew Local Authorities' attention to the possibility of direct payments in mental health, which many practitioners and senior managers had not previously considered. Furthermore, the pilot process enabled sites to focus on developing specific local procedures for direct payments in mental health. Both mental health staff and direct payments support workers indicated that they found it hard initially to envisage implementing direct payments in mental health, but that the pilot started to make direct payments a more concrete and tangible possibility.

Being part of the national project was generally experienced as a good opportunity to share experiences, successes and problems particularly about the difficulties of implementation and take-up. As a result, service users, in conjunction with their care co-ordinators, direct payments support workers, advocates and their families developed a number of innovative direct payments packages.

11.2 Conclusions and Implications

The pilot enabled direct payments support services, which were usually geared to working with clients with physical disabilities, to think about how they needed to actively support mental health clients. Rather than just passively respond to where referrals were coming from, this focus enabled the direct payments support workers to actively promote direct payments as an option to local mental health teams.

The pilot provided a positive context for sites to work with a new practice and concept (in mental health). This background context enabled sites to try things out that they would not ordinarily have done. In other words, they were able to take risks, experiment and test out limitations and possibilities. In some sites, this facilitated, temporarily at least, more flexibility and leeway in the system which increased take-up.

As with any research, there are limitations in the scope of this study and in the conclusions that can be drawn from it. Firstly, this research was based primarily on a pilot project encompassing five Local Authority sites. Whilst this was a good sample across England, we need to be cautious as to its wider interpretation and application. As outlined elsewhere, even between the five Local Authorities there were a variety of different ways in which information was recorded locally, which meant that standardised comparisons were difficult to make. Furthermore, a relatively small sample of mental health recipients and a short time-scale resulted in being unable to provide reliable quantitative 'evidence' and 'outcomes', particularly in relation to longer term impact of using direct payments. In addition, there are clearly differences between areas in terms of resource availability. Whilst this evaluation was able to provide an overview of the key issues involved in implementation, it is not able to offer a more strategic analysis of resource allocation, commissioning and social policy highlighting the need for further investigation in these areas.

The following sections summarise the main issues identified during the evaluation. Based on these issues, the final section presents a series of key recommendations.

IMPLICATIONS FOR POLICY AND SERVICE RE-DESIGN

This evaluation has raised a number of key issues in relation to broader issues of strategy and service re-design. A strategic approach to the introduction of direct payments needs to place direct payments in the wider context of service developments in mental health. Whilst the pilot enabled local sites to give higher priority to direct payments in mental health in terms of service planning and delivery, a variety of pressing and competing priorities in local agendas meant that wider implementation was, and may continue to be, inconsistent and patchy. Conflicting priorities between direct payments and other policies within the 'modernisation' agenda could hinder workers from the various organisational levels in prioritising the rethinking of assessments, support and funding arrangements necessary for people to access direct payments. Responding to a variety of related policy initiatives⁸⁷ was often experienced as overwhelming with insufficient capacity to attend to these demands. Further, the re-organisation of mental health services both nationally and locally, has resulted in continued changes in the configuration of local services.

There would appear to be an absence of strategic understanding of how these policies and guidelines fit together. Indeed certain policies are potentially in conflict. For example, it is unclear how the new proposed revisions to the Mental Health Act, with its primary focus on risk management, will work alongside the promotion of alternatives such as direct payments, which ideally have a positive risk taking approach at its heart. It has been noted by the NHS Confederation (2003) that these changes are likely to result in a greater amount of time spent by mental health professionals on legal related work. On the positive side, proposed moves which would strengthen the powers of advocacy, patients' and carers' rights may facilitate greater access to, and use of, alternative and user-centred support arrangements such as direct payments.

The issue regarding direct payments for what is considered to be 'health' care is still unresolved and needs serious attention (Maglajlic 1999; Glendinning et al 2000c). Despite mental health services increasingly being provided by integrated health and social services, there is still evidence of unhelpful distinctions between health and social care which undermine access to and the creative use of services and support. However, if direct payments packages were available for what has been traditionally construed as health care, it raises difficult questions of how much responsibility and monitoring the PCT would carry out in relation to the support given (Glendinning et al 2000c).

In terms of resources, it remains to be seen what impact the tighter eligibility criteria in line with Fairer Access to Care policies will have on the availability of more flexible and responsive services that may be purchased via direct payments. Given that a significant proportion of direct payments offered during the pilot were in relation to 'unmet need'⁸⁸, limited resources may have a significant impact on access and take-up of direct payments and services generally. Further research and evaluation could develop economic comparisons between areas and focus on economic re-modelling strategies which may support individualised funding⁸⁹.

This evaluation has highlighted the variety of different ways in which mental health service users would like to be supported outside the usual boundaries of service provision. This has included support around doing the kinds of activities that the service user themselves chooses, for example, extended leisure and educational activities and opportunities. It is important that services in general, and direct payments in particular, are able to respond to and resource such needs. This also includes extending the parameters and interpretations of community care to include such activities if it contributes to a person's social and emotional well-being. As well as leisure and education this may also include such things as equipment, alternative therapies and respite.

Caution needs to be exercised in interpreting the findings presented here particularly in terms of wider investment (and dis-investment) in specific mental health services. The implementation of direct payments clearly raises this issue. However, the underlying principle of choice and flexibility will mean that directly provided services which are still valued and used by people with mental health needs, will need to be maintained and developed. It is impossible to predict the future demand for direct payments and the data provided here only concerns those people who were offered and decided to take-up this option.

At the local level, lessons can be learned from recipients' use of direct payments about users' and carers' preferences which might inform the development of mental health service provision. Further, it would be worth investigating the choices made by individuals who did not wish to pursue direct payments to provide an assessment of service provision. It may be that service users may not opt for direct payments if directly provided services were more user-centred, flexible and responsive. In addition, there is some evidence from other countries that where Governments promoted individualised funding without resourcing community support networks in the non-profit sectors, it could result in a highly privatised system which limited the choice and control available to individuals (Lord and Hutchinson 2003).

This clearly highlights the tension between maximising the potential for individual choice and control whilst maintaining a wider commitment to the collective provision of services. The development of social policies and a strategic approach to service development need to balance the calls for the structures in which individuals can articulate their claims for the support they need to pursue self-defined goals and purposes (Stainton 2002) and the best conditions which will evolve and develop services that offer highly customised, specialised, publicly accountable and collective service provision and assistance (O'Brien, 2001).

One way of resolving this tension is through the development of strategies which support the collective pooling of resources. This could enable the development, extension and use of community resources and could result in the development of new communal services or the regeneration of services that have been run down (Ridley and Jones 2002; Stainton 2002 and Maglajlic et al 2000). Co-operatives could be developed which could help individuals combine their payments to purchase care collectively and, if necessary, help recipients with employment and administration difficulties. In the long run, this may counter some of the difficulties with employing PAs and meet gaps in service provision, especially for support in the evenings and at weekends (Ridley and Jones 2002). Such initiatives could also result in the development of contingency monies, and training and support for PAs and recipients (Lewis 2002; Spandler 2004).

CARE CO-ORDINATION

Previous research has indicated that the willingness of individual care co-ordinators is crucial in taking forward or stalling take-up (Hasler 2003, Witcher et al 2000). Evidence presented in this report makes it clear that it is both their willingness and their perceived and actual ability to offer direct payments that are crucial. Their ability is dependent upon a number of factors, not least their changing roles and responsibilities in relation to the wider organisational context as well as unmanageably large caseloads, risk-focused assessments, increased paperwork, staff changes etc. The actual 'weighting' of various factors helping and hindering implementation is hard to determine and future research may help clarify this⁹⁰. Feedback from service users suggested that there were key qualities of care co-ordinators which helped them to access direct payments. These included being persistent and pro-active, being able to make decisions around funding, being creative and flexible about assessing need and being able and willing to offer additional support if required by the service user.

The fact that many mental health service users have contact with health professionals such as CPNs rather than social workers did not necessarily inhibit take-up as previously suggested (e.g. Glasby and Littlechild 2002). In practice, workers from both disciplines used a variety of coping mechanisms to deal with their constraints and pressures, some of which lent them to look towards direct payments. In the context of depleted resources and inflexible services, some workers were able to use direct payments in a variety of innovative ways to access the support that individual services users identified.

At the same time, these very constraints also led the majority of care co-ordinators to be very cautious in considering and offering direct payments to clients who they felt might struggle with the responsibility. This led them to be selective and discretionary about clients to whom they felt willing and able to offer direct payments. Therefore, despite the advances described during the National Pilot, the changes necessary to ensure that all clients deemed eligible for community care services are offered direct payments is some way off.

ACCESS AND ALTERNATIVE MODELS OF SUPPORT

New Department of Health guidance (2003) makes it clear that competence to manage a direct payment (with assistance if necessary) should be assumed, not a client's incompetence. This means that as much support as is needed to manage this can, and should, be offered. It has been argued that the limiting factor on self-determination and direct payments is not the degree of disability, but rather the quality of support offered (Holman and Bewley 1999). As many proponents of direct payments have argued, competency is not a fixed state but is determined by the amount of support available to the individual (Hasler et al 1999; Ridley and Jones 2002). However, it is not clear how Local Authorities will be able to fund or provide the greater levels of support that many clients may require in order to sufficiently benefit from the greater involvement that direct payments offers, rather than it being just a token exercise (Murray-Neill 2000).

An important gap identified in this evaluation was the lack of knowledge of the various ways that clients can be supported to manage direct payments (see also Ridley and Jones 2002). Initiatives developed in the learning disabilities field may be transferable to mental health, such as circles of support and supported decision-making (see Holman and Bewley 1999; Ridley and Jones 2003). Support should be available from a variety of sources, and be provided in a variety of ways (see Holman and Bewley 1999; Henderson and Bewley 2000). User-controlled trusts and other proxy arrangements involve appointing someone or people to act on the client's behalf. This means that individuals do not have to handle the money directly while retaining control on how it is spent (Ridley and Jones 2002). Such alternative models could be used as mechanisms for back-up support to take over responsibilities should someone become 'unwell' (see Holman and Bewley 1999).

However, this evaluation also suggests that direct payments were often more likely to be accessed where family members and significant others were involved. Mental health service users may lack a close circle of contacts and significant others who could act on their behalf and this may distinguish mental health from other care groups, particularly people with learning difficulties, where family members/carers are more likely to be involved. This makes it even more important to utilise and develop alternative models of support in mental health. In particular, it may be that user groups, advocacy or other agencies could be supported to develop support co-operatives and trusts for service users who need it (see Maglajlic et al 2000; Murray-Neill 2000).

ASSESSMENTS AND INDEPENDENT PLANNING

The finding that few service users were aware of having an 'assessment', may prevent them having the opportunity to decide that they would like their needs met in other ways. In the Local Authority site which had the greatest take-up, the independent direct payments support agency took the pilot as an opportunity to operate more like independent planners in line with the model proposed by Salisbury (1998) and Dowson (2002)⁹¹. This model is aimed at reducing the inherent conflicts of interest involved in care professionals assessing need, gatekeeping resources and being service providers. Dowson and Salisbury argue that what is needed is a planning process that is led by the person requiring assistance, with the necessary support provided by an independent community planning service. This should be kept separate from both the funders and service providers thus reducing built-in conflicts of interest.

A lack of knowledge about direct payments amongst mental health professionals combined with the existence of local direct payments support agencies prepared and able to take on this role, helped drive a model which is in many ways closer in practice to that of the independent planning model advocated by Dowson (2002). However, because independent planning of this sort is not built into the system, it is unlikely to continue beyond the pilot stage, particularly once awareness and knowledge about direct payments increases.

This raises questions about the care planning models used within mental health and whether it is conducive to direct payments. We may need to consider promoting alternative approaches to assessment and care planning. This may involve the greater use of advocacy at the early stages of assessment. It is notable that Essex, a Local Authority with the highest mental health take-up of direct payments outside the pilot, has developed an advocacy team to promote the take-up of direct payments.

DIRECT PAYMENTS SUPPORT SERVICES.

The role of direct payments support services needs to be strengthened and resourced to support their input. The quality of support offered, crucial to widening access, will largely be dependent upon the ability of the support services. Direct payments support services are often the first step for both clients and professionals in getting information and advice and can therefore help alleviate concerns and barriers to greater access.

At the practice level, in addition to the willingness of individual care co-ordinators, progress in up-take of direct payments can also be promoted or stalled by the independence, pro-activeness and availability of support offered by a direct payments support agency. This support is crucial both to care co-ordinators and to clients in accessing, preparing and setting up direct payments. Individual direct payments recipients may need support at three key stages during the direct payments process, namely pre-assessment, setting up and ongoing support. Careful consideration needs to be given to who is able to provide such support as well as to the manner in which this support is offered and given.

There is no firm evidence about whether it is necessary to have a mental health-specific direct payments support service or worker within the agency. However, a greater understanding about some of the difficulties that mental health service users experience in accessing and using direct payments needs to be developed. Many recipients interviewed for this evaluation felt that the direct payments support agencies were often geared primarily to people with a physical disability (see also Dawson 2000). If the additional support that they need is not feasible within the remit or resources of the individual support agency, it may be possible to fund local mental health projects, user groups, advocacy projects and local black and minority ethnic community projects to enable them to offer additional assistance if their service users want to access direct payments. This would require good working relationships between those groups and the direct payments support agency, for example, by sharing training and information.

SUPPORT EMPLOYING PAS

Mental health service users were able to use direct payments to meet some of their needs in a variety of alternative ways. Approximately half of the recipients during the pilot were using direct payments to employ Personal Assistants (PAs). This was less than is usual in other care groups where employing PAs is much more common (Zarb and Naidash, 1994; Campbell, 1998; Glasby and Littlechild, 2002). Employing PAs was often beneficial for clients who were able to identify and recruit a suitable worker. However, perceived and actual difficulties regarding employing PAs were often a barrier to access, take-up and successful use of direct payments. Recipients experienced difficulties getting workers for such short hours and at particular times and wanted more accessible contingency funding and better back-up arrangements in case of difficulties (see also Halliwell and Glendinning 1998; Witcher et al 2000). Formal guidelines about paying PAs at a higher rate for specific skills, knowledge and experience and also for unsociable hours at evenings and weekends would help Local Authorities deal with such issues. For a more general discussion of the roles, rights and relationships between PAs and recipients see Glendinning et al (2000b), Ungerson (1997) and Spandler (2004).

In addition, Ridley and Jones (2002) also argued in their research that engaging an agency to manage employment issues may resolve many of the concerns expressed by some recipients. A new project initiated by the National Centre for Independent Living called 'Wider Options' is looking at alternative ways of employing PAs to help people who do not want to employ their own workers directly but wish to have more choice and control over their support arrangements. Essex for example, has established an agency⁹² specifically for supporting recipients to employ workers.

CHOICE AND CONTROL

Greater awareness and more information are required about specific mental health-related concepts and tools which may support service users' increased choice and control. Forward planning tools such as advanced directives need to be promoted both to care co-ordinators, direct payments support workers and direct payments recipients. These could ensure that during a mental health crisis recipients could retain as much control and choice as they are capable of exercising and this could help facilitate increasing control once the crisis has passed (Ridley and Jones 2002). However, the legal status of advanced directives may need clarifying, particularly as they are not favoured in the new government proposals to reform the Mental Health Act (see Szmukler and Holloway 2000).

In general we must be aware of the tendency to de-radicalise or 'downgrade' innovative ideas and practices such that they become less progressive and made 'more comfortable' (see Dowson 2002). There are a variety of ways in which the elements of user control at the heart of direct payments can be watered down. In mental health there may be a tendency for professionals to reduce direct payments to 'just' a 'therapeutic tool' through for example 'taking responsibility', and used as a means of monitoring and managing clients, ensuring they take their medication and overseeing the support arrangements that service users set up.

However, even if initial referrals to direct payments were not made in the 'spirit' of independent living and direct payments⁹³, the process itself was usually empowering for the recipient. In addition, workers could also begin to discover a variety of benefits themselves such as developing their own role in supporting clients' autonomy (Stainton 2002). It may be that the locus of control shifts over time as service users become more able to exercise control over their choices through direct payments.

More generally, these are part of the changing nature of power relations which de-centre the professional in terms of expertise and decision making, challenge the adequacy of professional knowledge and bring out more client-centred knowledge, definitions and alternatives. Further research could focus on how professionals (and service users) are able to adapt to these changing relationships through developing alternative modes of communication and practice. This entails a shift in the values and philosophy which underpin practice towards building greater capacity for choice and control and increasing client autonomy. This requires changes in the way professionals are trained and supported as well as organisational recognition and support.

In the longer term, the implementation agenda should be focused on enabling mental health service users to decide how they want to be supported. This may, or may not, include direct payments but is more generally about investing in sufficient, appropriate, flexible and user-centred support arrangements to facilitate and resource these choices.

11.3 Recommendations

In order to build on the National Pilot, a number of specific recommendations are highlighted:

RECOMMENDATION 1:

NATIONAL GUIDANCE AND DIRECTION

- 1.1 The option of direct payments in mental health needs to be promoted both through Local Authority and mental health routes. The National Institute for Mental Health in England (NIMHE), which has an infrastructure incorporating eight regional development centres, is well placed to have an active programme of dissemination and learning around direct payments. Similarly, the Association of Directors of Social Services (ADSS) could do much to raise the profile both with staff and elected members.
- 1.2 Further national guidance on implementing direct payments in mental health is needed to promote and support action at the local level. This will need to clarify:
- the relationship with other policy initiatives
 - the implementation of direct payments within the context of health and social care integration
 - the approaches and mechanisms to support awareness raising, access to and take-up of direct payments
 - the means for ensuring consideration of and access to direct payments within the CPA process and the role of care co-ordinators within this
 - the development of local monitoring and audit arrangements to inform the assessment of progress.
- 1.3 At central government level, further clarification is required in relation to the use of direct payments for 'health' related care. The overlap between health and social care strongly suggests that direct payments as an alternative choice to such services should be funded by health as well as by social services to reflect the reality of an holistic and 'joined up' approach. This means further development of the permissive mechanisms which support this, such as the transfer of funds under Section 28 of the NHS Act 1977 or the use of pooled budgets which can also support the commissioning of packages for those with complex needs.

RECOMMENDATION 2: GETTING STARTED

- 2.1 Each Local Authority should develop a multidisciplinary and multisector steering group with an identified project lead with sufficient authority to support the implementation of direct payments within the context of health and social care integration. The steering group needs to:
- work closely with commissioning structures to facilitate the strategic introduction of direct payments in mental health
 - consider the implications for on-going service provision as well as for system re-design
 - ensure that the systems and process for making applications for and administering direct payments are streamlined and, as appropriate, are embedded within existing systems that frame practice.
- 2.2 Local Authorities must develop/commission an infrastructure to provide support for people with mental health needs to access and take up direct payments. Such support must be adequately resourced, flexible and independent.
- 2.3 Local Authorities should ensure the allocation of sufficient funds to pump prime the implementation process (for infrastructure, development, training etc.).

RECOMMENDATION 3: ACCESS TO DIRECT PAYMENTS

- 3.1 Further work is needed to clarify the nature of the support required to access direct payments⁹⁴.
- 3.2 A number of strategies need to be developed to promote access to direct payments in mental health. These include:
- Local action to raise awareness amongst service users about direct payments. This will include the provision of accessible information and training which should involve training by recipients of direct payments (across care groups)
 - Specific consideration to be given to improve access to direct payments for people from black and minority ethnic communities and other marginalised communities
 - The issue of self-referrals should be considered as a way of promoting access.

RECOMMENDATION 4: PERSONAL SUPPORT

- 4.1 Within the development/commissioning of an infrastructure to support access and take-up of direct payments, Local Authorities need to ensure the provision of effective support at all stages i.e. promotion/advocacy, preparation/pre-assessment, starting up, and ongoing support.
- 4.2 Service users should be offered choice about how and who provides them with support to be able to take up and use direct payments. Other agencies may be able to provide additional assistance and support where needed (e.g. local voluntary mental health projects, user groups, advocacy projects and local black and minority ethnic community projects). Such organisations will need adequate information and funds to be able to provide this support.
- 4.3 Local direct payments support services need to develop expertise in working alongside people with mental health needs and be enabled to do so.
- 4.4 At the local level, formal guidelines need to be developed regarding the employment of PAs in mental health including paying at a higher rate for specific skills, knowledge and experience and also for unsociable hours at evenings and weekends.
- 4.5 Investment in the development of peer support is required. This will help service users with setting up and managing direct payments.

RECOMMENDATION 5: THE USE OF DIRECT PAYMENTS

- 5.1 In line with national guidance and the Independent Living philosophy, payments should be agreed for 'needs' rather than 'services' to ensure that service users are able to decide how they want to meet their needs.
- 5.2 Local Authorities need to develop guidelines that support a creative use of direct payments which really does facilitate positive choices.
- 5.3 Where the individual direct payments recipient is assessed as needing additional support in setting up and managing a direct payment, this should be costed in. A standard minimum level of additional setting up costs could be given regardless of the package size and this could increase proportionally depending on the complexity of the package and the number of hours allocated.
- 5.4 Due to the fluctuating needs of many service users, payments must be flexible enough to allow for changing circumstances. An individual should be assessed as needing an average number of support hours a week, but these could be used variably during the course of the year to account for changing circumstances. Where assessed as necessary, contingency funds need to be provided which can be drawn upon in exceptional circumstances.
- 5.5 Local policies and guidelines need to be developed to enable a greater potential for the pooling of resources for service users to use direct payments collectively to meet their needs. This would require investment to support the development of co-operatives and user-controlled trusts in which resources can be collectivised but remain under the control of the individual and their support network.

RECOMMENDATION 6: PRACTICE DEVELOPMENT

- 6.1 Training, supervision and guidance must be offered to help raise awareness and address the concerns among mental health professionals about direct payments and to support the implementation of direct payments in practice. Implications for the training, induction and supervision of staff need to be addressed by the Workforce Development Confederation and through practice development strategies.
- 6.2 Practice development should include:
- The implications of the Independent Living philosophy for practice
 - Consideration of the different models and approaches to supporting service users accessing direct payments. This would include the promotion of self-assessments, advance directives and learning from models of person-centred planning (e.g. circles of support and supported decision-making) underpinned by a positive approach to risk taking
 - Embedding direct payments within the CPA process
 - Empowering people and creating the conditions to build greater capacity to exercise choice and control.
- 6.3 Networks need to be developed to enable a greater sharing of good practice across areas. This could draw upon the experience and networks developed by the National pilot as well as organisations such as Values into Action and the National Centre for Independent Living.

RECOMMENDATION 7: MONITORING

- 7.1 Although national mechanisms are in place to monitor the overall uptake of direct payments in mental health, local monitoring systems should be developed to ensure equity of access for eligible service users and assess progress made.
- 7.2 In terms of 'performance indicators', monitoring which and how many clients have been offered direct payments as an option is equally if not more important than the numbers of people actually using direct payments.

**RECOMMENDATION 8:
FUTURE RESEARCH AND DEVELOPMENT**

- 8.1 Issues relating to equality of access⁹⁵ still require further research and clarification.
- 8.2 Action research is needed in relation to economic re-modelling to support greater flexibility in service provision⁹⁶ and in relation to the development of independent planning within mental health as an alternative assessment framework to support realisation of greater choice and control for service users.
- 8.3 Longitudinal research is needed to identify longer-term benefits and outcomes for people with mental health needs using direct payments.

⁸⁷ These have included the requirement to implement policies and guidelines such as the National Service Framework; the integration of health and social services, as well as other related initiatives such as Supporting People and Fairer Access to Care.

⁸⁸ Meaning that it was not a direct transfer of resources from a directly provided service to direct payments.

⁸⁹ See work developed by the Valuing People's Support Team within Learning Disability services.

⁹⁰ HASCAS in association with the Foundation for People with Learning Disabilities and the Health Service Management Centre at the University of Birmingham have been commissioned by the Department of Health to conduct an evaluation of the impact of the social care modernisation programme on the implementation of direct payments across adult care groups (2003-2006). Key objectives of this study are to identify principal explanatory factors which have led to variable implementation of direct payments and development of schemes within England. Further the aim is to evaluate the process of implementing direct payments within a framework of variables known to influence the course of policy implementation. Determining the relative weight of these variables will allow an assessment to be made of the impact of a range of variables on direct payment implementation and developing support provision.

⁹¹ See Chapter 7 for further explanation.

⁹² Essex Personal Assistance Support Service (PASS)

⁹³ i.e. used to just provide an extra service.

⁹⁴ See Appendix C on the work being developed by the Direct Payments Fellow at NIMHE Eastern.

⁹⁵ For example, for younger people and for people from Black and Minority Ethnic communities.

⁹⁶ The Valuing People Support Team (see Appendix C) is developing a national programme to help Local Authorities find ways to re-organise how money flows into services. Whilst this focuses on Learning Disability services, it should provide valuable learning and similar initiatives developed in the mental health field.

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- Zarb, G. and Naidash, P. (1994)
Cashing in on Independence: Comparing the Costs and Benefits of Cash and Services for meeting Disabled People's support needs. BCODP/PSI: Derby

Appendices

A Mental Health Exclusions

The Community Care, Services for Carers and Children's Services (Direct Payments) (England) Regulations 2003 specify that direct payments may not be offered to certain people whose liberty to arrange their care is restricted by certain mental health or criminal justice legislation as follows:

- (a) S/he is required to submit to treatment for his mental condition or for his drug or alcohol dependency by virtue of a requirement of a community rehabilitation order within the meaning of section 41 of the 2000 Act or a community punishment and rehabilitation order within the meaning of section 51 of that Act;
- (b) S/he is subject to a drug treatment and testing order within the meaning of section 52 of the 2000 Act;
- (c) S/he is released on licence under section 37 of the Criminal Justice Act 1991 subject to a condition that s/he submit to treatment for his mental condition or for his drug or alcohol dependency;
- (d) S/he is placed under guardianship in pursuance of-
 - (i) an application made in accordance with **section 7 of the 1983 Act**; or
 - (ii) an order made under **section 37 of that Act**;
- (e) S/he is absent from hospital with leave given in accordance with **section 17 of the 1983 Act**;
- (f) S/he is subject to after-care under supervision within the meaning of **section 25A of the 1983 Act**;
- (g) there is in force in respect of him/her a condition imposed in accordance with section 42(2) or 73(4) (including such a condition which has been varied in accordance with section 73(5) or 75(3)) of the 1983 Act;
- (h) there is in force in respect of him/her a supervision and treatment order within the meaning of Part 1 of Schedule 2 to the Criminal Procedure (Insanity and Unfitness to Plead) Act 1991;

People subject to equivalent Scottish mental health or criminal justice legislation.

People in these groups are required to receive specific community care services. Offering them direct payments in lieu of those services would not give a sufficient guarantee that the person would receive the services required.

B National Agencies & Resources

The following have been referred to in this report:

National Centre for Independent Living

250 Kennington Lane
London SE11 5RD
Tel: 0207 587 1663
www.ncil.org.uk

Values into Action

Oxford House
Derbyshire Street
London E2 6HG
Tel: 020 7729 5436
www.viauk.org

Valuing Peoples Support Team

In Control: Self Directed Services:
A National Programme to change how
Social Care is Organised in England
Programme Co-ordinator: Simon Duffy
Valuing People Support Team
36 Rose Hill Drive
Mosborough
Sheffield S20 5PN

NIMHE Eastern

Direct Payments Fellow: Robin Murray Neil
NIMHE Eastern
654 The Crescent
Colchester Business Park
Colchester
Essex CO4 4YQ

Joseph Rowntree Foundation

The Homestead
40 Water End
York YO32 6WP
Tel: 01904 629241
www.jrf.org.uk

c National Pilot Information

National Co-ordinator

Deborah Davidson.

Site Co-ordinators

Barnet: Miriam Mica; Hampshire and Surrey:
Tina Coldham; Leicester: Colin Gell;
Tameside: Carey Bamber/Rose Ferguson.

National Pilot Steering Group

Peter Beresford (Brunel University); Peter Campbell
(Survivors Speak Out); John Evans (Independent
Disability Rights Consultant); Alison Faulkner
(Mental Health Foundation); Janet Gibson
(WECIL Ltd) UKAN South West); Caroline Jenkins
(Mad Women); Laura Luckhurst (NCIL);
John Martin (Franz Fanon Centre); John McCracken
(Department of Health); Diana Rose (Sainsbury
Centre for Mental Health); Terry Simpson (UKAN);
Simon Stockton (Department of Health).

Participating Local Direct Payments Support Services

Barnet Direct Payments Support Service
Flightways
The Concourse, Graham Park Estate
Barnet, London NW9 5UX
Tel: 020 8205 9976

Hampshire

Southampton Centre for Independent Living
6 Northlands Road, Southampton SO15 2LF
Tel: 023 8033 0982

Leicester Mosaic

2 Richard 3rd Road, Leicester LE3 5QT
Tel: 0116 251 5565

Surrey Independent Living Centre

Astolat, Coniers Way
Burpham, Guildford GU4 7HL
Tel: 01483 458111

Tameside Direct Payments Support Agency

Loxley House, Birch Lane
Dukinfield, Cheshire SK16 5AU
Tel: 0161 368 5832