

Direct payments and mental health



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Direct payments and mental health: new directions

Karen Newbigging *with* Janice Lowe



RESEARCH *INTO* PRACTICE



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

Peter Beresford, New Directions conference, May 2004

'I use my five hours a week for shopping, lunch out, walks in the countryside, sometimes I save it up for weekend trips, and I do college courses such as "the expert patient".'

'As a result of being on direct payments I have more confidence, I have had no hospital admissions and I have a better quality of life. I now have people back for a meal and cook and bake. I have the motivation and support I need to take part in my own care.'

'In the case of people with mental health problems, direct payments can offer one-off solutions to a seemingly insurmountable problem, short term payments to help somebody during a particularly difficult period or longer term payments for care or support.'

Direct payments recipient



Executive summary

Direct payments are a means by which people who require social care directly receive community care monies so that they can choose and pay for their own support to meet their needs. Local authorities now have a duty to offer direct payments to people who are eligible and to make payments to those who want them. However since their introduction progress in ensuring that more people are able to access direct payments has been slow. This is particularly the case for people experiencing mental distress. The recently published report by the Commission for Social Care Inspection (2004) highlights the barriers that exist to greater access and take-up of direct payments. A recent evaluation of a national pilot to increase the take-up of direct payments by people with mental health needs identified the factors that support implementation (Spandler & Vick, 2004). This project builds on that work to understand how access to and take-up of direct payments by people with mental health issues could be improved.

This project, *New Directions*, set out to engage with service users and professionals to raise awareness about direct payments and their potential for people experiencing mental distress, particularly those from black and minority ethnic communities. The main aim was to engage in debate around common concerns and encourage creative thinking and problem-solving approaches. A process of four focus groups was developed and these focus groups provided a basis for a national implementation event that brought together mental

health service users, professionals and service providers to identify the positive action required.

The top ten messages from this project are as follows.

- People experiencing mental health issues should have easy access to a process whereby their needs for social care can be assessed. Local authorities need to be confident that access to such an assessment is easy and not equated with access to services, where the threshold may be much higher.
- Straightforward, accurate and accessible information is needed for service users, carers and professionals, particularly care co-ordinators. This information needs to be specific to mental health and use real life examples to demonstrate how direct payments can be used, their potential impact, and how to access support to pursue a direct payment. Training and practice development for staff is needed, providing accurate information and an opportunity to explore concerns.
- The provision of mental health specific advocacy and support is essential. Many of the schemes that have developed to enable people to access and take-up direct payments have been developed around the needs of people with physical disabilities. Advocacy and support sensitive to the issues for people experiencing mental distress need to be developed and commissioned.
- An easy and streamlined process is needed that reduces unnecessary paperwork and fits with the Care Programme Approach and additional local authority assessments. This is essential as the bureaucracy is a major barrier,

particularly both for users and care co-ordinators, who find it confusing and potentially overwhelming.

- Increasing the take-up by people from black and minority ethnic communities relies on developing resources and approaches that are specific to those communities. Outreach and direct support services specific to those communities need to be developed. The voluntary sector is best placed to do this. Further work needs to be undertaken to pilot different approaches to increasing take-up by people from black and minority ethnic communities.
- A cultural change is needed so that there is a tangible commitment to ensuring self-determination pervades mental health services. This should be evident in the way staff interact and support people experiencing mental distress. This is a necessary foundation for ensuring that the opportunity to access direct payments is pursued as a matter of routine.
- Leadership is necessary to drive forward the process of implementing direct payments, from national direction and guidance through to local leadership to manage the change in practice that the introduction of direct payments requires. Further guidance and strengthened monitoring at a national level is needed to support this. Local authorities need to refine policies and develop guidance for staff that makes clear their role in relation to direct payments and mental health. The implementation of direct payments in mental health is greatly aided by the existence of a local multi-agency steering group that adopts a strategic approach, sets out to increase the take-up and is committed to developing new ways of working.

- Fostering partnerships, creative thinking and collaborative problem-solving are essential to facilitate learning about the implementation of direct payments: for example, partnerships between black service user groups and advocacy services, between advocacy services and care co-ordinators, between service providers and commissioners. Bringing these organisations together provides a great opportunity to develop solutions jointly that individually may have seemed insurmountable.
- Direct payments need to be introduced in a planned way, with thought given to how existing services can be reviewed, reconfigured and recommissioned. Guidance on the implications of direct payments for re-shaping and recommissioning services needs to be developed so that local authorities can respond proactively to an increase in demand for direct payments and a shift to individualised funding approaches.
- Reviewing what direct payments cover in mental health is needed as the distinction between health and social care in mental health is not easy to make, often impossible, and arguably no longer relevant.

Implementing direct payments requires action on all these fronts by players at a national and local level and by those with a strategic and operational focus. Local strategic bodies, particularly local implementation teams or mental health partnership boards, are well-placed to co-ordinate action to introduce direct payments, as they bring together the different partners, including service users. They, therefore, have a critical role to play in shaping the strategic direction and reshaping services to promote choice, control and social inclusion.

A number of local authorities have been relatively successful in introducing direct payments in mental health. However the numbers remain small and further guidance, particularly in relation to financing direct payments, is required to narrow the gap between national ambition and local reality.

Part one

Background to direct payments and mental health: the New Directions project

Having choice and control in our lives is important to all of us. People experiencing mental distress can find their choices and control are jeopardised by the services they encounter. Direct payments are a means by which people experiencing these difficulties can exercise greater choice over the support that they receive to meet their social care needs.

The Direct Payments Act came into force in 1997. Since then, there has been a slow but steady growth in the implementation of direct payments (Commission for Social Care Inspection, 2004). Despite this increase, the number of people with mental health needs who have taken up direct payments has remained low, particularly in comparison with other groups. At the end of September 2003, the information from the Social Services Inspectorate indicates 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 (Spandler & Vick, 2004). Indeed just 229 mental health service users in England were accessing direct payments out of a total of 12,585 direct payments users. This is less than two per cent.

The aim of this project was to promote the use of direct payments for people experiencing mental distress, including those from black and minority ethnic communities. It started from a belief that direct payments have the potential to make a real and lasting impact on people's lives. The project therefore set out to engage service users and professionals, particularly care co-ordinators, in a dialogue about what action is needed to address the barriers to implementing direct payments in mental health. This report describes the learning from this, and draws on it to identify the action needed to comprehensively implement direct payments for people with mental health problems.

Chapter One

Introduction

This report provides a brief overview of the aims and methodology of the project, presents the key findings, and concludes with a focus on local implementation. **Part One** sets the scene. **Chapter 1** gives an overview of the focus of the report, the need for this project and the methodology used. **Chapter 2** provides the background to the project in identifying the barriers to implementing direct payments in mental health. **Part Two** identifies what needs to happen to address these barriers and considers the issues from three different perspectives: service users, care co-ordinators and managers. **Part Three** draws this together to identify what local organisations need to do to implement direct payments in mental health.

The information in this report is drawn from participants in four focus groups held across England, a national implementation event (the New Directions conference), and telephone interviews. Unless otherwise stated, quotes are taken from the focus group discussions and telephone interviews.

We have used the terms ‘mental distress’ and ‘mental health problems’ to describe the broad range of experience of mental health issues, the term ‘recipient’ to describe someone who is receiving a direct payment and ‘service user’ to describe people who are using mental health services.

Who is the report for?

The successful implementation of direct payments in mental health relies on proactive managers who are clear about the task, knowledgeable and committed practitioners and informed service users who are interested in exploring the options of direct payments. This report is therefore aimed at these three groups. It has a particular emphasis on the action that can be taken to implement direct payments in mental health, and therefore will be of benefit to local authority managers charged with introducing direct payments and care co-ordinators whose responsibility it is to promote access to direct payments for people with mental health problems. It is also aimed at joint strategic bodies, specifically local implementation teams and mental health partnership boards, who take the lead responsibility at a local level for shaping the vision and strategic direction of mental health services. The report should also be of interest to the National Institute for Mental Health (England) and its eight regional development centres, who play a central role in supporting local organisations to provide more responsive and person-centred mental health services.

The project

The benefits to people using direct payments are clear (Spandler & Vick, 2004), and it is evident that they can offer greater flexibility and more choice than existing services for people. They have real potential to facilitate social inclusion and access to mainstream opportunities (ODPM, 2004).

Previous work has identified a number of barriers to implementing direct payments in general (Commission for Social Care Inspection, 2004), and specifically for people experiencing mental distress (Ridley & Jones, 2002; Davidson

& Luckhurst, 2002; Spandler & Vick, 2004). Through a series of focus groups, this project focused on these barriers and what needed to happen for them to be addressed. Four focus groups were held: in Birmingham, Manchester, London and Maidstone, Kent. Their prime aim was to promote a dialogue with mental health professionals and service users about the potential of direct payments to offer choice and control to service users. Each of the focus groups targeted a different group of people in order to build a comprehensive picture of the difficulties and the potential solutions.

The focus groups targeted:

- service users. A particular effort was made to recruit service users from black and minority ethnic communities because mental health services are particularly unresponsive to their needs
- voluntary groups, self-help and advocacy groups, as they have a critical role in promoting and supporting access to and use of direct payments
- practitioners, particularly care co-ordinators and frontline workers, as they are key in facilitating and supporting the choice to access direct payments
- senior managers, as they need to provide leadership, ensure organisational support and develop the strategy for the introduction of direct payments.

Service users were recruited to facilitate the focus groups, and other service users, professionals and staff from direct payment support services were recruited as witnesses, to share their knowledge and experiences of direct payments. This process proved to be creative and energising and is

described in more detail in **Chapter 8**. It potentially provides a template for getting action started in those areas where direct payments have not, as yet, been successfully implemented.

Following these focus groups, a national implementation event was held in May 2004 to bring together the different stakeholders to reflect on the key themes that had emerged from the focus groups and to identify how the barriers to implementation could be addressed.

In addition, further information was obtained from telephone interviews with the lead managers for direct payments in five local authorities. These included authorities that had relatively high numbers of people with mental health problems receiving direct payments or where there had been a significant change in the numbers of recipients, according to Department of Health data. The local authorities selected were Essex, Leeds, Liverpool, Norfolk and West Sussex.

An overview of the process for the project is given in **Figure 1**. An outline for the focus groups can be found in **Appendix 2**, and the programme for the national event in **Appendix 3**.

The project benefited from the appointment of a project advisory group. This group included people with particular expertise in relation to direct payments and mental health, who were able to shape and comment on the direction of the project.

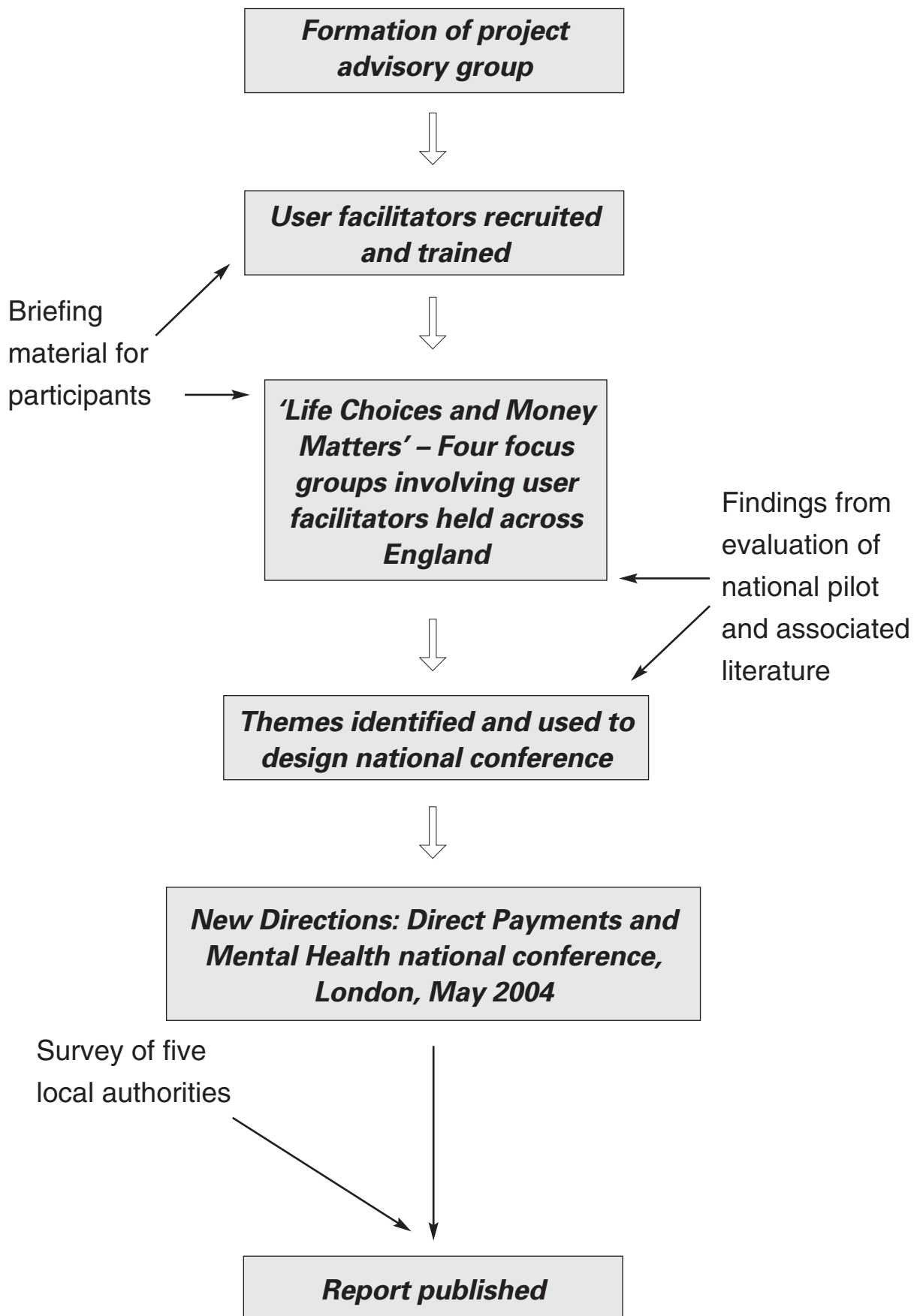
Summary

The New Directions project set out to:

- **promote a dialogue between service users and front-line staff and managers about how the barriers to implementing direct payments could be overcome**
- **engage service users and directly draw on experience of direct payments from different perspectives.**

This report summarises the key learning for users, frontline staff and managers.

Figure 1: New Directions project



Chapter Two

Barriers to implementing direct payments in mental health

‘Some seven years ago, after experiencing barrier upon barrier, I finally was able to gain a direct payment... Oh yes, direct payments have been around for some time now!! However, at the time the medical model was well and truly kicking!! That means active!! And my physical impairment was quite visible to the various people who assessed me. I was a wheelchair user, and when I wasn’t I was a zimmer frame or walking stick user!! Like I said earlier, for some reason I still experienced hidden barriers, but what was not explicitly supported for was my hidden impairment resulting from my mental health difficulties.

‘At the time direct payments were viewed as available for people with severe physical disabilities – mainly white wheelchair users!! I look back on those days, and even now I have to wonder how I would have managed with having both a physical and mental impairment without a direct payment.’

Julie-Jaye Charles, chief executive of Equalities, New Directions conference, May 2004

‘The routine consideration of direct payments for people with mental health needs is still a long way off. Positive action is needed to ensure that people with mental health needs are offered direct payments as a route to achieving independent living and social inclusion and that lessons are learned from the experience and preferences of those using direct payments

to inform service development.' Stephen Ladyman, minister for community care, New Directions conference, May 2004

It is clear both from individuals and from the government that there is a gap between the national ambition and the local reality in relation to direct payments. This project benefited from being able to draw on other work that has identified barriers to the implementation of direct payments (Commission for Social Inspection, 2004; Hasler, 2003); the specific barriers for people from black and minority ethnic communities (Banton & Hirsch, 2000; NCIL, 2001), and the barriers for people experiencing mental distress (Davidson & Luckhurst, 2002; Ridley & Jones, 2002; Spandler & Vick, 2004). The focus of the project was how these barriers might be overcome. The barriers that were identified during the focus groups and interviews were as follows.

Lack of awareness and confusion about direct payments

Widespread lack of awareness

'No-one has ever mentioned direct payments to me.' Mental health service user

'What about direct payments and carers?' Relative of a mental health service user

The widespread lack of awareness about direct payments in general and in relation to mental health specifically was evident throughout this project. Many of those participating in the focus groups knew nothing about direct payments, and most had the sense that direct payments are very complicated and too difficult to really understand.

As part of this project, more effort than originally anticipated had to be invested in providing information about direct

payments. A recent study completed for the Scottish Executive found that many mental health professionals do not know about direct payments and the majority are unaware of the flexibility and the variety of arrangements possible in their use (Ridley & Jones, 2002). We found that a lack of understanding about who can receive direct payments and the rare circumstances when people are excluded is widespread.

Confusion about direct payments

'I can't believe that the government has done this: got two schemes with the same name.' Focus group participant

In addition to simply not having heard of direct payments, there was considerable confusion about them. There are two aspects to this. First, there was confusion as to what was being referred to: the term 'direct payment' has recently been introduced by the Department for Work and Pensions to describe the direct payment of benefits into a bank account. Several participants attended the focus groups because they were expecting to get more information about this: for example, an older man came to hear about his pension being paid into his bank account and how this would affect him.

Second, among participants there was an assumption that direct payments are for people with physical disabilities. This is fostered by the emphasis in local authority policies that do not always make it explicit that people with mental health problems are also eligible. The language used in relation to direct payments is largely unfamiliar to mental health professionals (eg. independent living, personal assistant (PA) etc) and examples used in the literature typically relate to physical care. This contributes to fostering an assumption that direct payments are for people with physical impairments only.

Access to assessment and support

Assessment of social care needs

There is an important distinction to be drawn between access to an assessment of an individual's needs for social care and eligibility to receive a service. The way in which mental health services are organised means that the access to assessment may be dependent on whether an individual is eligible to access that particular service. Potentially this could dramatically restrict the number of people who will have their needs assessed. Further, the eligibility criteria for services may reflect more clinical considerations (eg. severity of symptoms) rather than the extent to which someone's independence is compromised.

Lack of a simple streamlined process

At one focus group, we discovered that care co-ordinators from one area had to complete eight different forms in order to enable people to access direct payments. In mental health services there is process that already exists for identifying the needs of people: the Care Programme Approach. The Care Programme Approach is well established within national mental health policy as the framework for practice, although its implementation has been variable, with practitioners often complaining of excessive paperwork (Newbigging, 2004). Unless attention is paid to ensuring a single, simple, streamlined process, there is a real danger that the associated paperwork will appear overwhelming for hard-pressed frontline staff.

Lack of appropriate support

Service users and carers can be put off applying for direct payments because of concerns about the practicalities:

particularly the recruitment and employment of staff. Support with this is now increasingly available but may be ineffective if the support service is geared around people with physical disabilities and is unfamiliar with, and consequently insensitive to, mental health issues and the fluctuating nature of mental health problems.

Previous experience of mental health services

Scepticism about direct payments to change personal situations

Some service users expressed a lack of confidence that direct payments would help change their experiences of exclusion and isolation and of being stigmatised. Their experience of having their needs assessed properly and services provided to meet those needs was, in general, poor. They were angry with mental health staff for their ignorance about direct payments, and sceptical that anything would come of the initiative. This disillusion was informed by people's previous experience of being promised much but given little or nothing. This was a common experience for service users involved in this project, and for black users was further compounded by their experience of racism in service delivery.

Organisational culture

Prevailing views of mental ill health

'We have been taught to think about mental health service users as people who are ill, who have something wrong with them, who need treatment. But direct payments fits in with a different way of thinking about the madness and distress that people experience; another way of understanding it; a way of

learning to cope and manage with it as an individual.' Peter Beresford, New Directions conference, May 2004

As Peter Beresford made clear in his opening comments to the national event, the successful implementation of direct payments relies on an understanding of a social model of disability and a commitment to meeting individuals' needs. Mental health services and professionals have for a long time disputed the nature of mental ill health and there are competing models and views of what the central issues are. Where the prevailing view of mental distress is biologically rooted and the emphasis is on treatment for that condition, the pursuit of independence and recovery may be inhibited.

Service users, carers, frontline staff and managers also described the culture and practice within mental health services as being risk adverse. The preoccupation with risk was seen to be incompatible with workers letting go of their control and supporting innovations in practice.

Assumptions about incapacity

National policy makes it clear that capacity should be assumed and that, although there are some people who by law are excluded from getting direct payments, they form a very small proportion of those in contact with mental health services. Concerns about the capacity of people with mental health problems to manage a direct payment were expressed by frontline staff, and echo a previous study that found this was one of the most important factors underlying professionals' reluctance to promote direct payments (Ridley & Jones, 2002). The view that if people were capable of managing a direct payment then they couldn't really have a mental health problem was an interesting variation on concerns about capacity.

Although direct payments should be offered as an option to all service users who are identified as having social/personal care needs, it would appear that they are either not offered or individual care co-ordinators are making a personal judgement based on the individual's capacity to manage a direct payment.

Not regarded as relevant to the core business

The model of mental ill health that underpins an organisation will affect how its staff behave and the amount of time and attention direct payments will receive. Ridley and Jones (2002) identified that if mental health professionals did know about direct payments, there was a tendency to view them as largely irrelevant to their work. A number of care co-ordinators involved in this project described being overwhelmed and exhausted by changes arising from mental health policy and associated initiatives and being unclear as to how direct payments policy links to these. Direct payments policy is arguably qualitatively different. It can be characterised as a bottom-up initiative, having been driven by disabled people keen to have more control and choice over their lives (Evans, 2003). However, with the introduction of national targets it is possible to lose sight of this. This signals a need to focus on how organisations can translate national targets into meaningful local actions to improve people's choice and control.

Concerns of frontline staff

Anxieties about the implications of direct payments

Care co-ordinators' explanations for why they found it difficult to implement direct payments were, typically, staff shortages, policy imperatives and the impact of organisational restructuring. It was, however, possible to move beyond these reasons and to explore more covert issues, particularly in relation to the reduction in care co-ordinator power necessary if direct payments are to become a

real option for users. Associated with this was an anxiety about the impact of direct payments on people's jobs – especially concerns that workers might not be needed anymore: for example, the community support function currently provided by mental health teams being replaced by personal assistants (PAs) recruited by service users.

Inadequate investment in training

'Often it is team members who are already enthusiastic about direct payments who elect to attend training and those who have not implemented direct payments do not. It needs to be mandatory.' Care co-ordinator

A lack of sufficient investment in training required to raise awareness of direct payments was mentioned by interviewees from the local authorities. It is not usually a requirement, nor integrated into other training programmes or part of new staff induction programmes. The lack of understanding of direct payments was likely to be compounded if care co-ordinators had no previous experience of commissioning social care for individuals. In addition to training, regular supervision and practice development, opportunities are needed to allow staff to explore their concerns.

Organisational barriers

Problems concerning use of direct payments for social/personal care but not health care

Direct payments can only currently be used for social/personal care, not health care, and this was identified as a particular difficulty for mental health service users. This was partly because differentiating between health and social care is a particular problem in mental health. There is a need to widen

the eligibility for direct payments and to clarify the types of care that can be funded.

Related to this is the fact that the majority of mental health care is delivered by health services, rather than social services, whereas for other client groups (such as people with a physical disability) a large amount of care is delivered or commissioned by local authorities/social services. It would appear that in some areas the promotion and training related to direct payments generally has mainly taken place within the local authority, and information and training has been directed at social workers.

Health and social care integration

Increasingly mental health services integrate health and social care. Connected with this, a lack of clarity of role around care co-ordination was expressed by front-line staff. Senior managers also raised concerns about a lack of clarity as to the responsibility for funding particular services.

Absence of a systematic approach to the introduction of direct payments

In general the approach to introducing direct payments in mental health can be described as opportunistic and ad hoc, often relying on individual practitioners' assessments and assumptions as to who might benefit.

In many areas, the issue of budgetary constraints also affected the type of care that direct payments funded. Managers often varied on what they would agree funding for, depending on the availability of finances. There is little evidence of a strategic approach, of thought having been given to how services might be reshaped and recommissioned to increase the resources available for direct payments.

Additional barriers for black and minority ethnic (BME) communities

Breaking Barriers (NCIL, 2001), a consultation event held by the National Council for Independent Living (NCIL) in partnership with Black Disabled People, raised a number of issues around barriers to accessing direct payments for these communities. These included lack of access to information, as well as language, cultural issues and inequality and inconsistency between local authorities in implementing direct payments and community care more generally. These barriers were confirmed by this project.

In addition, notions about mental ill health and BME communities and people's experience of limited access to appropriate mental health care, were seen as indicative of institutional racism in the structures and processes of social care generally, and mental health services specifically.

Summary

The barriers to implementing direct payments in mental health include:

- **widespread lack of knowledge and confusion, including inaccurate assumptions about who direct payments are for**
- **difficulties in accessing assessments and appropriate support services**
- **previous experience of mental health services leading to scepticism about their potential**
- **culture of mental health services, including preoccupation with risk and biological focus and therefore not seen as core business**
- **anxieties about the implications of widespread use of direct payments**
- **inadequate investment in training**
- **organisational barriers that include definition of what direct payments can be used for and an ad hoc approach to their introduction**
- **additional barriers for BME communities reflecting institutional racism and notions about mental ill health and black people.**

Part Two

Making direct payments a reality

This section considers the opportunity that direct payments can bring to people experiencing mental distress and how to overcome the barriers that have been identified in order to realise this opportunity. **Chapters 4, 5 and 6** summarise the key points from the discussions in the focus groups and the national implementation event from the perspective of service users, care co-ordinators and managers. **Chapter 3** outlines the opportunities direct payments represent.

Chapter Three

The opportunity

'I have been on direct payments for one year. To start with I was given 2.5 hours a week and now, since a review, I have five hours a week. I used to attend a day centre five days a week, but this was not stimulating and my five hours now are more valuable than five days used to be!' Direct payment recipient

Direct payments are envisaged as a means to improve the quality of life of people who wish to manage their own support, and to promote independence and aid social inclusion by offering opportunities for recovery, education, leisure and employment for people in need of community care (DH, 1997).

The policy guidance on direct payments (DH, 2003) states that direct payments 'promote independence, and they aid social inclusion'. Local authorities are therefore urged to 'think imaginatively about the provision of direct payments for both intensive packages and lower level services ... and about how direct payments can be assimilated into preventive and rehabilitative strategies'.

The potential of direct payments to empower individuals and to increase independence is consistent with the guiding values and principles of the national service framework for mental health (DH, 1999). Indeed, it states that 'people with mental health problems can expect that services will involve them and their carers in planning and delivery of care and offer choices that promote independence'.

Direct payments are one mechanism for meeting these objectives, and it is therefore no surprise that the importance of direct payments and their contribution to modernising day services is emphasised in the report on mental health and social exclusion recently published by the Social Exclusion Unit (ODPM, 2004).

The guidance on fair access to care is also relevant (DH, 2004). This makes it clear that there should not be eligibility criteria for the assessment of an individual's social care needs. The depth and scale of the assessment needs to be proportionate to the individual's needs and circumstances, with priority given to meeting these needs determined by the assessment of the risks to the person's independence.

National policy is therefore advocating an emphasis on choice, independence and inclusion and promoting direct payments as a means of achieving this.

Direct payments can be used in different ways. A recent study found great diversity in the way people experiencing mental distress were using direct payments (Spandler & Vick, 2004). Uses included paying for:

- social/domestic support, personal contact, personal care, transport
- practical support (with budgeting, shopping, gardening etc)
- educational support, arts and leisure activities
- respite and help with childcare, therapeutic support and night sitting
- pooling payments to employ someone collectively.

There were significant benefits identified from using direct payments, including:

- increased access to and enjoyment of mainstream activities that were non-stigmatising and not mental health focused
- greater independence and flexibility in support arrangements, and a positive impact on mental health
- improved feelings of confidence, self-esteem, assertiveness, motivation, sense of purpose about their life, and a sense of hope in being able to pursue some self-defined goals.

Promoting choice and independence

Direct payments are a means to an end. The aim is to secure greater independence and more choice over the support required to achieve that. Promoting choice and control as a way that independence can be achieved should be at the heart of mental health services. The emphasis that service users place on recovery reminds us that this is critical to them.

Providing a more flexible response

Direct payments mean that support is commissioned by the individual based on an assessment of their personal needs. If the assessment process relies heavily on self-assessment, the response to the needs identified will inevitably be more sensitive and take account of the changing nature of these needs. Direct payments have a greater potential to provide support that can 'flex' in response to individual needs, as illustrated overleaf.

Flexible support

One person employed a personal assistant (PA) to do two waking night sits per week when she felt she needed it most (for example, at weekends). This person had ongoing serious and escalating self-harm and 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.'

(Spandler & Vick, 2004)

Facilitating social inclusion

'There is a dignity in being an employer, employing your own personal assistant, rather than the indignity of being unemployed and receiving benefits.' Robin Murray-Neill, NIMHE, New Directions conference, May 2004

'I have seen too many day centres for example, with people chain-smoking their way through daytime television.'

What is stimulating about that? What is different from the old big hospitals?

'We need pro-active services that work with people to improve self-esteem and coping mechanisms, in a way that people can accept and understand, and that's particularly important for those from black and minority ethnic communities. We have to break the vicious circle of increasing dependence on services, failing to reduce isolation and social exclusion.'

Stephen Ladyman MP, New Directions conference, May 2004

Social exclusion and stigma can be common experiences for people with mental health problems. As direct payments enable the individual to define how their needs can be met, they create opportunities to make real friendships, to develop hobbies and interests, and to take steps into employment.

Facilitating culturally sensitive support

The experience of black and minority ethnic communities of mental health services has been poor. Services have misinterpreted and over-diagnosed mental health problems, have been inaccessible to communities and have often failed to provide support and treatment that was appropriate and acceptable. With the emphasis on individualised services, direct payments have the potential to facilitate access to culturally sensitive support.

As well as being recognised by government policy (ODPM, 2004), this potential was quickly recognised by those from BME communities who participated in this project. Despite this, BME service users had generally not been offered the opportunity. This failure was seen by some as the perpetuation of the institutional racism that they have previously encountered in their contact with mental health services.

Direct payments and culturally sensitive support

A south east Asian family used direct payments to employ a personal assistant (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 needs 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 eg. not to wake him up when he's sleeping.'

(Spandler & Vick, 2004)

A better quality of life

Greater choices and control, more flexible and culturally responsive support that aims to promote inclusion add up to a better quality of life.

Summary

The opportunities direct payments offer to mental health service users are:

- **choice and independence**
- **flexibility**
- **more culturally responsive and appropriate support**
- **inclusion through supporting access to leisure opportunities and educational activities, friendship and pathways into employment**
- **a better quality of life.**

Chapter Four

Having the choice: direct payments and people experiencing mental health problems

Receiving a direct payment to purchase your own care is a choice. Like any choice, this needs not to be seen as a once-and-for-always decision and needs revisiting on a regular basis as and when needs change. People need to know what is involved, what they will need to do, and what it means if they decide not to pursue a direct payment. Four particular issues emerged during the focus groups that will facilitate making this choice:

- access to straightforward, accurate information
- having an advocate or someone to speak on your behalf
- having access to appropriate practical advice and support
- having options available if you decide not to pursue a payment.

The way in which information, advocacy and support are provided needs to be sensitive to and appropriate for the individual's circumstances. This project specifically considered this from the perspective of black and minority ethnic communities, but equally attention needs to be paid to issues such as disability, gender and sexuality.

Straightforward, accurate information

Information needs to:

- be simple and accessible, and make clear that people with mental health issues can access an assessment of their social care needs
- emphasise a person-centred approach and be clear that direct payments are a way of getting individual needs met, as well as, or instead of, using existing services
- describe how to start the process, what is entailed and where to access local advocacy and support to take it further
- be relevant to mental health service users by including their perspectives and stories of individuals with mental health problems who have used direct payments
- be clear that direct payments are a choice. Users should be offered the choice about how their needs are best met, which might include either a direct payment or a direct service, or both. It is easy to raise anxieties if it is implied that everyone must have a direct payment. Information about what happens if someone chooses not to receive a direct payment should therefore also be available.

The information that was provided for the focus groups is summarised in **Appendix 4**. This included information about the benefits of direct payments for people experiencing mental distress, the ways in which direct payments have been used, examples of support arrangements and examples of how direct payments can result in more culturally appropriate support. This was supplemented by information on local support available: particularly user networks, advocacy and direct payment support schemes.

Information about direct payments needs to be available in different formats and different languages: tapes and videos as well as in written form, and in Braille and easy-to-read versions.

Breaking Barriers is a video¹ that features black and minority ethnic disabled people who use direct payments. It highlights the difficulties minority ethnic disabled people have had in accessing direct payments and the difference direct payments can make to a person's quality of life and well-being. This video was shown at the focus groups and gives a step-by-step description of the process you need to go through to get a direct payment.

One user said about the video:

'I am already inviting people around who might be interested in direct payments to watch it. Just as a regular person, not a special event.'

Information needs to be widely available in settings that the general public access, such as libraries. It was also suggested that information could be broadcast on radio stations for black and minority ethnic communities and that using drama such as forum theatre, arts line, poets, rap artists or finding a celebrity to advertise direct payments would draw people's attention to them. In addition, people with mental health problems can be specifically targeted: for example, providing a pack of information for all those on the Care Programme Approach who therefore might be eligible to receive direct payments.

Accessible information, whether it is written or in a different format such as a video, has the advantage of being relatively

¹ The video was made by a group of disabled people from black and minority ethnic communities supported by the National Council for Independent Living (NCIL) and Equalities, the National Council of Disabled People and carers from black and minority ethnic communities. The video/DVD is available with English subtitles and translations in Urdu, Somali, Hindi and English.

easy to disseminate. However, anxiety may continue to be a barrier, even when people have received such information. It was suggested at the focus groups that taking the information to people was important, particularly for those people who might not easily come across it: for example, outreach to community centres or targeting people before they leave hospital. The need to invest in outreach work to reach users from BME communities was highlighted. It was thought important to organise events that involve people who experience mental distress and are using direct payments, as this gives people real opportunity to explore issues that might be of concern to them. The experience of this project has been that there is enormous value in service users coming together to explore the implications of receiving direct payments. **Part Three** of this report outlines a process for this.

Advocacy

'Last year 45 referrals for direct payments for people with mental health problems were received. It is vitally important to have an independent organisation to provide objective advice and support for direct payments. Advocacy works in partnership with the disabled person and as much as possible with the statutory agencies. Challenge, from time to time, is inevitable, and an independent organisation can make challenges without conflict and faithfully act in accordance with the wishes of the disabled person represented.'

Independent Living Association, Essex

Advocacy in making the choice about direct payments was described as:

‘Speaking up for yourself or another person, to secure rights, meet needs or support people to make informed choices.’

Focus group participant

Everyone is capable of exercising choice. Empowerment leading to choice and control is an important concept in advocacy. A description of the role is outlined below.

The advocate role

The role of an advocate in supporting access to direct payments:

- **to support you and help you do things you may not feel confident to do on your own**
- **type letters; fill in forms; make telephone calls on your behalf**
- **represent you, or just be with you at meetings, assessments or interviews**
- **do their utmost to assist you and gain the services you require.**

Equalities, National Council of Disabled People and carers from black and minority ethnic communities

Advocates also help users to think through the process of direct payments step by step, and about what is involved (drafting adverts, recruitment, application forms). In this project, we found that this type of advocacy was a central part of what direct payments support services offered.

Below is an illustration of how advocacy can enable people to use direct payments.

'Advocacy can stimulate lateral thinking and innovative solutions to problems.' Focus group participant

The need for advocacy

In this case, the family of Mr Y provided for most of his care needs. They felt they needed some respite to continue to provide care.

An advocate became involved and the possibility of a direct payment was looked at. Mr Y did not have the capacity to sign a direct payment agreement. Therefore, a trust was established using members of the family and an independent person as trustees.

The direct payment was paid into the trust and, after some initial difficulties in recruitment, a suitable personal assistant was found to provide assistance for two days per week. This allowed the family to continue to provide assistance for the other days. The arrangement is continuing to work well.

Practical support

Service users at the focus groups identified the provision of practical support with managing money and associated paperwork as necessary. Independent direct payments support agencies are able to provide advice on setting up and managing a direct payment, as well as ongoing practical support. Their independence from statutory services was stressed as being essential, as many service users reported

negative experiences of statutory services. The ideal support agency was described by focus group participants as:

- ‘needing to be visionary’
- ‘a place for creative thinking to flourish’
- ‘having an inclusive approach across client groups’
- ‘doing all the outreach and making it easier to access direct payments.’

This is supported by the information from the five local authorities interviewed. All had direct payments support schemes that were, typically, independent organisations run by disabled people: for example, the Independent Living Association. It is vital that these support schemes understand mental health issues, as described by focus group participants:

- ‘an understanding and personal experience of mental distress’
- ‘a belief in recovery and a “can do” attitude.’

The earlier the direct payments support service is involved, the more likely the user is to be successful in receiving a direct payment (Spandler & Vick, 2004). Support schemes need to address the lack of confidence service users may have in their ability to manage direct payments and to move from a known service to care services that are unknown to them. They can do this by:

- encouraging and supporting service users to assess their own needs (for example, carrying out a self-assessment using a tool such as the Avon mental health measure). This usually produces a more accurate and holistic view of needs

- bridging the gap between assessor and user, and this is especially important given that users often dread reviews and assessments and feel that the outcome will be negative. It will be particularly important for people from black and minority ethnic communities
- providing practical help, particularly with advertising, recruiting, interviewing and employing staff eg. personal assistants
- managing and holding money for people who are not able to have or do not have a bank account
- practical help with contracts, job descriptions, payroll
- intervening in employee/employer disputes and a knowledge of employment law
- developing support networks for recipients. In Norfolk, a large rural area, funding was secured to develop a support network in response to a need identified by users that those without the support of relatives/friends found managing direct payments challenging. The network supports isolated users and also provides support to personal assistants.

Flexibility and a 'can do' culture of creative solutions to overcoming the barriers is an important characteristic of direct payment support services. They are seen as bringing an important influence to bear on care co-ordinators in encouraging them to empower service users through increasing choice and control.

The quality of such schemes to support people in areas that they feel most anxious about has been previously identified (Davidson & Luckhurst, 2002). However, there was concern expressed by interviewees that, although these schemes can

be effective in this respect, resources were limited and therefore demand was greater than the amount of support that could be offered. Resource limitations can adversely impact on the time available and the quality of the support offered: by, for example, reducing the opportunity to do the outreach work particularly necessary for black and minority ethnic communities and those living in rural areas.

The value of peer support

Support to access direct payments is often conceptualised in terms of a formal support service. However it was evident from the focus groups that there is a real place for peer support. The support network developed in Norfolk, described above, illustrates this. Peer support can provide:

- an opportunity to share experiences and solutions to deal with any problems being encountered
- friendship, to combat the isolation that a person may be experiencing
- an opportunity to ‘pool’ direct payments to participate in shared activities.

Options other than direct payments

Receiving direct payments is a choice – a point that cannot be stressed enough. This means that deciding not to pursue a direct payment needs to be viewed as a positive choice, and not a failure. The basis for this decision obviously needs to be understood and any issues that suggest that the decision has been made on the basis of inaccurate information or assumptions about the level of support available need to be addressed. The process of assessing individual needs should enable both the person and the care co-ordinator to clearly

identify what the person needs. If a decision to not pursue a direct payment is made, then it remains the responsibility of the care co-ordinator to identify how best the individual's needs can be met. This may well have implications for the provision of existing services in becoming more responsive to that particular set of needs.

Black and minority ethnic communities

The current government monitoring statistics provide breakdown by user group and age but not, as yet, by ethnicity (although it is proposed that this information will be collected). However, this project and previous work (Banton & Hirsch, 2000; Hasler, 2003) suggest that people from black and minority ethnic (BME) communities are not getting fair access to direct payments. It was evident at the focus groups and the national event that:

- information about direct payments is not easily available or accessible for people from BME communities
- direct payments are not offered as a matter of course for these communities, arising from the lack of awareness about the potential of direct payments to facilitate the provision of more culturally sensitive support
- outreach to different communities is an essential way of engaging people with direct payments. However, comments were made about limited funding being available for this.

These obstacles can begin to be addressed by:

- developing accessible and appropriate information in a variety of languages and different formats
- raising awareness about direct payments and their potential to facilitate culturally sensitive support

- recruiting members of the local community to disseminate information
- outreach and advocacy specifically aimed at BME communities, using the process described in **Chapter 8**
- working in partnership and commissioning black and minority ethnic organisations, such as the Mellow Campaign and Equalities, to develop targeted information, training and support for people from BME communities
- reviewing current processes and, in particular, ways of assessing needs to develop ways of working that are accessible, acceptable and appropriate for the different communities.

Summary

To access direct payments people experiencing mental distress need:

- **accurate and accessible information**
- **advocacy**
- **practical support provided by a mental health aware support service on those issues that are causing the most anxiety**
- **the opportunity to access peer support**
- **alternative options if people choose not to receive a direct payment**
- **targeted information, outreach and appropriate support for people from black and minority ethnic communities to ensure fair access.**

Chapter Five

Making it happen: direct payments and care co-ordinators

'Direct payments have the potential to empower practitioners and user survivors.'

Care co-ordinators are the main point of access to direct payments. Care co-ordinators need to:

- assess needs for social care and facilitate person-centred planning and self assessments
- discuss direct payments with all mental health users and carers requiring social care
- provide accurate and relevant information about direct payments and the options available
- signpost people to direct payments support agencies as early as possible
- support decision-making and informed risk taking.

It is clear from this that the implementation of direct payments will rely on knowledgeable care co-ordinators committed to the principles of independent living and willing to explore a relatively new and possibly unknown direction.

Providing information to care co-ordinators about direct payments

Care co-ordinators' lack of knowledge about direct payments has been identified as a major obstacle to increasing access (Ridley & Jones, 2002; Spandler & Vick, 2004).

They need information about direct payments that places it in the context of other government initiatives in mental health. The information needs to include examples from mental health to which care co-ordinators can relate.

Training and practice development for care co-ordinators

While training on its own will not secure the implementation of direct payments, the sites we interviewed identified effective training for care co-ordinators and other staff as supporting implementation. Training needs to include:

- social model of disability, independent living philosophy and ‘recovery’
- what are direct payments, how can they be used and what are the benefits?
- eligibility and exclusions
- decision-making, supported decision-making and advance directives²
- person-centred assessment and self-assessment
- direct payments for carers
- the role of direct support services
- ensuring fair access and strategies to outreach to minority communities.

In one area, two levels of training are offered: an introduction and an in-depth training session including meeting support organisations, the direct payment finance team and the service user network. A video/DVD is also circulated to all teams, with

² An advance directive is a document prepared and agreed in advance with health and social care professionals setting out how the person would like to be treated and what they find helpful (and unhelpful) in the event of a mental health crisis

information about direct payments. Training such as this needs to be supported by development activity: for example, another area has bi-monthly meetings of all care co-ordinators who are working with people who use direct payments, to share ideas and support each other in addressing difficult issues.

‘Training on direct payments has to be mandatory and service users should deliver it. The most powerful way of changing culture is to educate the workforce.’

It was strongly suggested that training and development activity needs to guide care co-ordinators to revisit the values and principles (such as maximising independence and empowering clients) that may have brought them into this type of work. Direct payments for their clients provides a tangible way of translating good values and principles into good practice and may also motivate and sustain them in their work.

Practice development needs to include formal training and supervision, with worked examples of the successful use of direct payments by mental health service users. This should include sessions delivered by direct payment recipients, so staff can understand the impact of direct payments on people’s lives and how they can improve the choices available. Ideally this would form part of an induction to the organisation and/or the role of care co-ordinator. Attention needs to be paid to ongoing development. Regular opportunities to meet with service users, opportunities to work alongside a support service and access to peer support were all identified as valuable by the focus groups. In addition the merits of using technology to provide people with information and keep people up-to-date were also discussed.

Being clear that promoting access to direct payments is part of the role of care co-ordinators

Mental health services are provided by health and social services that are increasingly joining together to provide a single point of access to help and support. It is therefore just as likely that a care co-ordinator will be a community psychiatric nurse as a social worker. All members of staff will therefore need to understand that assessing needs and promoting access to direct payments is a key part of their role. Where staff are not used to commissioning services for individuals, additional thought will need to be given to how they make the transition in role. It is important to consider workload management, so that the role in relation to direct payments is not viewed either by the staff member or the organisation as an extra task. Workloads need to be reviewed and possibly adjusted to enable work in relation to direct payments to be undertaken thoroughly.

Integrating direct payment process with the Care Programme Approach

An aspect of ensuring direct payments is part of the role of care co-ordinators is ensuring that any paperwork is consistent with the requirements of the Care Programme Approach. An application process that involves too many forms and that is not consistent with Care Programme Approach documentation is likely to deter care co-ordinators. There was discussion about situations where the CPA has been poorly implemented and whether this might adversely affect the introduction of direct payments.

Organisational support

The approach and support from the organisation within which the care co-ordinator works will be important in whether direct payments remain a complicated and difficult issue. In some focus groups, a profound difference was evident in the expectations of senior managers and practitioners in relation to direct payments. Some senior managers had little understanding of the degree of support and leadership required if care co-ordinators are to offer their clients direct payments.

Addressing the obstacles identified requires a commitment to do so, and the imagination and creativity to explore what needs to happen, which may well involve new ways of working or organising. Statutory organisations generally do not reward initiative or creative thinking, and often encourage dependency and are risk-averse, both where service users are concerned and with their staff. Promoting and accessing direct payments for users requires care co-ordinators and others to be free to use their initiative, to take informed risks and to explore their anxieties and concerns. The importance of care co-ordinators being responsible for their own learning and development in relation to direct payments and organisations supporting this was therefore emphasised throughout this project.

Summary

In order to promote direct payments, care co-ordinators need:

- **information and training**
- **positive support and encouragement from their team leader**
- **organisational support and direction**
- **an easy process, that is part of the Care Programme Approach**
- **opportunities for regular review and reflection of their progress in implementing direct payments.**

Chapter Six

Leading for change: direct payments and managers

The importance of managers, at all levels, committed to direct payments and the principles of independent living was evident in this work and echoes previous research (Hasler & Stewart, 2004; Spandler & Vick, 2004).

‘Highly motivated leaders can shift mountains.

‘It is the job of the manager to be the “plunger” to unblock the blocks to change. Managers at all levels have to articulate the vision and the process.

‘Leadership must be at all levels, with partnership trusts creating a positive context for direct payments; ownership by the board who expect performance reports on direct payments and an emphasis on getting the right people involved.’

Leroy Lewis, South Essex NHS Partnership

Leadership that emphasises challenging the status quo to create new visions and possibilities is vital in supporting innovation and change. This means keeping the underpinning values in mind; helping others to describe those values and the vision; modelling the values through behaviour and interaction with service users, and stimulating the creative and emotional drive in others to learn about and implement direct payments.

Team leaders

Team leaders are essential in supporting creativity and leading care co-ordinators in overcoming the obstacles that have been identified. The role of the team leader is to keep team members on track, to sustain the focus on independent living and direct payments and to motivate staff to implement them. The team leader can facilitate the implementation of direct payments through:

- putting direct payments on the team agenda and identifying the action that needs to happen for direct payments to be routinely offered
- providing access to training and practice development opportunities in relation to direct payments
- building a positive working relationship between the team and the direct payments support service so that it is used appropriately
- focusing on disengaged groups and ensuring that the barriers to access are addressed for these groups – for example, people from black and minority ethnic communities
- using supervision to reflect on direct payments and the issues raised for the individual practitioner
- reflecting with the team on progress in relation to direct payments
- sharing the learning with other teams
- feeding key messages about issues in relation to direct payments to senior managers.

In the focus groups a spiral of success was described: seeing direct payments working in other areas and the difference they can make to people's lives was described as highly motivating.

Senior managers

'It is essential that senior managers not only understand that people with mental health problems are entitled to direct payments but are clear about implications of this for staff within their organisations.'

'There needs to be a champion; someone identified at senior operational level; someone who holds the vision, values, promotes partnership working and can take steps in the dark and drive change.'

Our interviews with the local sites confirmed that good leadership, support and enthusiasm from senior management in promoting direct payments and the concept of independent living, especially at the level of directors of social services, are vital to successful implementation. This support should include forward planning to promote and expand direct payments in the future, possibly by recommissioning services, and a commitment to increase take-up by under-represented groups (for example, black and minority ethnic service users).

The areas that senior managers need to pay attention to are:

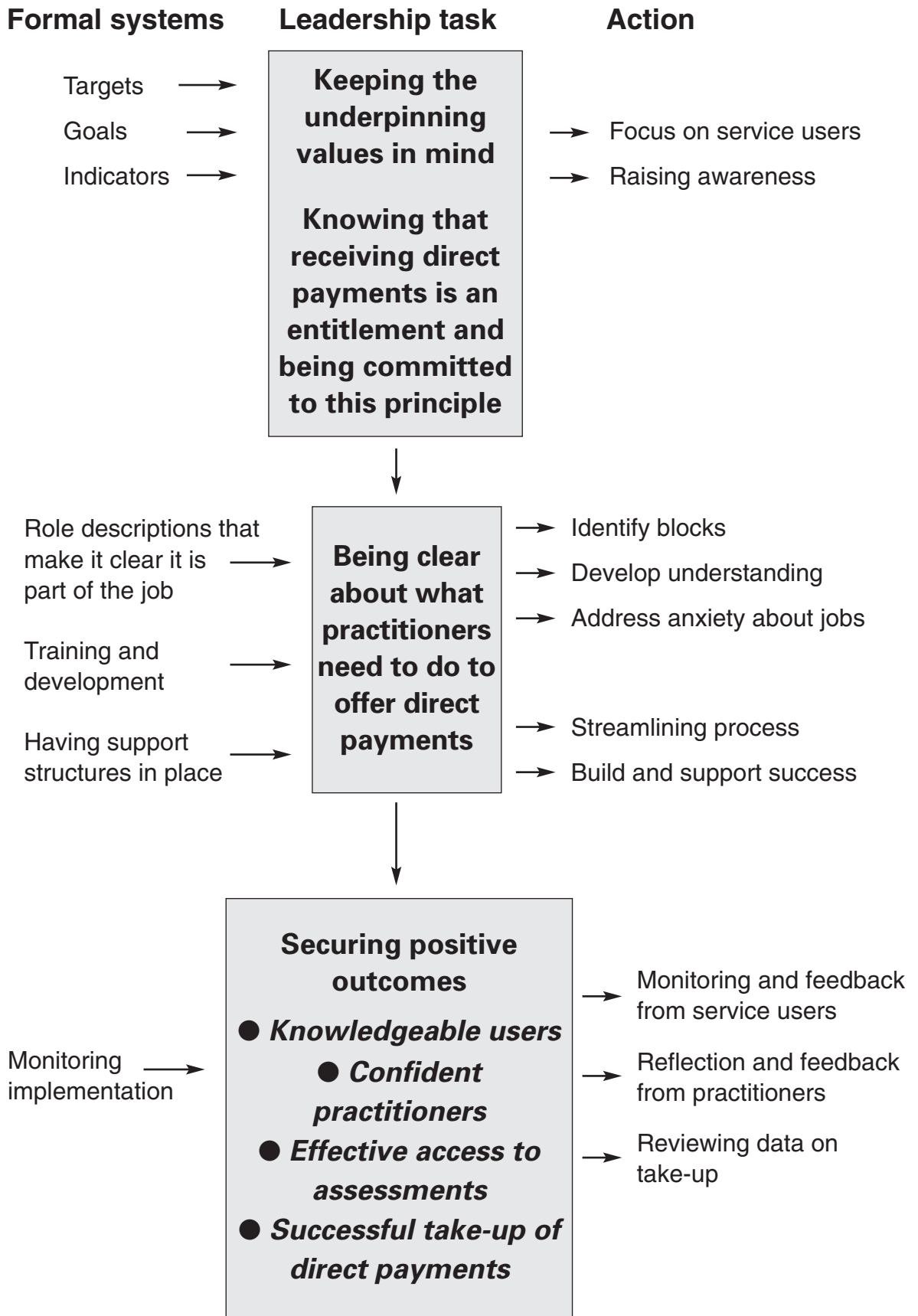
- providing a focused approach to the introduction of direct payments through the development of a multi-agency steering group to oversee implementation and integration into the role and tasks of the partner organisations
- identifying resources to support the implementation of direct payments
- developing leadership to support creativity, targeting team leaders and steering them to supervise and support their staff to implement direct payments

- ensuring effective training and practice development are available to care co-ordinators and other staff through the involvement of training departments when introducing direct payments
- reviewing, reshaping and recommissioning existing services, particularly day services
- shifting from block contracts to release money for direct payments and devolving responsibility for budgets to team leaders
- developing and introducing policies that support the introduction of direct payments (for example, developing CPA policy, processes and systems to ensure the incorporation of direct payments)
- finding opportunities to celebrate success
- building partnerships with other organisations to achieve the aim of social inclusion.

The leadership style required was described as transformational: ie. leadership that focuses on the process and people involved rather than merely on hitting the targets.

It was evident that people in the leadership role had to pay attention to many things at once: a theme that is developed in the next chapter but also illustrated in **Figure 2**.

Figure 2: Leading for change



Cultural change

'Direct payments must be seen as a real option rather than a matter of last resort and this requires cultural and other changes. The focus needs to be on the service user, a belief that they know best what their needs are and how to best improve their health and well-being.'

'We were successful in changing the culture because we used a lot of different approaches with different people – workforce, service users, carers, senior managers and frontline staff.'

One of the areas to which senior managers and team managers will need to pay attention is ensuring the organisation's culture supports the implementation of direct payments. At heart of this is the need to shift from a medical or biological model of viewing people as 'ill' to a social model that emphasises capacity and recovery. It was evident from the focus groups that there are a number of features of mental health service culture that will inhibit access to direct payments. These are:

- a focus on illness and diagnosis
- providing a crisis response and not planning with service users on all aspects of their lives
- preferring professionals' definition and assessment of needs to self-assessment
- lack of or limited understanding of the social model of disability and the independent living philosophy
- strong emphasis in mental health services on managing risk and avoiding new initiatives that may involve departures from accepted practice

- viewing service users as passive recipients of care and therefore not encouraging them to take responsibility and control of their support arrangements.

In order to achieve this, a number of areas need attention, some of which have been addressed in other parts of the report. These include:

- thinking differently and relating to service users as whole people with social and health support needs, who are capable of making choices and taking control
- involving direct payment recipients in providing training
- using success stories to inspire and motivate
- linking a care co-ordinator with a direct payment 'buddy'
- improving the knowledge base of professionals and their managers
- having a good direct payments support service to advise and work collaboratively with staff
- building partnerships with other organisations to work together to realise the goals of independence and inclusion.

With the move towards integrating health and social care, concerns were expressed about the loss of the social care perspective with its emphasis on rights. Mental health trusts need to ensure that the social model and underpinning values and beliefs are sustained and nurtured through the process of integration.

Many workers in statutory services have developed a scepticism and cynicism about central government initiatives and new directions. Direct payments represent a different type of policy (ie. bottom-up) and their introduction will be facilitated by staff being freed up to think, to use initiative and to take decisions. Statutory organisations experience themselves as

being slowly depleted of staff and resources, while the need for services increases. This can foster resistance to change and anxiety about losing jobs. This therefore points to the process of introducing direct payments being well managed so that, if services are being recommissioned, staff are well supported through this process.

Building partnerships

In his opening remarks at the New Directions conference, minister for community care Stephen Ladyman set the context of direct payments by describing the dreadful reality of social exclusion experienced by many people with mental distress. He emphasised the need for different organisations to work in partnership to address this exclusion.

One conference participant described partnership as:

'All partners need to come together to form a common goal using joined up thinking and direction from central government driven by mental health service user/survivors.'

The potential partners identified by participants at the national implementation event are:

- mental health service users
- local authorities
- Direct Payments Support Agency
- health and social care trusts
- voluntary sector, including providers and advocacy organisations
- carers
- informal support
- central government.

The aim of partnership is that all partners come together to deliver a common objective: that is, to enable service users to use direct payments as a matter of choice. This means that there is a shared vision of the possibilities of direct payments for people experiencing mental distress. The success of partnerships depends on partners going beyond limited views of each other to develop a real understanding of each other's contribution, grounded in shared action. Where partnerships can be difficult, one of the keys to making them work is to be clear about the roles and responsibilities and therefore different contributions that individual partners bring with them. The importance of clarifying the respective roles of care co-ordinators and the Direct Payments Support Agency was identified during the focus groups.

Positive partnerships are rarely developed quickly or easily and we heard from various participants of the importance of organisations learning together. As with any new development, the early days are a time of maximum uncertainty, creating the conditions for anxiety. Acknowledging this, sharing a commitment to work together to the same end and being prepared for the long haul this involves are necessary.

Adopting a strategic approach

The need to adopt a strategic approach, managing the introduction of direct payments and supporting staff, users and carers through the process of change has already been referred to. There is a danger that the introduction of direct payments will happen in an unplanned, ad hoc and opportunistic fashion, led by enthusiastic care co-ordinators.

Attention needs to be given to making the whole system work and fit together. Changes to practice will have to be

underpinned by changes in service commissioning: for example, moving away from block contracts to release money for direct payments. This has far reaching implications that will need to be explored at both a local and national level.

Structures and processes that facilitate this will need to be established. The development of a multi-agency steering group to spearhead the introduction of direct payments has been shown to have enormous value (Spandler & Vick, 2004). Most areas have existing multi-agency strategic groups, local implementation teams or partnership boards. The review and reshaping of mental health services to improve the experience of people with mental health problems are their *raison d'être*. The direct payment agenda therefore needs to form part of the work of these groups and the development of a steering group therefore needs to be formally linked.

Summary

For direct payments to be offered as a matter of routine managers need to:

- **be committed and able to articulate the principles of independent living, choice and control for mental health service users and carers**
- **be clear about what this means for staff in terms of their role and everyday practice**
- **provide clear direction and support creative problem-solving**
- **build partnerships with other organisations to support this aim**
- **reflect on the culture of the organisation and how it might be developed to support the principles of independent living**
- **ensure the process of introducing direct payments is well managed and not ad hoc**
- **be strategic and plan for reviewing, reshaping and recommissioning current service provision.**

Part Three

New directions: implementing direct payments in mental health

The discussions during the focus groups and at the national event made it clear that action at the same time across the different organisations is needed. This section therefore considers how to hit all these buttons at once. **Chapter 7** considers what each of the different organisations will need to do. **Chapter 8** describes the process that was used for the focus groups that, if replicated at a local level, may help the process of implementation get started. It also looks at how bringing together different organisations can lead to problem-solving and provides examples from the focus groups. The final chapter identifies action at a national level that is needed to support local implementation.

Chapter Seven

Hitting all the buttons at once

Implementing direct payments in the way that is intended will involve changes on a number of fronts. The factors that have been identified as supporting implementation in mental health are summarised in the box below. The work in the focus groups, at the implementation event and the interviews with local sites built on this to begin to identify what needed to happen within the different partner organisations to actively facilitate implementation. The intention in providing this detail is to provide a framework for local discussion and a basis for local action.

Factors supporting the implementation of direct payments

Within the context of the national pilot, factors identified as supporting the implementation of direct payments in mental health included:

- **effective leadership at strategic, operational and practitioner levels**
- **a steering group comprising key stakeholders to oversee implementation**
- **the provision of monies to pump prime the implementation process**
- **a proactive and sufficiently resourced direct payments support service that acts independently and intervenes early in all stages of the process**

- in the initial stages of implementation, the appointment of a specific mental health support worker within the direct payments support service
- the ability of local direct payments support workers (or independent living advisors) to be able to offer specific and sensitive support to people with mental health needs
- the assistance of user groups, advocacy projects and other organisations in promoting and supporting access to direct payments
- collaborative working between professionals involved with individuals
- at the local level, a willingness to be flexible about the ways in which direct payments could be used
- training for care co-ordinators, particularly the inclusion of positive working examples with which workers could associate and opportunity for workers to articulate their concerns
- the development of specific and streamlined procedures for processing direct payments in mental health.

(Spandler & Vick, 2004)

Action by local authorities

Local authorities have a duty to offer direct payments to those requiring social care and they are currently being performance managed on the numbers of people they have on direct payments. We identified the following steps as helpful for local authorities to take.

- 1 Establish a multi-agency steering group, formally linked to local implementation teams, partnership boards or other multi-agency strategic bodies, bringing together the different partners to identify how direct payments will be introduced in mental health.
- 2 Identify a project manager who acts as a 'champion' for direct payments and mental health and has specific responsibility for managing their introduction and working with local services, local support agencies and the local authority to address specific obstacles.
- 3 Develop the local authority policy to ensure it is relevant to mental health.

'It's not necessary to have a formal policy as they are often out of date. It is more important that the local authority is committed to the principle and accepts responsibility to deliver direct payments.'

While a formal policy on its own will not guarantee implementation, policies serve an important function of providing clarity and a framework for those working within the organisation. However, a recent survey of local authorities (Tobin & Vick, 2004) found that the majority of policies had been developed in relation to people with physical disabilities and that there was less encouragement and guidance for the take-up of direct payments by people with mental health problems. Practical guidance on how to operationalise direct payments for mental health staff is therefore needed and should include:

- principles underpinning direct payments
- eligibility and exclusions

- action to promote fair access
- what direct payments can be used for, with an emphasis on promoting widest application
- assessment and care planning, including integration with the Care Programme Approach
- access to advocacy and different types of support
- monitoring access
- monitoring of financial issues
- arrangements for review.

NIMHE is currently developing a guide to action that will support the development of local policies and practice.

- 4 Raise awareness both among senior staff and members within the local authority about the potential of direct payments for people experiencing mental distress.
- 5 Ensure access to the assessment of social care needs and that this function is not compromised by the integration of health and social care in mental health.
- 6 Develop information in different formats that specifically targets people with mental health problems and is appropriate and accessible to those from black and minority ethnic communities.
- 7 Commission direct payment support agencies that are equipped to support people experiencing mental distress to access and take-up a direct payment.
- 8 Review existing provision to improve the quality and to ensure it is focused on promoting social inclusion so that people have a real choice between direct payments and a directly provided service.

Action by primary care trusts

- 1 The introduction of direct payments needs to be set within the context of joint commissioning. The action identified under local authorities is therefore relevant here.
- 2 In partnership with others, particularly LITs/partnership boards, take the opportunity to develop and recommission existing provision, particularly day services.
- 3 Promote direct payments with general practitioners and other frontline staff so that people are being referred for an assessment of their social care needs and that practice staff understand their potential to meet these needs.

Action by local implementation teams/partnership boards etc.

- 1 Develop a strategic vision for increasing choice and control for people experiencing mental health problems.
- 2 Review and reshape existing provision.

Action by mental health trusts

- 1 Ensure that where health and social care are integrated access to an assessment of social care needs is not compromised by eligibility criteria for services.
- 2 Ensure access to training and development in direct payments for senior managers, team leaders and care co-ordinators.
- 3 Ensure that the CPA and the process for direct payments is integrated and paperwork minimised.
- 4 When integrating health and social care, ensure that a social model of mental ill health is actively sustained and nurtured.

- 5 Foster a shift in organisational and professional culture towards a philosophy of independent living.

Action by direct support agencies

- 1 Take steps as necessary to ensure that the support provided is relevant to people experiencing mental distress and addresses the issues that people are most anxious about.
- 2 Take specific action to ensure that support is responsive to the diverse black and minority ethnic communities.

Summary

- **Implementing direct payments involves change and development on a number of fronts.**
- **This means that action is required by different organisations, all working together to facilitate change.**
- **Local authorities and local implementation teams have a key role in setting the strategic direction.**
- **Mental health trusts need to ensure that existing processes and practice are developed to support the local strategy.**
- **Direct support agencies need to ensure they are both mental health sensitive and culturally competent.**

Chapter Eight

Getting going

Direct payments are a different type of policy, having been driven by disabled people. Their introduction needs to reflect this. In conducting this project we developed a process that started with service users learning more about direct payments and enabled them to participate with frontline staff in addressing the barriers. This process has had enormous value and is described in some detail here, as replicating it at a local level could provide a valuable starting point.

Training and use of service user facilitators

The first step we took was to identify and train service users as facilitators for the focus groups that we planned to hold. We recruited service users from black and minority ethnic communities. Ideally they would have also been direct payment recipients but, given the difficulties people from these communities have in accessing direct payments, this was not possible.

The training for the user facilitators was designed to provide the opportunity to learn about direct payments and to develop skills in group facilitation. The process for the training, which ran over the course of a day, is summarised over page. Witness sessions were a key element of the focus groups, allowing for discussion and thinking between the witness and the group. The witness was asked to talk about their own experience of direct payments, thereby prompting questions from people in the group so that the whole group talked and learned.

Each witness session had a facilitator who encouraged people to explore with the witness questions they had and who took on the job of noting down useful information on a flip chart, thereby freeing up the witness to think and engage fully with the group.

Developing facilitation skills for direct payment focus groups: outline of group learning process

1 Discussion on the aims of facilitation

- Encouraging participation and keeping boundaries
- Defining ground rules
- Keeping the focus on the task of the group
- Managing conflict in groups

2 Discussion on themes in group work

- Nature of groups
- Anxiety in groups
- Turn taking
- Timekeeping

3 Role of the facilitator

- The contribution user facilitators bring
- Being clear about the task
- Managing the group
- Recording the work of the group

4 Practising facilitation

- Timekeeping
- Allowing and encouraging participants to ask the witness questions
- Clarifying issues

5 Reflection on the work of the session

- Thoughts about the role of facilitator
- Aptitude or willingness to take it on
- Interest in and thoughts about direct payments.

The session had two good outcomes, as both the potential of direct payments and individuals' ability to facilitate were explored. Eight out of 11 service users involved in the training were keen to facilitate at the focus groups, and four of these people facilitated groups at the national event. Their presence made an essential contribution to these forums, as they:

- created a confidence in other users to speak and be heard
- worked hand-in-hand with workshop leaders and witnesses
- gave a strong message about the importance in the project of black and Asian users
- gave an opportunity to learn facilitation skills for use in the future.

The process of the focus groups

The focus groups served the purpose of:

- informing users and professionals about direct payments
- increasing confidence in the use of direct payments for mental health service users
- promoted the development of networks
- identified practical solutions and ways of overcoming barriers
- motivated people to take the lead at a local level.

The workshop is the 'tried and tested' method of most small group sessions in conferences and focus groups. However, workshops can create anxiety in users, skilled practitioners and others through an expectation to be the expert and convey information in formal ways that may not be their usual ways of communication and therefore difficult to do. In order to maximise the learning the focus groups therefore involved

different ways of giving information and sharing ideas: ie. witness sessions, workshops, use of video, use of personal experience and summaries of the research evidence.

'It has provided me with a great deal of information to take back to the mental health team. I hope to be able to share some of the enthusiasm and commitment I have experienced today.'

'Invigorating to share ideas and network with other boroughs/counties. I feel now I have a support network to give me confidence in my job.'

'I have renewed my enthusiasm being in the company of such a diverse group of dedicated people.'

The programme for the focus groups is in **Appendix 2**. The witness session that has been described earlier was a vital component. It created an opportunity for participants to ask questions about direct payments and to actively explore the implications for them. The witnesses included service users receiving direct payments, social services managers, direct payments support service staff, care co-ordinators and a NIMHE fellow for direct payments.

Questions that witnesses were asked and had been briefed to be prepared to answer included:

- What led you to investigate and pursue a direct payment for yourself or someone else?
- How did you go about claiming and using a direct payment for another or yourself?
- What lessons have you learned about direct payments and their importance to others or me?

This process will achieve more than a workshop aimed at

giving information. The next section identifies how practical issues were addressed during the focus groups.

Breaking logjams

The focus groups provided an opportunity to ‘break logjams’ and overcome obstacles that prevent access to direct payments. For example, one of the focus groups for African Caribbean survivors was poorly attended so the participants, drawn from different organisations, worked together to explore the underlying reasons for the poor attendance and then identified issues that they felt they could realistically tackle. They decided to address the lack of culturally appropriate information and have agreed to:

- produce a culturally specific leaflet and commission an artist to design it
- write an article for the Mellow Campaign newsletter that targets people from the African Caribbean community
- submit a bid for a direct payments development grant to the Department of Health to focus on support for the African Caribbean community to access direct payments.

During another focus group it emerged that not one mental health service user in the locality was receiving a direct payment. This was despite:

- there being an active direct payments support agency
- the manager responsible for direct payments saying that all social workers had received copies of the procedure on implementing direct payments
- 10,000 leaflets on direct payments having been distributed to GP surgeries and voluntary sector organisations

- the development of a database on frequently asked questions about direct payments
- the electronic library having the Department of Health booklet.

So what was missing? Why was no one on direct payments? This question was actively explored during the focus group. It emerged that:

- eight forms needed to be filled in on behalf of each person referred for direct payments
- only social workers had received information, had access to the database with additional information about direct payments and were equipped to support their clients
- the support agency was primarily an organisation for people with physical disabilities, and it was no coincidence that a good number of users with physical disabilities had been supported to choose to receive direct payments.

During the focus group the support agency seized the opportunity to offer the following support to mental health service users:

'If one of your clients says: "I might be interested in receiving a direct payment" you fill in a one-sided referral form and we will visit your client to visit to discuss and on that visit we will:

- *give them a booklet about the employment of personal assistants (PAs)*
- *help the user to find and select a PA*
- *advise about all aspects of employing a PA*
- *manage the account for paying the PA*
- *supervise and support the PA.'*

They also agreed that service users could self-refer to the agency and offered direct payments training to whole teams.

This is a powerful illustration of the progress that can be made to overcome the obstacles. If progress on implementing direct payments is to be made then this type of creative problem solving needs to flourish. Replicating this process of training facilitators and the focus group methodology outlined here has the potential to engage with service users and professionals directly about their concerns and to foster collaboration to address the barriers.

Summary

- **The process developed for this project can usefully be replicated at local level to bring together local stakeholders to plan for the introduction of direct payments.**
- **This process involved recruiting and training service users to run focus groups, which then provided an opportunity for staff and managers to identify what needs to be done.**
- **The process proved effective in facilitating local areas to identify ways of overcoming barriers to implementation.**

Chapter Nine

Future directions: matching national ambition with local reality

The ambition at a national level to implement direct payments as a means to independent living is evident. However it is also evident that this ambition is not being realised at a local level for people experiencing mental distress.

It is clear that the successful implementation of direct payments in mental health needs a change in approach to people using services and to the way in which mental health services are configured and provided. These have been outlined in this report. There are, however, issues that this project has identified that need to be addressed at a national level to support local implementation. These are as follows.

- 1 Review the definition of what direct payments can cover in mental health, and possibly more widely. The distinction between health and social care does not sit comfortably with the changing shape of mental health care or the ethos of enabling service users to specify what they want to use the payment for.
- 2 Provide guidance to ensure that access to an assessment of personal social care needs is not restricted and not confused with service eligibility. This has implications for a broad range of frontline staff, in health as well as social care, to encourage them to refer people for assessment. It also has implications for the location of the assessment function.

- 3 Ensure equity of access. It is evident that much more effort is needed to ensure that people with mental health issues from BME communities are gaining access to direct payments. The approach needs to reach out to communities and develop the capacity within these communities in relation to mental health and direct payments. National initiatives that serve to model this to local areas would be of benefit.
- 4 Provide guidance on reviewing and decommissioning services in the light of direct payments. The introduction of direct payments provides a significant opportunity to reshape daytime support, to provide pathways into employment and to enable people to develop lasting friendships. However the process needs to be well managed so that direct payments remain a 'brick in the wall of independent living' and not an end in itself. Therefore guidance for local authorities and mental health services is needed to support this process.

'It's taught me an awful lot, things that I haven't realised in my life before about myself, like not being assertive enough and not saying what I want. I think that's what led me to mental health problems. So in a way it gives you back control and you suddenly realise "Yeah, I have got a right to be in control of my life. I am not going to let other people tell me what to do and control my life".' Direct payment recipient

Summary

Action is needed at a national level to:

- **review the definition of what direct payments cover in mental health**
- **provide guidance to ensure equitable access to assessment for social care and to direct payments**
- **model ways of increasing the take up for BME communities and direct payments**
- **provide guidance on reviewing and recommissioning services.**



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Appendix One

Project advisory group

Professor Peter Beresford	Centre for Citizen Participation Brunel University
Sue Collins (chair)	Joseph Rowntree Foundation
Deborah Davidson	Health Services Management Centre Birmingham University
Sandra Griffiths	The Mellow Campaign
Pauline Heslop	Service user consultant
Janice Lowe	HASCAS
Katy Murray	Essex County Council
Karen Newbigging	HASCAS
Shahid Sardar	MIND

Appendix Two

Focus group format: life choices and money matters

- 10am Arrival, welcome and refreshments
- 10.30am An introduction to direct payments
- 11.15am Witness sessions
- Possible questions the witness will answer:
- What led me to investigate and pursue a direct payment for myself or someone else?
 - How did I go about claiming and using a direct payment for another or myself?
 - The lessons I have learnt about direct payments and their importance to others or me?
- Each witness session will have a facilitator who will encourage people to explore with the witness some of the questions
- 12.30pm Lunch
- Message board available for people to write comments, connect with each other, exchange phone numbers, email addresses etc.
 - There will also be people on hand to answer questions from individuals about direct payments
 - Equalities video showing
- 1.30pm Input from the local direct payments support agency
- 1.50pm Witness sessions – as above

- 3.00pm Round up – whole group resumes to reflect on the learning in work groups and to think about the next steps:
- what further information is needed?
 - whether they wish to attend the implementation event to be held in mid May
 - how to take direct payments forward for themselves or another
 - where do we want to be in six months' time?
- 3.30pm Tea and close

Appendix Three

National implementation event programme

New directions: direct payments and mental health

- 9am Registration
- 9.30am Julie Charles (chair), Chief executive, Equalities Chair's welcome & introduction to direct payments for people who use mental health services
- 9.50am Keynote speakers
Stephen Ladyman, Minister for Community Care
Peter Beresford
The vision. The potential of direct payments for mental health service users – matters of choice and control
- 10.30 am Helen Spandler & Tina Coldham
Implementing direct payments in mental health – an evaluation
- 11.20 am Coffee
- 12noon Workshops and witness sessions
- 1 Advocacy and the advocate and direct payments
Sarah Bescoby
 - 2 Direct payments and reaching out to black people Julie Charles & Sandra Griffiths

- 3 Implementing direct payments in mental health – an evaluation and a pilot site experience
Helen Spandler and Tina Coldham
 - 4 Direct payments – training, learning and cultural change Robin Murray-Neill
 - 5 Leadership to effect change and embed direct payments in the mind of an organisation
Leroy Lewis
 - 6 Support and relationship – the experience of a direct payment support service worker and a direct payment customer Jacquie Byron and Dorothy Redfern
 - 7 Care co-ordinators – direct payments in the context of concerns and constant organisational change and demand Nicola Vick
 - 8 Partnerships – local authorities and direct payment support services working hand in hand
Katy Murray
- 1pm Lunch, video playing, message board
- 2pm Leroy Lewis and Robin Murray-Neill
Making changes – getting direct payments on the agenda and in the mind
- 2.30pm Workshops and witness sessions repeated
- 3.30pm Plenary – putting it into action
- 4pm Close

Appendix Four

Information about direct payments

Handouts given out at all focus groups and the national event were:

- 1 Direct payments: an overview of the policy context
- 2 Examples of people using direct payments and their support arrangements. These have been included in the appropriate section in this report
- 3 Direct payments and black and minority ethnic service users
- 4 Uses of direct payments
- 5 Direct payments: factors supporting implementation
- 6 Frequently asked questions about direct payments
- 7 Copies of the Department of Health guide: A guide to receiving direct payments from your local council – a route to independent living

The first five are available on the HASCAS website at www.hascas.org.uk and the last two on the Department of Health website at www.doh.gov.uk/directpayments



Further reading

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Vasey S (2000) *The rough guide to managing personal assistants*. London: NCIL.

Equalities. *Breaking barriers video*. London: Equalities. Available from Equalities (see helpful organisations).



Helpful organisations

Diverse Minds
Granta House
15-19 Broadway
London E15 4BQ
diverse minds@mind.org.uk

Equalities – The National Council of Disabled People and
Carers from Black and Minority Ethnic Communities
Waltham Forest College
707 Forest Road
London E17 4JB
0208 527 3211
enquiries@equalitiesnational.org.uk

Health and Social Care Advisory Service
King's Fund
11-13 Cavendish Square
London W1G 0AN
0207 307 2892
www.hascas.org.uk

Mellow Campaign
Unit 210, Bow Technopole
153-159 Bow Road
London
E3 2ES
0208 709 5873
mellow.centre@elcmht.nhs.uk

National Centre for Independent Living
250 Kennington Lane
London SE11 5RD
0207 587 1663
www.ncil.org.uk

NIMHE Eastern
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