"DIRECT WHAT"

A Study of Direct Payments to Mental Health Service Users

SCOTTISH EXECUTIVE

"DIRECT WHAT" –
A STUDY OF DIRECT PAYMENTS TO
MENTAL HEALTH SERVICE USERS

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The views expressed in this report are those of the researchers and do not necessarily represent those of the Department or Scottish Ministers.

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EXECUTIVE SUMMARY

This research was about Direct Payments and explores the obstacles and support needed by mental health service users, including people with dementia, to receive them. A Direct Payment is money paid by the local authority directly to a disabled person so that they can arrange the community care support that best meets their individual needs. It potentially offers disabled people greater choice and control over their community care support. The payment can be used either to purchase support through agencies or to employ personal assistants.

Recent research (Witcher et al, 2000) had found limited implementation of Direct Payments across Scotland and no schemes that were making Direct Payments available to mental health service users. In commissioning further research, the Scottish Executive wished to examine the barriers to access to Direct Payments by mental health service users and explore ways that such access could be enhanced.

AIMS & METHODS

The main aim of this 6 month study was to explore what factors inhibit Direct Payments to mental health service users and the ways in which their provision could be encouraged. The research design was essentially qualitative, focusing on 3 local authority areas.

The research had three parts. The first was a telephone survey of all local authorities in Scotland to establish whether and how many mental health service users were receiving Direct Payments. The second explored the idea of Direct Payments with mental health service users, people with dementia, carers and professionals in the statutory and voluntary sectors. The third element was individual case studies. Interviews or focus groups were carried out with:

- 2 mental health service user groups
- 1 support group for younger people with dementia
- 1 carer group
- 3 senior social work managers
- 3 senior care managers or equivalent
- 3 organisations supporting people with mental health problems
- 3 organisations supporting people with dementia
- 2 independent advocacy organisations
- 9 individual mental health service users

KEY FINDINGS

Both generic and specialist home care services were supporting people with mental health problems and dementia at home. The voluntary sector played a major role in providing both support at home and during the day. Research participants highlighted a number of perceived shortfalls with existing community care services:

- home support did not always meet individual needs
- support provided during the day was mainly in traditional day centres and there was limited vocational or employment support
- there was a severe shortage of evening and weekend support
- there were few opportunities for users and carers to have breaks from each other
- there was a general lack of choice of type of service and between different providers

Extent of implementation of Direct Payments

The all-Scotland survey found disappointingly little progress in implementing Direct Payments over the past two years, and even less progress in terms of including mental health service users and people with dementia. Three new Direct Payment schemes were operating and there were 70 more recipients than in 1999. Only two Direct Payments recipients were mental health service users in two separate schemes. In addition, one third party scheme had four recipients who were mental health service users.

Eleven authorities (including one authority reporting both a pilot Direct Payments scheme and an indirect payments scheme) had third party or indirect payment schemes. Three local authorities still had no arrangements for making payments, and one had some arrangements that did not fit the definition of either direct or indirect payments.

Only one of the 1999 pilot schemes was now fully operational; the remainder were still pilot schemes 2 years later. Two third party schemes from the previous survey had converted to Direct Payment schemes. Ten out of 16 direct payment schemes planned to include mental health service users, while three had no plans to do so, and another three were undecided.

Awareness of Direct Payments was low even among social work department managers. Many participants were hearing about Direct Payments for the first time through this research. A common initial reaction to the research questions was "direct what?".

Potential advantages and disadvantages of Direct Payments

When Direct Payments were explained, users generally reacted positively to the idea. While some were hesitant because they did not yet know enough about it, others said, "sounds brilliant". The anticipated benefits were that Direct Payments might mean having greater say over their support, and being able to create the life they chose rather than having it decided for them.

Professionals in both the local authority and voluntary sector organisations identified many of these same benefits. However, they had a number of reservations that for them appeared to outweigh the positive benefits.

The major perceived disadvantage of Direct Payments was having to handle the payments and manage financial arrangements, particularly in view of fluctuating or worsening mental health difficulties. There was little or no awareness that it is possible to use Direct Payments to choose a support agency rather than to directly employ personal assistants. Mental health service users were anxious about becoming employers and dealing with the paperwork. Professionals and carers highlighted potential difficulties in the relationship with personal

assistants and for misspending payments. The risks of exploitation and fraud were also highlighted.

The negative views of Direct Payments expressed in this research are in marked contrast to research studies involving actual recipients of Direct Payments, which have found recipients identifying few, if any, disadvantages to Direct Payments (Witcher et al, 2000). This suggests that fears and anxieties are largely dissipated once people start using Direct Payments, or that ways can be found to overcome these barriers.

Main barriers to progress

Participants in this research identified five main barriers to promoting Direct Payments to mental health service users:

- issues around community care assessments;
- the lack of knowledge and understanding of Direct Payments;
- uncertainties about eligibility;
- anxieties about people's ability to manage;

and

- fears about the potential impact on local authority jobs and services.

Issues around community care assessments

Most of the focus group participants were not receiving any community care services and therefore felt they might be ineligible because they had not had a community care assessment. Health services and voluntary sector organisations were their main service providers. Secondly, both mental health service users and carers felt that community care assessments sometimes underestimated the needs of people with mental health problems as their needs were "not so obvious", especially on a good day, or the outcomes of community care assessments were "service-led".

Criticisms of community care assessments, including the perceived lack of a person-centred approach, highlighted a potential stumbling block for Direct Payments to mental health service users that would need to be addressed by broader community care policy and practice.

Lack of knowledge and understanding of Direct Payments

Not having information about Direct Payments was a fundamental barrier to progress. Some participants in the research were hearing about Direct Payments for the first time, including the professionals. While an obstacle in itself, the lack of information and knowledge was also a symptom of other barriers and concerns including the prejudicial and judgemental attitudes of some staff. Service users in this research felt that if professionals were not in favour of or did not feel confident about Direct Payments then information would not reach them and they would not be encouraged to apply. Taken together with misunderstandings about eligibility for Direct Payments, this could form a formidable barrier to access for mental health service users.

Uncertainties about eligibility

It was commonly assumed that many people with mental health problems or dementia would be ineligible under the requirement that recipients must be 'willing and able to manage a payment', even though the guidance also states that it is possible to receive as much assistance as necessary to manage Direct Payments. Local authority managers often assumed that mental health service users known to them would invariably be excluded under mental health legislation. There was limited knowledge of Direct Payments legislation or practice guidance.

Mental health service users were sceptical that Direct Payments would be treated as a priority by local authorities or that adequate resources would be allocated for Direct Payments.

Anxieties about people's ability to manage

A recurring concern was of giving any cash payments to people whose judgement may be impaired either temporarily or permanently. There was limited awareness of different options for assistance, such as circles of friends/support, attorneys, trusts, relatives, etc. Indeed, participants were generally unaware that recipients could receive as much support as necessary to manage Direct Payments.

Research participants identified the bureaucracy and paperwork required to monitor Direct Payments as a potential disadvantage.

Professionals and carers suggested mental health service users might have difficulties managing the employer:employee relationship - for example, when personal assistants needed to be more directive, and if needing to handle difficulties within the relationship. Professionals identified a potential for exploitation by relatives or employees.

Fears about potential impact on jobs and services

Professionals were concerned about the potential impact of Direct Payments on their own workload. They also argued that the balance of services would be changed for the worse if more people opted for Direct Payments, reducing the choices of those who did not have Direct Payments. Users suggested that increasing choice through Direct Payments would bring improvements to existing services, who would either have to "smarten up their act" or go out of business.

Supporting mental health service users to access Direct Payments

Participants suggested a number of concrete practical proposals for supporting mental health service users to access Direct Payments. One of the proposals was to develop more person-centred assessments as the necessary foundation for Direct Payments. Greater publicity and information was needed so that mental health service users had a better chance of making an informed decision whether they wanted, and could manage, a Direct Payment.

Amending legislation and guidance, in particular clarifying the criteria for eligibility, would support inclusion of mental health service users. There was a need for active support for Direct Payments provided by independent organisations. Support organisations would be a

source of peer support, advice and helping with ideas about how to use Direct Payments, and provide training and support in handling the money. Because of the nature of mental illness and dementia, there was a need for planning for contingencies and for the future. Finally, it was emphasised that procedures would need to be accessible and easy to understand, so that unnecessary bureaucracy and paperwork did not put mental health service users off Direct Payments.

Conclusions

To date, implementation of Direct Payments in Scotland has been disappointingly limited and most especially so for mental health service users. While Direct Payments potentially offers a way to facilitate more flexible service provision and to offer mental health service users greater choice and control over their support, this research identified a number of barriers which first need to be overcome. At the heart of getting it right for mental health service users was perceived to be person-centred assessment, proper support, advice and access to training, and Direct Payment schemes that were flexible to allow for different arrangements and for transitions. In other words, what was needed was community care assessment and support that were dynamic and person-centred.

CHAPTER 1: RESEARCH CONTEXT & BACKGROUND

INTRODUCTION

1.1   The Community Care (Direct Payments) Act, introduced in 1996, gave local authorities the power to offer people a cash payment instead of direct services. These cash payments were to purchase 'personal assistance', a term derived by disabled groups to define support that is personal, and assistance meaning help from another person with all the activities of day-to-day life (Hasler et al, 1999). The payments can be used to pay an agency to provide the support the individual wants, as well as to directly employ personal assistants.

1.2   The Scottish Office Guidance defined a Direct Payment as

> *"...a payment made by a local authority to an individual whom it has assessed as needing Community Care Services. The local authority makes the payment instead of arranging the services it has assessed the person as needing. The person then uses the payment to secure for himself or herself the relevant services." (Scottish Office, Social Work Services Group, 1997)*

(Annex 1 contains further details of the legislation and guidance)

1.3   A Direct Payment is paid directly <u>by</u> the local authority <u>to a disabled person</u> whom it has assessed as needing community care services and who is over 16 years or is a disabled parent who wishes to purchase services for their children. A key criterion is that the person must be 'willing and able' to manage a Direct Payment 'alone or with assistance'. An individual can receive as much support as he/she needs to manage this payment and, if directly employing personal assistants, to fulfil the duties of being an employer, but must remain in overall control.

1.4   In practice, Witcher et al (2000) found a great deal of confusion about what constitutes a Direct Payment. A number of local authorities have set up indirect payment schemes and disabled people can receive support for independent living from the Independent Living Fund. Given the confusion that can and does arise, it is worth defining indirect payment schemes and the Independent Living Fund at the outset.

Indirect payments

1.5   Other types of payment schemes offer similar benefits in terms of independent living to disabled people but do <u>not offer direct control of the payment</u>. These indirect payments are sometimes referred to as 'third party', or 'quasi' payment schemes. Under such schemes the local authority does NOT make payments directly to the disabled person but through another agency, who may or may not support the person in using the money. A number of indirect payment schemes were set up because it used to be illegal (in England and Wales) to make cash payments direct to disabled people.

The Independent Living Fund

1.6   The Independent Living Fund was set up by the Government in 1988 to enable disabled people to employ their own personal assistants. The original criterion was that recipients must be in receipt of Attendance Allowance. In 1993, two new funds were created, the Independent Living (Extension) Fund, which continues payments to those who had been receiving ILF since 1988, and a new Independent Living (1993) Fund. The criteria for the 1993 Fund involve assessment by the social work department and to be eligible the following criteria must be met:

- person must be aged 16-65 years
- receive the highest care component of DLA
- be able to live in the community for at least 6 months
- person must live alone or with people who are unable to fully meet the person's needs
- have savings of less than £8,000 (except those over 60 years who can have up to £12,000)
- have income that is insufficient to cover the cost of care needed
- be assessed as at risk of needing residential care
- the local authority must be willing to provide at least £200 worth of services or Direct Payments per week
- the joint local authority and ILF (1993) Fund must not exceed £625 per week when the care package is set up (maximum from ILF is £375)

1.7   Individuals who are receiving ILF monies can also be in receipt of a Direct Payment from a local authority.

IMPLEMENTATION OF DIRECT PAYMENTS

1.8   In looking at Direct Payments for people with learning disabilities in Scotland, Values into Action (VIA) found that despite offering 'exciting opportunities' and 'considerable flexibility and value to those who felt let down by existing service provision', Direct Payments presented fundamental challenges (Henderson & Bewley, 2000, p27). The main challenges were identifying resources; a fear of stimulating a demand that could not be met; and concern about the implications for local authority services and staff.

1.9   An earlier study commissioned by the Central Research Unit of the Scottish Executive found that not only was there limited evidence of implementation of Direct Payments in Scotland, but the future of many schemes was precarious (Witcher et al, 2000). Many were pilot schemes and few local authorities that did not have a Direct Payments scheme had any plans to develop one. The notion of 'independent living', implying more choice and control to live the life one chooses, requires a major shift in the way community care services are assessed and delivered. Indeed, Witcher et al (2000) suggested that major cultural change is required before Direct Payments can be implemented fully.

1.10   Echoing the findings of the VIA research, Witcher et al found widespread acknowledgment of the underlying principles of Direct Payments, while its development was fraught by concerns about a lack of funding to operate schemes; perceived threats to the funding or future of local authority services; anxiety about the perceived implications for social workers' role; anxiety about people's ability to manage payments; and a lack of adequate support for recipients. Witcher et al (2000) concluded, however, that 'with the right

approach and support infrastructure…barriers can be dismantled or, better still, prevented from arising altogether'.

1.11   VIA's long standing work on Direct Payments demonstrates that 'a clear context of choice, control and supported decision-making are essential to make Direct Payments a success' (see for example, Henderson & Bewley, 2000; Holman & Bewley, 1999; Bewley, 1997). This is supported by Hasler et al's guidance to local authorities on implementing and managing Direct Payments. Cash payments instead of direct services provide a concrete opportunity to turn the rhetoric of community care into reality, and to practice the principles of person-centred support so often espoused in Joint Community Care Plans.

MENTAL HEALTH SERVICE USERS

1.12   The Community Care (Direct Payments) Act, 1996 was intended to cover all 'disabled people' (other than specified exemptions regarding mental health or criminal justice measures such as supervision orders), which, as Hasler et al (1999) point out, means restrictions by impairment group are unlawful under the terms of the Disability Discrimination Act 1995. Despite this, research has consistently found that Direct Payment schemes are largely targeted at people with physical impairments, and rarely, if at all, at people with mental health problems and other disabilities. Demonstrating ability to 'manage a payment alone or with support' and establishing that the person is 'willing to accept a Direct Payment' were raised as concerns in relation to mental health service users, including older people with dementia, in the previous study (Witcher et al, 2000). The acceptance of the responsibilities that accompany being an employer of personal assistants or equivalent may be particularly problematic for mental health service users depending on the difficulties the person faces, the relationship required and the availability of the support needed.

1.13   In exploring the omission of mental health service users from current schemes, it is necessary first to acknowledge that the term 'mental health problems' is a contested one. It is often used to cover a wide range of conditions as diverse as depression, anxiety, phobias, eating disorders, schizophrenia and also dementia. The eligibility of mental health service users for Direct Payments will need to be decided on an individual basis according to the specific circumstances and nature of mental health problems.   This study has been commissioned at a time of major change both in mental health legislation and in the understanding of mental health problems, in particular the notion of 'incapacity'.

1.14   The recent Adults with Incapacity (Scotland) Act 2000 incorporates in law for the first time the notion that 'incapacity' is not a fixed state, recognising rather that a person can become incapacitated through illness or cognitive difficulties at any period in their lives, and that this may be a temporary state. The individual's right to be self-determining is a key principle and the Act underlines the central importance of advocacy in ensuring the individual's wishes are respected. Direct Payments Regulations will be amended to cover attorneys and guardians when the relevant provisions of the Adults with Incapacity Act are commenced (details of Direct Payments legislation and guidance are included at Annex 1). This has a particular bearing on the consideration of Direct Payments for older people with dementia.

1.15   The vast majority of people with mental health problems live in the community, but relatively few receive community care services. The 'Scottish Community Care Statistics

1999', recently published by the Scottish Executive, highlight the domination of hospital based provision in mental health. Day care attendance has increased since 1980 and there has been a slight increase (2.5%) in the number of people receiving home care between 1998 and 1999. A total of 2,216 home care clients were categorised as having mental health problems, with a majority (57%) aged between 18 and 64 years.

1.16   The provision of domiciliary services is generally agreed to be a significant element of community care provision, enabling many people, predominantly older people, to remain in their own homes where this is their choice. A programme of research commissioned by the Scottish Executive provides important contextual information on the nature of domiciliary or home care provision across Scotland (Curtice et al, 1998). Although the statutory sector is the major provider of domiciliary care overall (76% of total hours provided were in this sector), the voluntary sector is more likely to provide services for people with mental health problems and dementia than either the local authority or private sectors.

1.17   Curtice et al (1998) found that many voluntary sector agencies were not providing either 'personal' or 'nursing care'. The nature of the home care service received by mental health service users has not been explored in any detail. Further, the traditional boundary drawn between domestic and 'personal care' is believed to over simplify the nature of provision to mental health service users. For example, overtly domestic tasks such as shopping can provide valuable opportunities for enhancing social skills and support, and increasing an individual's independent living skills.

ELIGIBILITY CRITERIA FOR DIRECT PAYMENTS

1.18   One of the criteria for Direct Payments is deciding whether the person is willing to accept a payment instead of a service such as domiciliary services, and another is the ability to manage the payment on his/her own or with support. Clearly, in the face of poor promotion of Direct Payments with mental health service users and the complexities of mental illness, a critical issue must be one of providing the necessary support to enable people to make informed decisions, both in terms of willingness and ability to manage a payment. As Hasler et al (1999, p39) argue, 'being "willing" or "able" are not fixed states, they are determined by the amount of support (information, assistance etc) available to the individual'.

1.19   Handling money can cause problems for individuals with dementia and their carers and as the illness progresses the person often becomes less able to cope with money. However, agencies offering dementia care and advice such as Alzheimer Scotland advocate making plans while the person with dementia can understand and discuss matters. This would suggest some scope for involving people with dementia in considering cash payments instead of services at the earliest stages of dementia.

1.20   For those with little experience of exercising choice and control in their lives, thought needs to be given to supporting them in decision-making. The role of someone independent like an advocate supporting the individual to have broader choices and establishing a willingness to take on a Direct Payment in the first instance will be crucial, particularly where there is a difference between what the user wants and what the carer wants. It should be recognised, however, that while an independent advocate would be a very useful participant

if the person can access one, having an advocate should not be a determining factor in whether or not Direct Payments are offered.

1.21   Research that has asked older people their views on Direct Payments has found that, initially at least, older people may be unsure about the suitability of this option (Payne et al, 1998).   However, the authors caution against interpreting uncertainty as an indication of unsuitability of this option and argue that efforts should be made to find out what it is about the idea that causes concern and to identify the practical support needed to address such concerns.

1.22   Although a person can have as much or as little assistance with managing a payment as he/she wants, the 'ability to manage' was raised as an issue for mental health service users in the recent study of Direct Payments by Witcher et al (2000).   Assistance can come from a number of sources including advocates; supporters as in a 'circle of support/friends'; someone appointed to take on the employer role on behalf of the user; a trusted Personal Assistant; friends; and also family members, bearing in mind there may be conflicts between the individual and his/her family.   Individual assessors will still be required to make a judgement on the 'appropriateness' of the support arrangements.   Flexibility needs to be built into the system for people whose impairments include continuous or frequent illness, who may well not be in a position to manage a Direct Payment all the time.

SUMMARY

1.23   In summary, previous Direct Payments research studies have identified a number of issues that this study sought to investigate.   Central to this research have been the need to explore the 'suitability' of the Direct Payments option for people with mental health problems or dementia; to establish what it is about the idea that causes concern for potential recipients, carers and professionals; and to identify the practical support needed to address such concerns.   The degree of flexibility required of schemes, and the nature and level of support needed by mental health service users, both initially to establish willingness to accept a payment as well as to manage the responsibilities of an employer, have been explored.

STRUCTURE OF THE REPORT

1.24   In Chapter 2, we provide an overview of the study's aims and objectives and the research methods used.   The main findings of the research are reported in Chapters 3 to 6. Chapter 3 examines the community care services received by participants in this study and the perceived shortfalls in services.   Chapter 4 explores participants' views of the option of Direct Payments to mental health services users and the perceived advantages and disadvantages.   Chapter 5 looks more closely at the barriers to implementing Direct Payments to mental health service users, and Chapter 6 identifies the support mechanisms that will need to be in place for them to access Direct Payments and ideas for promoting Direct Payments. Finally, Chapter 7 draws out the main conclusions from the study and discusses the implications for policy and practice.

CHAPTER 2: STUDY AIMS AND METHODS

INTRODUCTION

2.1   The Scottish Executive commissioned Scottish Health Feedback to carry out a study of how Direct Payments could be facilitated to mental health service users. The study built upon recent research examining the implementation of Direct Payments across Scotland by Witcher et al (2000), which found only 13 out of 32 local authorities operating a Direct Payments scheme. None of these schemes were making Direct Payments to users of mental health services. Most schemes did not have a clear recruitment strategy and little thought had been given to how take-up among mental health service users could be promoted.   In commissioning further research, the Scottish Executive wished to explore ways that Direct Payments can be facilitated to this group.

2.2   The research was completed within 6 months between March and August 2001.

AIMS

2.3   The main aim of the research was to identify factors inhibiting Direct Payments to people with mental health problems including dementia, and to explore ways in which their provision could be encouraged.

2.4   The Scottish Executive identified six key objectives for the research:

1. To explore with a sample of local authorities that are operating or piloting a Direct Payments scheme, the barriers that currently prevent users of mental health services from receiving Direct Payments;

2. To explore mental health service users' and their carers' perceptions of Direct Payments;

3. To identify the nature of home based services currently received by people with mental health problems and consider how Direct Payments might impact on service provision;

4. To explore the views on Direct Payments of organisations that provide support to people with mental health problems;

5. To identify ways in which Direct Payments to mental health service users can be encouraged and facilitated;

6. To identify any mechanisms that require to be in place to enable people with mental health problems to effectively manage Direct Payments

METHODS

2.5   As an exploratory study seeking to examine different perspectives on a hypothetical situation, i.e. whether Direct Payments would be suitable for mental health service users and the practical support needed, the design adopted was largely qualitative. Intensive interviews and focus groups were the main methods used.

2.6   The study was carried out in three Local Authority areas chosen in consultation with the Scottish Executive to represent the geographical spread and different circumstances and including one area operating a third party or indirect payments scheme. There were two main parts to the study:

> *Part 1* was a broad exploration of the nature of home-based services received by people with mental health problems, the perceived suitability of Direct Payments and the practical support that might be required to facilitate payments to mental health service users.
>
> The informants in Part 1 were service users, carers of people with mental health problems or dementia, managers/coordinators of voluntary organisations giving support to people with mental health problems and dementia, and relevant senior Social Work managers.
>
> *Part 2* focused down through a number of case studies to examine individual perspectives of a sample of mental health service users who were current recipients of community care services, carers and social workers/care managers.

2.7   Additionally, the Central Research Unit (CRU) asked Scottish Health Feedback to carry out a telephone survey of all 32 Local Authorities in Scotland to update selected items of information obtained during the course of previous research carried out for CRU namely:

- whether the Local Authority administered a Direct Payments scheme
- if so, whether there were any mental health service users in the scheme.

2.8   This Local Authority survey was carried out during March 2001 before the start of the main research, so as to inform the choice of three areas to be studied.

2.9   Within the limitations of the time (6 months) and resources for the study, Scottish Health Feedback sought to work in partnership with disabled people by:

➢ involving experts from the Scottish Personal Assistance Employers Network (SPAEN) as advisors generally to the research and on specific elements including the focus groups and case studies;
➢ employing a disabled co-facilitator to explain about Direct Payments in focus groups;
➢ setting up a Research Advisory Group of individual mental health service users, representatives of user and carer organisations, and representatives of relevant national voluntary organisations in the fields of mental health, dementia and advocacy;
➢ consulting with user and carer organisations in drafting the original research proposal.

The All-Scotland Telephone Survey

2.10   Information from the original survey was obtained from the previous research consultants regarding details of the contact person in each local authority (although some of these had changed, most were still relevant). A letter was sent to the relevant person outlining the nature of the updating information required, giving them a description of the new study and definitions of a Direct Payment Scheme and a Third Party Scheme. A short structured questionnaire was devised which asked if the local authority currently had a Direct Payments Scheme, a pilot scheme or a Third Party Scheme. It also asked about the number of recipients, how many were people with mental health problems, whether they had ever had any recipients who were mental health service users and whether there were plans to include mental health service users in the future.

2.11   The telephone survey was carried out over approximately 3 weeks during March-April 2001, with delays arising as a result of one local authority seeking approval for this element from its ethical committee. Records for all 32 Local Authorities were entered onto an Approach database and collated. The findings (see Chapter 3) were presented as an interim report to the Scottish Executive in May 2001.

Focus groups

2.12   Four focus groups were arranged for the end of May and beginning of June 2001. Groups discussed two main topics: first, direct experiences of paid help to support independent living; and second, the idea of Direct Payments and the support that people with mental health problems or dementia would need to access them. (Copies of the focus group topic guides are included at Annex 3).

2.13   Two focus groups comprised mental health service users, one comprised carers of people with mental health problems or dementia, and one was an existing dementia support group. The groups were arranged in four local authority areas, one outside the study areas. In total 23 people took part in the focus groups: 13 were users of mental health services, 8 were people with mild dementia and 2 were carers (one of a person with dementia). Although every effort was made to involve carers in a focus group by arranging it through a local voluntary organisation that worked closely with carers, and at a time and place convenient for local carers, several individual carers who had agreed to participate were unable to attend on the day. Overall, almost equal numbers of men and women took part: 11 men and 12 women.

2.14   Scottish Health Feedback worked in partnership with known local user and carer groups and voluntary organisations including Scottish Association for Mental Health, a local Association for Mental Health and Alzheimer Scotland Action on Dementia projects in each area to help approach and recruit people into the groups, and to make the necessary practical arrangements such as booking venues.

Interviews with local authority and voluntary sector staff

2.15   Interviews were carried out with a senior manager for mental health services and/or dementia and one senior care manager/social worker in each of the three local authorities.

These interviews focused on the nature and level of community care support received by people with mental health problems or dementia and the impact Direct Payments might have on these services, the perceived advantages and disadvantages of Direct Payments to this group and what support might be needed to ensure people with mental health problems or dementia were able to use Direct Payments. (Copies of the interview guides are included at Annex 3).

2.16   In summary 6 interviews were carried out with the following local authority staff:

1 Senior Manager for Mental Health Services
2 Senior Managers for Mental Health & Addictions
1 Senior Manager for Older People's Services
2 Community Mental Health Team (CMHT) Managers

2.17   Interviews were held with managers/coordinators in voluntary organisations that provided support to people with mental health problems or dementia and independent advocacy organisations. In summary, 8 interviews were carried out with staff in the following organisations:

2 local Scottish Association for Mental Health projects
2 local Alzheimer Scotland Action on Dementia projects
1 Richmond Fellowship Scotland project
2 Independent Advocacy organisations
1 Community Development Trust

Case studies

2.18   Case studies of individual mental health service users in each of the three local authority study areas were carried out. (Copies of the interview schedules used are included at Annex 3). In addition, a pilot interview was carried out with an individual with dementia and his carer in a fourth local authority. During July and August 2001, individual interviews were carried out with seven people with mental health problems and two people with dementia, two carers/relatives, and seven care managers and two support workers. This is summarised in the table below. One of these case studies was an interview with a couple, where one spouse was a person with dementia and the other was a relative/carer. Alzheimer Scotland had advised the couple of the research because they had previously expressed an interest in finding out more about Direct Payments. We have changed individuals' real names in the report to preserve their anonymity.

Table 1: Summary of case study interviews carried out in the three areas

Interviewee Category	Authority A	Authority B	Authority C	TOTAL
MENTAL HEALTH SERVICE USERS				
• Approached	4	15	9	28
• Agreed to participate	3	3	2	8*
• Interviewed	2	3	2	7
• Refused to participate	2	12	7	21
PEOPLE WITH DEMENTIA				
• Approached	0	0	1	1
• Agreed to participate	0	0	1	1
• Interviewed	0	0	1	2**
• Refused to participate	0	0	0	0
Care managers interviewed	1	3	3	7
Support workers interviewed	2	0	0	2
Carers/relatives interviewed	1	0	0	2**
TOTAL NUMBER OF INTERVIEWEES	6	6	6	20**

* One person agreed to participate then declined to be interviewed on 3 occasions.
** Includes a pilot interview with an individual with dementia and his spouse carer carried out in a fourth area

2.19	The number of case studies achieved was less than originally planned (12 case studies), and for only one was the planned set of three interviews with the service user, carer/relative, and care manager achieved. In seven case studies, information was obtained from the service user and care manager only. The sampling frame for selecting people to be approached was drawn from lists held by the social work departments of mental health service users including those with mild dementia, who had been assessed and were receiving community care support, either support at home or during the day.

2.20	Potential interviewees were chosen using random methods. However, an attempt was made to ensure a mixture of ages, gender, ethnic background, and to ensure that at least three were individuals with mild dementia. Care managers/social workers made the initial approach and obtained consent/refusals. Individuals were given a letter from the researchers, a consent form, a leaflet explaining the research, and background information on Direct Payments from the Scottish Executive.

2.21	Across the three areas, 21 mental health service users approached by care managers/social workers refused to take part in the research, and only one of the three authorities was able to identify an individual with mild dementia. In summary, 20 interviews were carried out with the following people:

- 2 individuals with dementia
- 7 mental health service users
- 2 carers (one was a joint interview with a service user)

- 9 care managers or key/support workers

2.22   Reportedly some mental health service users had refused because they were currently well and did not want to be labelled by the research as service users. Conversely, people who were unwell could neither cope with a research interview nor with the notion of managing a Direct Payment. Local authority managers' view was that for some, the research would be "another mountain to climb" when life was difficult enough. As the majority of care managers and support workers had little or no knowledge of Direct Payments, this in itself may have influenced whether, and how, they approached service users.

2.23   Other professionals suggested that some mental health service users were unable to differentiate between research exploring issues and views in a hypothetical sense, and actually being offered Direct Payments, and were anxious in case taking part changed their current support arrangements. A major challenge in undertaking these interviews was that Direct Payments were entirely outwith the majority of people's experience.

2.24   Travel expenses were paid to participants in focus groups and interviews and a small fee in recognition of their involvement and contribution. User and carer organisations also received a donation.

DATA ANALYSIS

2.25   With permission, focus groups and interviews with individuals with mental health problems or dementia were tape-recorded at the time and transcribed in full. Other interviews were hand-written and notes typed for analysis.

2.26   Common themes and emerging patterns across the data were identified and the data coded and analysed using N5, a specialised computer software package for analysing qualitative data. Initial themes were discussed with the Research Advisory Group in July 2001.

CHAPTER 3: COMMUNITY CARE SERVICE LANDSCAPE

INTRODUCTION

3.1   This chapter presents the main findings about community care services received by the people participating in the study. It draws upon data from the focus groups exploring what service users and carers said about community care services, and the structured interviews with local authority and voluntary sector managers/coordinators about the range of services offered in the three study areas. As the people with dementia involved in the study were at the early stages of dementia, the kinds of services supporting people with severe dementia may not be represented below.

3.2   It first presents a brief pen picture of each local authority area and the type of community care provision available to people with mental health problems and dementia, then explores more broadly the nature of services provided by the statutory and voluntary sectors to this group; individuals' experiences of community care services; and finally, highlights the perceived service shortfalls according to different participants.

PEN PICTURES OF STUDY AREAS

3.3   **Authority A** was an urban area, which had a pilot Direct Payments scheme with five recipients, one of whom was a mental health service user. Procedures around Direct Payments were evolving and a number of independent living initiatives were being brought together under new proposals for self-directed services. In this area, a local association for mental health was a "major provider" of home support and day services including helping people to access community facilities. The generic home care service was the main local authority provision, and in addition, some people received support from community support workers employed by the Community Mental Health Team (CMHT). Around 150 people were on the Care Programme Approach (CPA). The Social Work Department ran a day centre focusing on employment for people with all types of disabilities. An intensive home care scheme jointly with the local NHS Trust provided more intensive home care support predominantly to older people with mental health problems.

3.4   **Authority B** was a rural area with a wide geographical spread and major transport problems. Authority B also had a pilot Direct Payments scheme with 10 recipients, but none were mental health service users. The Direct Payments scheme was managed through an independent voluntary agency commissioned by the local authority to operate the scheme, and this agency had strong links with a local mental health user and carer network. The main local authority services were generic home care services with specialist dementia home care assistants, and day care centres for older people. Day care was said to be under-developed in this area for people with mental health problems, although there was one day centre run by the Social Work Department, and day hospitals. Additional home care was provided by private and voluntary agencies such as Crossroads Plus and Scottish Association for Mental Health.

3.5   **Authority C** was a mixed area geographically, which had a third party scheme with 50 recipients, four of whom were mental health service users. In addition to generic home care, this area had 7 specialist home support workers attached to the CMHT. These support

workers worked both on a one-to-one basis and organised group day care programmes. The CMHT also employed a specialist alcohol worker, housing officer and welfare rights officer and was developing a core unit for people with Korsakoff's psychosis. The voluntary sector provided support workers to people with mental health problems living in their own tenancies and in supported accommodation. One voluntary agency provided vocational employment opportunities, and another had recently set up a 'Clubhouse' centre, which was described as follows:

> *"A model that has been extensively researched in the United States and Canada. It's a form of support run by and for the users. The clubhouse ethos is that there are no secret or unshared places so no staff offices. There's no area members are not allowed into. Its about self-help, self-support with workers on tap." (local authority manager)*

Two specialist voluntary sector agencies were supporting people with dementia at home and through the provision of day care seven days a week.

GENERIC AND SPECIALIST HOME SUPPORT

3.6   In all study areas, it would appear that people with less severe mental health problems were able to access generic home care services, while there was the "next tier of support services dedicated and specific to mental health" to meet the needs of people with 'severe and enduring' mental health problems. Generic home care services were provided in the main by local authorities but in Authority B private agencies were providing around a quarter of such services. Specialist home care support for people with mental health problems or dementia on the other hand was predominantly, though not exclusively, provided by voluntary agencies.

3.7   In Authority C, this 'next tier of support' was translated into support from seven specialist home support workers as part of the multi-disciplinary Community Mental Health Team (CMHT). The same CMHT also had dedicated welfare rights and housing professionals. In Authority B, 'intensive home care services', provided jointly with the NHS, ensured that older people with high support needs could remain in their own homes and some people with mental health problems accessed the service. Authority A had specialist dementia home care assistants attached to its generic home care provision.

3.8   In whatever form, having specialist workers was felt by local authority managers to be the best way of ensuring support workers who were "sensitive to the needs of people with mental health problems or dementia". One of the key roles of the specialist workers employed within the CMHT was perceived by professionals as providing "an early warning system for the rest of the team".

3.9   In general, supported accommodation for people with mental health problems in all areas was provided through the voluntary sector.

3.10   While the professionals interviewed could identify a range of local authority and voluntary services available to support people during the day, evening and at weekends, the reality for many users in this study was that they did not receive any community care services at all. This situation had made one individual philosophical:

"I seem to cope with most things, but a lot of my coping strategy is just to say 'to hell with it, you know', fair enough the windows need a wash but there's always tomorrow." (mental health service user)

3.11   Mental health service users often commented on their experiences with the psychiatric services, particularly about the help they received from community psychiatric nurses (CPNs) and in particular their dissatisfaction with the relationship with psychiatrists. As this was outside the scope of the research, it has not been reported in any detail in this report. .

DAYTIME PROVISION

3.12   For people with mental health problems or dementia, daytime provision of some description was provided in all study areas through both the statutory and voluntary sectors, although as one manager in Authority B reflected:

"There's no proper infrastructure of day services, which is something Social Work is embarrassed about".

3.13   Day centres or drop-in facilities were the mainstay and were invariably provided by voluntary agencies, with local authorities as the minor player. Several users spoke about attending a Resource Centre, which allowed them "to get out and socialise, have lunch" for between one and five days a week. Day hospitals managed by the local NHS Trust also offered support during the day to some of the participants.

3.14   In addition, specialist support workers from statutory and voluntary agencies had begun to support some individuals to use ordinary community facilities during the day. In Authority C, a specialist voluntary agency organised day care support within an ordinary house for up to four people at a time. Others were implementing innovative ideas such as the Clubhouse model mentioned earlier. Authority A ran a day centre focusing on vocational employment open to people with any disability, and in Authority C, a voluntary organisation provided limited employment opportunities. While these alternative forms of daytime provision certainly did exist, they were only meeting the needs of the minority.

ADVOCACY & SELF ADVOCACY

3.15   Support groups managed both by mental health service users themselves and by specialist voluntary organisations were an important aspect of community and social support for many participants. An Alzheimer Scotland support group organised regular meetings at a day centre and arranged social events, and these were valued by the participants:

"We've been to several concerts and it's been very useful. I certainly enjoyed them and the group it's very positive. I can just speak for myself . You can't always put why it's positive but it is, it seems to me anyway. I've been to several things that I wouldn't have by myself." (person with dementia)

3.16   Authority B provided the financial support to an independent organisation to deliver its Direct Payments scheme and this group worked closely with a mental health self-advocacy group. The user group operated drop-in facilities across the area and other services such as a

user helpline. Independent advocacy organisations were working with individuals with mental health problems and dementia providing practical and emotional support, although these were not mentioned by any of the users in the study.

SOCIAL WORKERS

3.17   One of the key roles of social workers/care managers was clearly that of assessor of community care needs and arranging 'care packages', that is, ensuring that a range of support services are provided to meet individual needs. Users valued practical advice from social workers, for example, advice about welfare benefits or housing issues:

> *"I had to move from London when I was ill. I moved back up here so I had a lot of housing problems and social security needs and my social worker sorted it out for me. Had it not been for him, I wouldn't have been able to change flats and stuff like that, so he was a big help on the Housing Benefit and stuff like that." (mental health service user)*

THE NATURE OF FORMAL SUPPORT

3.18   Formal or paid community care support, in contrast to informal care which is unpaid, encompassed a range of practical help for individual mental health service users or people with dementia in their own homes, and social support enabling individuals to access mainstream community facilities. Practical support included helping individuals to get up in the morning and getting to bed, "doing things around the house" like housework or shopping, preparing and eating meals, help with budgeting, "keeping clean and tidy to acceptable levels", helping with medication, and "helping with any neighbour problems". The emphasis was on doing things with and not for people, ensuring they maintained or increased skills. While the tasks undertaken were often no different from how generic services worked with other client groups, the amount of time allowed to complete tasks varied. For instance, Authority B specifically allocated more home care time when working with clients with dementia.

3.19   In addition to one-to-one support, specialist home support workers from a CMHT in Authority C organised group day care activities. One-to-one support provided by all community or home support workers, whether employed by statutory or voluntary sector organisations, covered essentially the same tasks and emphasised social support. Voluntary sector agencies generally felt better able to provide a so-called "flexible response" and one that was individually "negotiated with the client", and also appeared to place greater emphasis on social support.

3.20   Local authorities provided a "degree of recreation", though resources were scarce and authorities were themselves critical that they accorded less priority to social support compared to practical support for daily living. A manager from Authority C commented:

> *"Due to pressure on resources they (*specialist home support workers*) are heavily focused on the instrumental end of support." (local authority manager)*

3.21   The following comment from a user illustrates that social support was not the norm:

"She (home support worker) wasn't supposed to really go down to P or whatever but I wanted to go down to P to get things for the house. And I thought, and she says, 'Ok I'll take you down'. You know they've got cars, so we went and I had beans on toast and it was lovely. I really enjoyed it, and there was no harm in it, it was just up the road and I'm no gonna get killed so." (mental health service user)

3.22   In theory, social support was an important aspect of the support offered to mental health service users and people with dementia. As one voluntary sector manager said, "we provide social, emotional and practical support to enable independence and develop their own friends." This was achieved both through one-to-one support and group provision at drop-ins and day centres.

3.23   It is perhaps overly simplistic in the mental health field to distinguish rigidly between practical and social support, however, as this does not fully capture the emphasis on 'doing things with rather than for people with mental health problems'. Professionals described the role of home support workers as "operating more at the befriending level and reducing social isolation." In addition to helping people through practical difficulties like paying rent, individual support workers performed an important role in maintaining community contacts:

"We tend to focus on something that's really important for me to do like it was my dad's birthday last week, so she spent a whole day with me in Glasgow with him." (mental health service user)

3.24   Both users and professionals highlighted the role of home support workers as monitoring individuals' mental health. One mental health service user described the role of support workers as:

"Somebody who's there just to make sure you're actually safe" (mental health service user)

3.25   However, this watchful role was not always welcomed, even if its value was recognised by users, as one woman with dementia explained:

"They come in half the time and they don't, they're always looking for somebody to go to you know and I think they always come to me! The home helps at first they irritated me coming in because I might be lying in my bed and I'm not jumping up so they can clean everything. But my daughter's kept them on because she likes to know there's somebody coming in." (person with dementia)

3.26   Home support workers ensured that people with dementia were not socially isolated:

"She just comes down and we'll go and have lunch and things like that and then she goes away again." (person with dementia)

3.27   Specialist agencies provided respite or short breaks for carers so they were able to continue caring, in addition to providing breaks for users who were socially isolated.

Although mentioned as part of the spectrum of provision provided by the voluntary sector, respite or short breaks were hardly mentioned by users or carers.

PERCEIVED SERVICE SHORTFALLS

3.28   Only a minority of focus group participants actually received formal community care services and while some were content with the services they received, others reported problems and gaps in services. Many of the individuals interviewed appeared satisfied with the community care services they received and found it difficult to imagine how they could be provided differently. One interviewee felt that the relationships he had with his support workers would change for the worse if he were to become their employer. In his eyes, if "money were to change hands", it would negatively alter the "friendly relationship" he had with them.

3.29   Respondents in the voluntary sector suggested a lack of adequate community care services of any kind for people with mental health problems and dementia, and an independent advocacy provider commented:

> *"It's very much a lottery depending on where you live in this authority – there*
> *are a lot of people with mental health problems without support workers."*
> *(independent advocacy organisation)*

3.30   Proposing changes to support services was felt to be a risky business. The quality of the relationship between user and individual support worker either enabled or deterred individuals from asking for more or different kinds of community care services:

> *"I've actually got this fear that I get sectioned for going high. I do have this*
> *fear that if I start complaining about a service or saying something's wrong*
> *that they're just going to turn around to me and say, 'she's going high again'*
> *and section me." (mental health service user)*

3.31   Such a fear was even expressed in relation to self-help groups because of a perceived "close link to the paid services." The fear was that complaints would be perceived negatively even by user support groups and reported to the psychiatric services - "they'll get in touch with paid services and then you've got no control of your life again" (mental health services user).

3.32   There was a strong consensus with the previous research in terms of people's experiences of community care services provided or purchased by the local authority. Participants' accounts highlighted six key shortfalls in existing services:

- Lack of individualised home support services
- Segregated and inadequate daytime support
- A lack of evening and weekend support
- Insufficient opportunities for a break
- A gap in meeting social needs
- A general lack of choice

Home support not individualised

3.33 Problems were identified with the general lack of flexibility inherent in service systems and the lack of person-centredness. For instance, commenting on home helps one woman said,

> *"They don't do a lot when they come in. They're not allowed tae do windows, they're not allowed tae do anything. I mean these are the things you want. I'd love tae get ma windows cleaned and they went, 'oh no we don't do windows now'. Tell me what's the bloody point in having home helps that canna pull oot a bed and clean it, cannot dae windows?" (person with dementia)*

3.34 Home support services were providing the help people needed but not always at the times that suited them:

> *"I'd like to sleep as long as I like or as late as I like. I've nothing to jump up for unless I'm going somewhere. I hate to be disturbed at half eight in the morning. The guy that came in with my tablets this morning at eight o'clock in the morning." (person with dementia)*

3.35 The relationship between user and support worker was sometimes problematic but users often felt unable to say anything to change poor relationships with their paid support worker:

> *"There was no way a relationship was gonna develop between my son and this chap. The friction he had with one of his workers ended up with him being dumped in a park." (carer)*

3.36 The quality of relationship with individual support workers was recognised by users as a critical factor in deciding the quality of community care support:

> *"I like my support worker, wouldn't change her, she's absolutely wonderful. If I was getting another worker, I'm not so sure I would be so happy with the service." (mental health service user)*

3.37 Professionals highlighted a shortfall in specialist home care provision and, in Authority A that did not have specialist mental health support workers, drew attention to the failings of generic home care services:

> *"It would be really helpful to have a dedicated home care service. We've already identified the need and then a home help organiser might sometimes do another assessment. Another thing that happens is that they (generic home care service) sometimes withdraw the service after a short time, not really understanding why people are refusing access. Sometimes the home care worker isn't clear about their role with someone with mental health problems." (local authority manager)*

Segregated and inadequate day services

3.38   Users often preferred mainstream community activities, getting help to "lead a so-called normal life", including having employment. Support for employment was inadequate:

> *"A lot of people want jobs. We don't have a specific vocational training project. The reality in this area is that many jobs in the electronics industry are poorly paid and people don't stick them long. Just Christmas money that's all. There's a shortage of meaningful employment opportunities for people." (local authority manager)*

3.39   Daytime facilities of any description were highlighted as a significant gap in community care services in Authority B. A major problem as in other rural areas was that of transport, which had hampered the development of specialist daytime resources. Day services in this area were described as "patchy" and inequitable, available in some towns and not others and transport costs across the area prohibited wider participation. The voluntary sector in this area was unable to cope with demand:

> *"We continuously have a waiting list of 30 for our services. They are trying to address provision. There are two outreach projects now with specialist home care where local authority staff will visit homes where people are unable or refuse to attend the day centre. There is a generic day centre but it is not specifically for dementia and it is overwhelmed. There are three NHS units which are very good models but again there are waiting lists of people wanting more days." (voluntary organisation supporting people with dementia)*

3.40   One person wanted to feel better "able to get up in the morning without being told to get up". Some had dreams of what they would like to do but needed support to achieve them. This included a young mother who felt she would like to be doing more but had childcare problems, and others who needed help to either pursue an ambition or rekindle an old interest:

> *"I used to love going to boot sales and I wouldn't mind going there on a Sunday for two reasons with somebody. One to get me there and two, to stop me buying rubbish. I remember going and after saying 'why did I buy that?', so I really need someone to keep an eye on me." (person with dementia)*

3.41   Attending a day centre was not the first choice of most users. For example, a carer of a man with dementia talked about how hard the day centre staff had worked to involve her husband at the centre one day a week but with limited success as "he's quite a private person, he doesn't want to sit in front of other people and do painting or anything like that." People did not want to be slotted into patterns of services. They had individual needs. Some even avoided existing services wherever possible:

> *"Because they tend to be a bit sort of twee and I'm not the sort of bloke in favour of going down that route", (mental health service user).*

3.42   Applying the same treatment to everyone denied individuality:

> *"There was this connections project that I went to the theatre with. It was fine but the thing was at the interval, the woman who was taking the group gave one of the people ten pounds to get everyone a cup of tea or a glass of juice. I had a five pound note in my pocket and I hit the bar. Because I'd been in my own house for four years I deserved more than a glass of lemonade." (mental health service user)*

3.43   This was also recognised by voluntary sector professionals who commented on the lack of suitable places for people with mental health problems to go during the day:

> *"They go to groups all lumped together and the less well ones have an adverse effect on the more well ones – the mix is all wrong." (voluntary sector organisation)*

Lack of evening and weekend support

3.44   A major gap in services highlighted by users, carers and professionals was undoubtedly a general lack of adequate support in the evenings and weekends in all study areas. Even where users had commented positively on other aspects of community care support, they tended to highlight a shortfall in support during these times. While a voluntary agency stated it provided "an evening 'tuck-in' service between the hours of 7:30-11:00 p.m," the need was for out-of-hours support. Problems could be magnified at night, and there was often nowhere to turn:

> *"No access to services at night and weekends because the only options you've got are actually family, friends or phoning the hospital and if you phone the hospital sometimes they're busy or whatever and they can't talk tae you. You come off the phone and you think that was a waste of time, I am a complete failure." (mental health service user)*

> *"I have family but by the same token, your family have got to do their own thing and I feel that the weekends really my daughter she's dashing over to keep me occupied but I'm no very great at the weekends. I feel very lonely at the weekends." (person with dementia)*

3.45   The consequence of not providing out-of-hours support was, from the experience of both users and carers, that "it ends up as a medical problem" and results in inappropriate treatment. Professionals acknowledged that "weekend and overnight service is not developed sufficiently", and the gap remains.

Insufficient opportunities for a break

3.46   Few users or carers spoke about respite or short break experiences. Users wanted to go on holiday but there was either no staff or not enough resources to enable them to go. Professionals also highlighted a lack of what they referred to as 'crisis respite'. Often the

only respite that could be accessed in a crisis or otherwise was hospital-based, and this was not ideal for anyone:

> *"My son is in hospital for two weeks for a respite period. It's primarily for his sister and myself, and the thing that hurts me is the fact that I instigated this period in hospital because we just reached the point where we couldn't take any more." (carer)*

Gap in meeting social needs

3.47   In addition to the need for home support mental health service users, carers and care managers interviewed identified the need for supporting individuals to participate in ordinary social activities in the community. These needs were not being met in the majority of cases, and the identification of such need therefore represented new demands. As one carer said:

> *"Mum is on her own a lot and is lonely. I have tried to get her involved in going to groups but she gets anxious about how she's going to get there and back. Ideally she needs someone who she could build up a rapport and gain confidence in." (carer)*

Lack of choice

3.48   Professionals in local authorities pointed up the general lack of choice for mental health service users in the community, both in terms of type of service and between different providers. They also highlighted a gap in support for people with Korsakoff's Psychosis. While one manager spoke about this lack of choice in overall terms, "there's not enough in terms of range, diversity and quantity", another referred to the narrowness of services and poor social opportunities:

> *"Choice tends to be quite limited. It's mostly statutory services, there's not a lot of other places for people to go for support. There's not enough in terms of supporting people's social networks outwith services. We're not good at individual support into work or normal social lives. Community care has become about where you're looked after, not what you do. We're trying hard but it's difficult for statutory services to be flexible." (local authority manager)*

SUMMARY

3.49   All three study areas had both generic and specialist home support services for people with mental health problems or dementia, though they differed in how this was managed and the number of specialist workers employed. Specialist home or community care workers were attached to a CMHT in Authority C, specialist dementia workers to generic home care services in Authority B, and were employed by an intensive home care service provided by health and social work in Authority A. The voluntary sector played a significant role in the support of people with mental health problems and people with dementia. This was both in

terms of one-to–one support to people at home and out in the community, and group provision such as day care programmes or centres.

3.50   Formal or paid community care support encompassed a range of practical and social support including help with housework, shopping, preparing meals, help with budgeting, personal hygiene, help with medication, getting people into and out of bed, handling disputes with neighbours and helping individuals to take part in community activities. The emphasis was on "doing things with and not for people". It was observed that despite a range of services, community care services were inadequate to meet needs so that many people with mental health problems were managing in the community without any community care support, relying solely on informal support and with some back-up from psychiatric health services.

3.51   While not an extensive survey of community care services, this part of the study did highlight a number of shortfalls in them as perceived by research participants, including the lack of flexibility. Users were frustrated with aspects of home support that did not meet their individual needs. They were also critical that daytime support in segregated centres was the only option. There was an inadequate range of daytime provision including few vocational or employment opportunities. The chronic lack of out-of-hours support often left no alternative but to turn to medical services or to suffer in silence, and insufficient holiday or short break opportunities for both users and carers put added strain on families and individuals. Professionals acknowledged a generalised lack of choice in mental health services over who provided support, when it was provided and how. While this research was about Direct Payments and not about reviewing mental health services overall, the research has highlighted perceived shortfalls in traditional services that need attention.

CHAPTER 4: EXPLORING DIRECT PAYMENTS AS AN OPTION FOR MENTAL HEALTH SERVICE USERS

INTRODUCTION

4.1 This chapter first reports on the survey of local authorities, which identified the authorities with Direct Payment or third party schemes and whether mental health service users were recipients of these schemes. Drawing on data from the focus groups and interviews with users, carers and professionals in local authorities and voluntary organisations, it then examines a number of fundamental issues such as perceptions around the eligibility of mental health service users for Direct Payments; the general awareness of Direct Payments among users, carers and professionals; and the potential advantages and disadvantages of Direct Payments as perceived by different participants.

SURVEY OF LOCAL AUTHORITIES

4.2 During March 2001 a telephone survey of all 32 local authority social work departments was conducted to discover which local authorities currently had a Direct Payments scheme, a pilot scheme or a third party scheme. The survey also asked about the number of recipients, how many were people with mental health problems, whether they had ever had any recipients who were mental health service users and whether there were plans to include mental health service users in the future. The key findings of the survey are summarised below (findings by local authority are included at Annex 2):

- There had been only a slight increase in the number of Direct Payments schemes since the last survey – 16 schemes compared to 13 in 1999. Seven of these were pilot schemes. Two others, including one pilot scheme, still had no recipients;

- There were also 11 third party schemes operating (one local authority reported both a pilot Direct Payments and a third party payments scheme);

- Three local authorities had no scheme of any kind, and one operated some form of individual payments;

- Only one of the earlier pilot schemes was now fully operational, the remainder were still pilot schemes 2 years later;

- Two third party schemes from the previous survey had converted to Direct Payment schemes;

- Only 2 current Direct Payment schemes had recipients who were mental health service users, and these had only one such recipient each;

- One third party scheme had 4 recipients who were mental health service users;

- 10 out of the 16 direct payment schemes that currently had recipients, planned to include mental health service users while 3 had no plans to do so, and another 3 were undecided;

- There were 213 recipients of direct payments as at April 2001, an increase of 70 recipients from the previous survey, which had found 143 recipients.

4.3   In short, there had been little progress in implementing Direct Payments generally over the past two years and even less progress in terms of including mental health service users and people with dementia.

ELIGIBILITY CRITERIA

4.4   The previous survey (Witcher et al, 2000) had found considerable variation between local authorities in the conditions that required to be met to qualify for a Direct Payment. The subjective judgement of individual social workers/care managers was shown to play a major part in deciding eligibility. Participants in this study were consistently uncertain about the issue of eligibility and non-eligibility. For instance, in Authority A, a local authority manager stated that because most of those on guardianship under the Mental Health (Scotland) Act, 1984 were older people with dementia, by implication people with dementia would be excluded from any scheme. National guidelines currently state that recipients must be:

- assessed as needing community care services
- aged 18+ (16+ as of December 2001)
- able and willing to manage Direct Payments alone or with assistance
- not subject to certain mental health or criminal justice legislation

4.5   The last criterion is expanded in policy guidance (Scottish Office, 1997). In respect of "certain mental health legislation", this means patients who are:

- subject to after-care under a community care order under the mental health legislation;
- detained under mental health legislation who are on leave of absence from hospital;
- subject to guardianship under the mental health or criminal justice legislation;
- restricted and conditionally discharged;
- subject to equivalent mental health legislation in England or Wales.

4.6   Deciding upon appropriate community care services for people with mental health problems was complex compared to determining what support individuals with physical disabilities needed, and users felt this in itself would fundamentally affect eligibility for Direct Payments. The term 'mental health problems' is generally used to cover such a vast range of conditions:

> *"If you've got Alzheimers or if you're physically disabled, if your legs don't work, it's very clear. But the trouble with a mental illness is that some people can manage OK while other just collapse completely." (mental health service user)*

4.7   Some mental health service users and voluntary sector managers commented on what they perceived as the "medicalisation of mental illness" which prevented social support needs from being identified in the first place, let alone met, and pondered whether this might mean that many individuals with mental health problems would not be considered for Direct Payments:

> *"Mental health is seen as medical so it makes it difficult to ask for social support."* *(voluntary sector manager)*

4.8   There was a fear expressed that some people would "slip through the gap", because there was confusion about the Direct Payments guidance regarding mental health. Consequently, "the very people who would benefit from it most" might be excluded. Although current guidance advises that people who are on leave of absence from hospital are not eligible, the case regarding people on Section 18 was unclear to the research participants:

> *"People get discharged from hospital under a Section 18 which is a six month order where they can be pulled back into hospital at any time, but I don't think that counts as a 'leave of absence'."* *(mental health service user)*

4.9   Interviewees were also confused about what would make an individual ineligible for a Direct Payment and care managers often assumed most mental health service users would be ineligible by definition. For instance, one individual's care package was said to be "so minimal" and the level of support they would need to manage a Direct Payment would be so great, that it would "not be cost-effective". It was assumed that others would be excluded because they would require "such a high level of support to manage", or they would be excluded under mental health legislation. In some cases, there were distinct differences of opinion between care managers and service users about opting for Direct Payments.

4.10   Care managers cited poor motivation as a reason that a Direct Payment would not be suitable for some clients. However, in certain circumstances, motivation (or the lack of) did not appear to inhibit the service user from expressing an interest in the scheme. All this highlights that professionals' lack of awareness and understanding of Direct Payments, especially of the eligibility criteria and the fact that as much support as needed to manage can be offered, has an influence over whether it is even considered, let alone offered to mental health service users.

4.11   An indirect but important finding of this research was how people with mental health problems or dementia had problems relating to the term 'disabled people'. There appears to be a mismatch between the terminology used in Direct Payments and how people who have experiences of mental health services perceive themselves. When it was explained in the focus groups that a criterion for eligibility was that the person must be disabled, participants had difficulty relating this to their own situations. Disabled is not generally a term used in mental health. It does not follow that mental health service users would be excluded on this basis, but it might affect whether individuals themselves would seek access to Direct Payments.

AWARENESS OF DIRECT PAYMENTS

4.12 Overall, there was a marked lack of awareness about Direct Payments not only among mental health service users and carers, but also among professionals in social work departments and voluntary organisations, except in Authority B that had an active support organisation managing its Direct Payments scheme. As was clear from the previous study, understanding of Direct Payments in terms of eligibility criteria, for example regarding age restrictions, and how Direct Payments differed from other schemes, such as the various Independent Living Schemes, was confused. The following quotation illustrates how one participant had confused Direct Payments with the ILF:

> *"It is a payment the local authority have the power to make but not a duty to make it. I believe the user must have a need for £200 worth of care/support needs to qualify. There is no clarity that it should be given to mental health service users." (voluntary organisation manager)*

4.13 All this is not surprising considering there were still few training opportunities regarding Direct Payments for care managers or operational and senior managers within social work departments: this study found evidence of active training and dissemination about Direct Payments in only one authority, in which the Direct Payment scheme was managed by an independent organisation. In addition, the response to a question about whether clients with mental health problems or dementia who are assessed for community care services are routinely told about Direct Payments was a resounding 'No'.

4.14 Professionals varied in their knowledge of the existence of either the Direct Payment or third party scheme operating in their own area. In Authority B social work managers were aware of the existence of an independent organisation to "take over setting up the scheme" following a community care assessment but little else; they had no involvement with the scheme because it did not yet involve mental health services users. A voluntary organisation manager had an advantage in sharing an office building with the Direct Payments organisation, and had received information and training about the scheme. Consequently, she was most knowledgeable about Direct Payments:

> *"The user must have an assessment by the social work department to assess needs. The user is able to say what he/she really wants rather than the social work department. Users would have more control." (voluntary organisation manager)*

4.15 Another voluntary organisation manager in this same area was aware of the basic purpose of the scheme but had had no training. The manager of this project for people with mental health problems felt that "its (the Direct Payments scheme's) remit is mainly aimed at those with physical disabilities". The scheme was perceived as of limited relevance to people with other disabilities and resources allocated to Direct Payments were generally inadequate – "it is unrealistic money". The independent advocacy organisation interviewed in the same area had supported people on Direct Payments and were most clear about the benefits to individuals:

> *"The idea is for people to buy in the services they need rather than have provision by the local authority. It works very well with ILF money. It provides a lot of choice. You have to account for the money – it is closely monitored." (independent advocacy organisation)*

4.16   In Authority A social work staff were aware of the purpose of Direct Payments to "give people choice and control" but were generally ignorant about how the scheme operated. They felt more familiar with "the workings of the ILF". Voluntary organisations supporting people with mental health problems and dementia in this area had not heard much about Direct Payments. One project coordinator had decided to accompany a carer to one of the focus groups by way of learning more about it.

4.17   In Authority C, social work managers in mental health were largely ignorant of how the third party scheme operated but knew of its existence. One voluntary organisation manager in this area said:

> *"I have information sent from the Scottish Executive (about Direct Payments) but have had no training. I have a file with the information and I'm keeping a watch on developments but there is no push from the local authority here." (voluntary organisation manager)*

4.18   Mental health service users and carers were the least informed about Direct Payments. The characteristic response to questions asked by the research was "direct what?". Although some people said they would know to first approach social work departments or Independent Living Centres to find out more about Direct Payments, most users, especially people with dementia, were unaware of the Direct Payments option or who to ask for more information. Voluntary organisations supporting people with mental health problems and dementia, not local authorities, had been the source of information on Direct Payments for the few users and carers who had any knowledge of this option.

4.19   One local authority suggested hesitancy in providing information about Direct Payments to mental health service users because they were "uncertain of its appropriateness". The manager went on to say:

> *"Not until we have a better scheme worked up with certain issues resolved. If some people were told at a time when they were in a dependent environment like a hospital, if we threw in that they could get the money instead of services, I think finding providers would probably distract them and be an added thing for them. It would be a diversion." (local authority manager)*

4.20   This dearth of information to users and carers in one person's view reflected a general lack of user involvement in services:

> *"The information people generally have given to them is abysmal. The care managers do assess the users' needs then it goes to the local authority to decide which services are to be offered. The user is not informed about the different services available, including Direct Payments." (voluntary organisation manager)*

POTENTIAL ADVANTAGES OF DIRECT PAYMENTS

4.21   The anticipated benefits of Direct Payments bore a close resemblance to the advantages highlighted in the previous survey of Direct Payment recipients by Witcher et al. The main benefits anticipated by mental health service users, including people with dementia, were that Direct Payments might serve to remedy the service gaps they had identified in existing mental health or dementia services. The pen picture below illustrates some of the benefits perceived by mental health service users.

Pen Picture 'Bob'

Bob is a male in his 50s who lives in a ground floor flat with his wife in an urban area. He has a diagnosis of schizophrenia and a 'mild physical disability'. The Community Mental Health Team provides a home help three times a week to help with domestic duties, a support worker once a week to check on him and to organise trips out, and another support worker once a week to do art activities.

Bob was happy with the support workers he has but not the home help. He felt the home help told him and his wife what to do and this caused him a great deal of stress. He would like to have the home help changed. He was also critical that the home help did not do enough work and often sat about chatting too long. He wanted the home help to help clean the bathroom and the kitchen because his wife did this and she found it difficult. He had asked to have a new home help but didn't feel anything was happening.

Overall, Bob thought that Direct Payments was a good idea because 'you would be your own boss'. A Direct Payment could be useful for him and would especially help in the situation with the home help. He thought it would give him more control over making sure the home help did what he/she was supposed to do, over the tasks they performed and the times they offered a service. Bob did wonder what might happen if the home help was sick and he could not pay them their wages. He thought there might be a problem in finding someone else to cover sickness and provide the service. Bob was good with money and would be able to manage the financial side of the scheme but might need help with the paperwork and filling in forms, or if he was unwell. To do this he would need more advice on how the payments would be made, how he would pay the home help and how he would go about selecting employees.

However, Bob's care manager did not think he would be able to cope with the added responsibility of a Direct Payment because Bob was poorly motivated, which was associated with his mental health problems. Further, she did not feel that a Direct Payment would make any difference to the type of support he would choose. She did think that a Direct Payment would give Bob more choice over his home help service, although she did not think this would benefit him overall.

Benefits identified by users

4.22   Direct Payments had the potential to enable users to organise support in a more individual, tailor-made way to suit their own needs. Users anticipated having greater say and control over who provides support, what they do and when they do it. Independent living was a term that represented "freedom" for one mental health service user and for others it meant having in-built flexibility to change patterns of living to suit themselves.   The following quotations illustrate positive reactions to the idea of Direct Payments:

> *"It's your personal package, it's yours and you're actually creating it even if you've got someone working with you. You're creating it, stating what you need, not what anybody else needs, it's actually what you need." (mental health service user)*

> *"It's something I'd look at twice. I don't need it at this time but if anything happened to my wife yes I'd be in a pickle because she deals with the money and the pills. I haven't a clue what's going on." (person with dementia)*

4.23   A wider range of potential benefits was identified as in the previous research including increased skills and intrinsic benefits. Users highlighted the potential of Direct Payments to increase individuals' self-esteem and self-confidence through giving more control over their lives:

> *"It would be higher self-esteem to think that you were now in control of your services" (mental health service user)*

> *"I play badminton on a Friday afternoon. To gie you an example, if I couldn't for some reason but still wanted to play badminton I'd then have the option of taking my own group, playing another time in order to keep me well as it were." (mental health service user)*

4.24   One mental health service user proposed buying the services of a "life coach" and had ideas about using Direct Payments to pool resources with other people in a similar situation to create more responsive services and meet gaps, for example for support in the evenings or weekends:

> *"If I got a chunk of money I'd like access to a personal assistant, a secretary, what they call a sort of life coach to help organise your time. Sometimes it's very confusing, you've got a lot of time and not sure your best way to organise it. And for myself and a lot of other people with mental health problems, good communal facilities - I can see a possibility where you got around with other people and imagined what you wanted and we've got enough people here to finance it." (mental health service user)*

4.25   This comment echoes the work of Stainton, cited in Maglajlic (2000), who highlighted how initiatives coming from users pooling resources to develop new services have indeed made the most creative use of direct funding to date.

Benefits identified by carers

4.26   Carers identified a similar range of potential benefits from Direct Payments including increasing independence through choice and the potential for more flexible and responsive services. In addition, carers highlighted how being able to choose the nature of the support to fulfil an ambition such as having a job or socialising more, could provide a sense of normality and inclusion:

> *"I think for him it would be just normal, a feeling of being normal you know 'cause that's what he wants to be. He wants to be working, he wants to have a job and he wants to be the same as everybody else you know." (carer)*

Pen picture 'Martin'

Martin and Sarah are a married couple who were interviewed together. They live in an urban area. Martin has dementia and his wife Sarah works full-time and acts as his carer. They have a young son living with them, and Sarah cares for her elderly mother. Martin has a support worker who comes in every morning throughout the week to help him get up and get washed and dressed. Monday to Friday, he attends two different day centres. One of the day centres requires a carer to be present with him. Martin has support from Alzheimer Scotland and Crossroads. Every Sunday a worker from Alzheimer Scotland stays with Martin for a few hours, so that Sarah can care for her mother.

Martin wants to change the type of services he receives but is unsure how. He suggested he wanted to attend college and do other things with his life. Sarah and Martin both feel more emphasis on social support might be beneficial. As Sarah said, 'Maybe someone to take you out instead of just coming and sitting in the house, to take you somewhere, whether it be for a meal or you know, to visit, maybe the cinema'

Sarah noted that the lack of communication and continuity in Martin's current care providers had been stressful both for herself and for Martin. She felt that they lacked control and that they were 'at the mercy of what they can provide and when they can provide it'. Direct Payments potentially offered an opportunity to improve continuity and control over who provides services, as they would decide whom to employ. This could be someone who had more in common with Martin, both in terms of interests and age. A Direct Payment would also provide a degree of flexibility when something unexpected or unusual happened. Sarah suggested, 'it would only be you phoning one person to say 'can you do this evening' and that would be it, whereas you haven't got the same freedom when it's an agency'.

Martin felt the main disadvantage of receiving a Direct Payment would be having to handle the financial side, as he had difficulties managing money and knowing what things cost. He did not think he would have a problem dealing with the paperwork, as he had experience of being an employer. Sarah felt she would have to keep track of Martin's support needs and priorities in order to work out what the payments need to be spent on. She didn't think she would find it very easy to hire and fire people and trying to decide if someone or a service wasn't working out. Due to Martin's short-term memory problems, as an employer, he would have difficulties keeping on top of the paperwork and would require assistance in filling out forms. If this responsibility were to fall to Sarah, she would need some support.

4.27   One carer in this research identified how having a Direct Payment might help his son to be independent because he would be able to travel to places as and when he wanted, something he was currently unable to do.

Benefits identified by professionals

4.28   Social work and voluntary sector managers were similarly clear about the potential benefits of Direct Payments to mental health service users, echoing the benefits perceived by users and carers. Professionals identified a range of potential benefits including increasing individual choice and control, enabling more flexible and tailor-made services, increased independence, empowerment and increased self-confidence thus improving the quality and appropriateness of support to clients. Additionally, they identified dignity in choice and increased status arising from becoming an employer instead of a service recipient:

> *"To have choice in how you rely on the state would be more dignified. We try but we're quite traditional. The client might think of their needs more in terms of going to the pub etc." (local authority manager)*

4.29   Another potential benefit might be that increased independence would get people "off the mental health treadmill" and enable them to "see other opportunities", or increase their personal horizons. This point was made by one of the advocacy workers about younger disabled people in particular. That Direct Payments would address a power imbalance between users and professionals was welcomed by people in the voluntary sector as a "healthy challenge to services".

POTENTIAL DISADVANTAGES OF DIRECT PAYMENTS

Disadvantages raised by users

4.30   The most significant concern or disadvantage of Direct Payments identified by users stemmed from a belief that they would have to manage the financial arrangements independently, which would be especially daunting at those times when people with mental health problems did not feel well enough. This was a concern also shared by professionals, who identified a need for "an audit trail" and "transparent accountability" for the payments. One person did feel that having a Direct Payment would generally be like "taking on a bit more of the bureaucratic problems of life" at a time when it might be difficult to cope, thus creating an added burden or stress for the individual.

4.31   The main concern about the fluctuating nature of some mental illnesses was the difficulties this might throw up in directly managing money at these times, or that due to their mental state, people might misspend the money:

> *"With my manic depression I shoot high where I'm totally delusional and I go so low where I can't get a thought into my head and you know this happens randomly all over the place. I wouldn't be able to manage a care package you know when in the depths of a low where you canna move and you cannae think and you don't want to do anything and equally when I'm totally high I can conquer the world. The thing*

with hypermania is when you go manic you can go off on a huge spending spree, so I could quite easily go off and blow the money on something else." (mental health service user)

4.32   A second major concern of users was how some individuals might manage personal assistants when they felt unwell:

"You can go very paranoid where you believe there are schemes out there to get you. I believe that they're maybe the image of someone else, they maybe don't look like that at all but could be. I might think they're my mother coming in and I don't want my mother in my house so I would send them away and would get nothing done that day." (mental health service user)

4.33   Transport and access were especially problematic in rural areas and raised certain practical concerns for implementing Direct Payments. One user from the rural authority was anxious that the pool of potential employees would be small and this would compromise individual's privacy:

"Living in a tiny village I would have huge difficulties finding someone you know basically willing to come to the village and the alternative would be employing one of my neighbours who might just gossip about me." (mental health service user)

4.34   The complexities of becoming an employer and the additional responsibilities were sometimes daunting. Users were concerned about how they would manage health and safety, as well as such things as hiring and firing staff, arranging employer's insurance etc and the additional paperwork involved. One person said,

"I would be happy to be picking someone, sort of looking at who's the best one, but I'd rather the local authority handled the paperwork." (mental health service user)

Disadvantages raised by carers

4.35   Carers also felt that handling additional paperwork was a disadvantage as they envisaged that this task would fall to them and "there are not enough hours in the day as it is". In the case of someone with dementia, carers already played a major role in managing the person's finances. It did not make sense to carers that a Direct Payment would be paid to their relative whose financial affairs they were now handling. Carers also thought the responsibilities involved in becoming an employer could add unwelcome stress for people with mental health problems, and there was a risk that directly employed staff might be unreliable or turn out to be untrustworthy or exploitative.

Pen picture 'Simon'
Simon is a young man in his twenties who has mental health problems, and had drug and alcohol problems in the past. He has a tenancy with a supported housing agency in a rural area and has a care manager, a Community Psychiatric Nurse, an Occupational Therapist and two support workers. Simon is very happy with the service and level of support he receives and when asked, did not think a Direct Payment would be something he would want. He might however consider using a Direct Payment to employ someone to clean his house or support him to take part in more social activities. But he felt he might have a problem 'spending the money' on services rather than on other things, and would need support with paperwork and 'someone who kens what they're on about' to help manage the money. Simon was unsure what would happen to a Direct Payment if he became unwell and had to go into hospital as 'everything stops when you go into there'. Consequently, there would be periods of time when his employees would have no work and he wasn't sure how this would work out. Simon's care manager also thought Simon could use a Direct Payment for activities that were more social, for example going out for bar lunches or to the cinema. However, the care manager had regular contact with the Scottish Association for Mental Health support worker and could ask her to carry out specific work with Simon. If Simon started to receive a Direct Payment, the care manager was anxious that such a link would be lost. Overall, Simon's care manager did not think he would be motivated to take responsibility for a Direct Payment and would have difficulties being committed to his role as an employer.

Disadvantages raised by professionals

4.36   Professionals identified a number of dilemmas surrounding Direct Payments to mental health service users. These included concerns about the management of finances including the potential for misspending the money. Other researchers have found this to have little foundation (Hunter, 1998). They were also concerned about the exploitation of people with mental health problems or dementia:

> *"I would have concerns with vulnerable people being taken advantage of because they had been given money to manage, by unscrupulous relatives and neighbours." (voluntary organisation manager)*

4.37   There was disquiet about the potential use of Direct Payments to facilitate certain aspects of social life such as going to the pub, rather than receiving the "therapeutic benefits" of day care. Professionals were concerned about the potential isolation of people with mental health problems when support workers are not employed by Social Work, Health or the voluntary sector, which could be detrimental to individuals:

> *"Certain signals can trigger that a person's mental state has changed. With DP may not always pick up the signals. There needs to be a more sophisticated appreciation of the risks and precursors to the dangers, social, practical and emotional that the person can get into but that can be prevented." (local authority manager)*

4.38   The disadvantages of Direct Payments perceived by professionals can be summarised as concerns about:

- the difficulties arising from 'fluctuating conditions' associated with mental illness;
- devolving budgets to users was problematic in authorities that had difficulty devolving budgets to care managers;
- putting an additional burden on users who were already not coping well;
- the need to ensure proper support arrangements are in place;
- and, that some people with mental health problems refuse any help from services, which would basically disbar them from Direct Payments.

4.39   For one social work manager, the notion of Direct Payments fundamentally challenged his somewhat limited beliefs about the nature of mental illness and the role of services:

> *"The ability of some people with mental health problems to carry on a well ordered life is open to question on a day-to-day basis. People lose self-awareness and there's a naïve assumption in Direct Payments that people will deal with their own affairs in a consistent way. By definition, someone is getting a service because their life performance has some sort of deficiency and they need compensatory help to enjoy other bits of their life." (local authority manager)*

4.40   In contrast, another social work manager in the same authority, perceived the challenge as more a matter of recognising people's capacity and the need to embrace supported decision-making:

> *"Anyone with dementia would be in a similar position to someone with learning disabilities in the scheme. They would need a network of support from the Direct Payments scheme, citizen advocates, etc who can relieve them of the technicalities of managing it. The user needs to understand what they are giving consent to." (local authority manager)*

4.41   In theory, voluntary organisations supporting people with mental health problems and dementia were in favour of Direct Payments as a way of empowering users and giving greater choice of who provides support. From a rights perspective people had "the right to make decisions" and Direct Payments would seem to offer greater "flexibility in choosing the specific help they needed, from whom and when they wanted it". They also had a number of concerns, however, that in their opinion might outweigh the positives. These were:

- whether individuals would be sufficiently motivated to manage a Direct Payment;
- that users would not understand all the issues involved in becoming an employer and would therefore not be able to manage properly;
- that there would be resource implications both for local authority and voluntary sector services and staff;
- about the inherent difficulties many people with mental health problems, but especially people with dementia, have with managing money;
- about the safety of users and protecting people from exploitative care workers;
- the importance of proper support services being in place before offering Direct Payments;

- that unless carers became eligible for Direct Payments, people with dementia would be excluded.

SUMMARY

4.42   The research found only a slight increase in the number of Direct Payment schemes operating in Scotland over the past two years and that there was still only a very modest number of Direct Payments recipients. That all but one of the pilot schemes identified in the previous research was still a pilot two years later, and that several authorities continue to operate third party schemes, suggests that local authorities continue to be cautious about implementing the Direct Payments legislation. In addition, the fact that just two recipients across Scotland were mental health service users would suggest there are serious barriers to progress regarding the inclusion of this group.

4.43   Current eligibility criteria appeared to research participants to exclude a great many people who are currently receiving community care services, as they will be subject to sections of the mental health legislation. Further, people with mental health problems or dementia did not think of themselves as being disabled and did not recognise Direct Payments as being relevant to them.

4.44   Awareness of Direct Payments was low even among social work department managers and care managers. It was suggested by managers that uncertainties about whether Direct Payments should be offered to mental health service users deterred local authorities from disseminating information about Direct Payments more widely.

4.45   The general reaction of users in this research to the idea of Direct Payments was positive. While some were hesitant because they did not yet know enough about it, others said, "it sounds brilliant". Users could anticipate the benefits might include having greater say over their support, and being able to create the life they chose rather than having it decided for them, though many were unsure they would be offered this option, especially those with dementia:

> *"So it's like your care package that you've made for yourself, totally comprehensive and totally you decide what it is you need?" (mental health service user)*

4.46   Professionals in both the local authority and voluntary sector organisations also identified many of the same benefits. However, they had a number of reservations were perceived by them to outweigh the positive benefits.

4.47   The major disadvantage of Direct Payments highlighted by all the research participants was managing the financial arrangements, particularly in the face of fluctuating or worsening mental health. Participants were generally unaware that Direct Payments recipients can receive assistance to manage the payments. Users were also anxious about taking on the responsibilities of becoming an employer and dealing with the paperwork that they perceived might be involved in managing payments and employees. Professionals highlighted potential difficulties in the relationship with personal assistants and the potential for misspending payments. There was an increased risk of exploitation if personal assistants were recruited and employed directly by individuals, and mental health services would lose a

valuable early warning system because personal assistants would not be directly employed by Social Work, Health or a voluntary sector organisation.

CHAPTER 5: OBSTACLES TO PROGRESS

INTRODUCTION

5.1   The benefits of Direct Payments for mental health service users have yet to be demonstrated. The survey of Scottish local authorities reported in the previous chapter found only two mental health service users who were recipients of Direct Payments. Further, the National Centre for Independent Living identified only 10 mental health service users who received Direct Payments in the UK (Heslop, 2001).   This Chapter draws together the findings on the barriers preventing mental health service users in Scotland from receiving Direct Payments. The findings are discussed under the following broad headings:

- access to community care assessment;
- lack of knowledge and understanding of Direct Payments;
- the legislation and guidance on Direct Payments, including eligibility criteria;
- concerns about the ability of mental health service users to manage practical aspects of Direct Payments;

and,

- fears about the potential impact on jobs and services.

COMMUNITY CARE ASSESSMENT

Poor access to community care assessment

5.2   Most of the focus group participants were not receiving any community care services and therefore imagined that an initial barrier might be that they had not had a community care assessment.   Health services and voluntary sector organisations were their main service providers.   Secondly, users and carers felt that community care assessments sometimes underestimated the needs of people with mental health problems as their needs were "not so obvious", especially on a good day.   There was also a suspicion that the outcomes of community care assessments were often 'service-led' – that is, were linked closely to the allocation of the kinds of services already available - rather than being 'person-centred', or geared primarily to the needs of the individual:

> *"It is a bone of contention here, particularly for those who have had a lot of support from day care services, that those users can't have the money in place of day service even if they preferred to have a different service. This would pose particular problems for people with mental health problems or dementia as a lot of them do not have a home care service only day care or a voluntary sector support worker or drop-in centre which is a block purchase. The local authority won't cough up money in place of those so that would restrict which mental health service users went onto Direct Payments." (voluntary sector manager)*

5.3   Criticisms of community care assessments, including the perceived lack of a person centred approach, highlighted a potential stumbling block for Direct Payments to mental

health service users that would need to be addressed by broader community care policy and practice.

People treated as a group not as individuals

5.4   Concerns and issues about Direct Payments tended to be raised and discussed in ways that considered mental health service users as a group. They usually also referred to worst-case scenarios. While the point was well made that in practice Direct Payments need to be decided on a person-by-person basis, participants tended to generalise about mental health problems and applied their concerns regarding Direct Payments across all individuals with such a label regardless of their diverse needs. Treating mental health service users and people with dementia as a group is potentially discriminating given that capacity has to be assessed on an individual basis, and also given the vast range of needs experienced by those facing mental health problems. As one service user argued, the phrase 'mental health problem' describes diverse experiences:

> *"No-one has exactly the same mental health problem as someone else, it's a very personal thing you know. Even the way your brain works, nobody's brain works the same. Trying to squeeze people into certain groups is the worst thing in the world." (mental health service user)*

Lack of choice and user involvement generally in mental health services

5.5   Research participants claimed that a lack of involvement in decision-making was a common feature in mental health services, and that many people had become passive recipients of services, "grateful for anything they get". Mental health service users were in one professional's opinion a "disempowered group". While this was not put forward as an argument against introducing Direct Payments per se, professionals in both local authorities and voluntary organisations drew a sharp contrast between the philosophy of Direct Payments and traditional mental health services, which were said to "encourage dependency" and largely to be making decisions on people's behalf. If this were the case, choice and decision-making in people's lives would need to be addressed first before introducing Direct Payments to mental health service users and people with dementia.

LACK OF KNOWLEDGE & UNDERSTANDING OF DIRECT PAYMENTS

5.6   The previous research by Witcher et al (2000) found a clear correlation between having experience and knowledge of Direct Payments and a positive attitude towards them. Their research found that the absence of information about Direct Payments was a fundamental barrier to making any progress with implementation for mental health service users. However, the lack of knowledge and understanding is also as much a symptom of other barriers and concerns, as it is a barrier in itself. Some of the participants in the research were hearing about Direct Payments for the first time, and this included professionals whose knowledge was often rather sketchy, with some notable exceptions.

5.7   If professionals had concerns about Direct Payments to mental health service users, they would be unlikely to actively promote and disseminate information among users. It was a catch-22 situation. The less professionals knew about Direct Payments and the less

opportunities they had to discuss their concerns openly, the less likely they were to raise the issue of Direct Payments with users, and the demand for this option remained limited or non-existent. Users felt that if professionals were not in favour of or did not feel confident about Direct Payments in the first place, then information would not reach them and they would not be encouraged to apply:

> *"And then they'll put every block in your way when you're trying to go for it if it's something that they don't approve of for you." (mental health service user)*

5.8   Taken together with misunderstandings about eligibility for Direct Payments discussed below, this lack of knowledge could form a formidable barrier to mental health service users trying to access Direct Payments.

NATURE OF DIRECT PAYMENTS

Uncertainty about eligibility

5.9   Professionals were uncertain about the eligibility criteria for direct payments in relation to mental health service users, which was related to their lack of knowledge and understanding of direct payments, including a lack of familiarity with the legislation and guidance. It was the perception of research participants that there was insufficient detail to explain exclusions under mental health legislation, although this is specified in official Guidance (Scottish Office, 1997). Overall, the research found professionals to be uninformed about who would be eligible and a tendency for them to assume that most mental health service users would somehow be ineligible.

5.10   For instance, in one local authority manager's opinion, anyone receiving services under mental health legislation was "very needy" and by definition "ineligible for Direct Payments". In his area alone, many young people accessing general mental health services were also "chaotic drug users". The reality was that many mental health service users also had other disabilities, including learning disabilities, which made meeting their needs more complex. Another suggested that the majority of mental health service users seen by social work departments would be excluded from Direct Payments for the following reasons:

> *"We have many people who are subject to legislation under long term Sections in the community. Most people with mental health problems spend some time in hospital. There'll be quite a large group who might be excluded from Direct Payments who'll be on Community Treatment Orders or on leave from hospital." (local authority manager)*

Insufficient resources allocated to Direct Payments

5.11   Mental health service users and carers were sceptical about the priority that would be given to Direct Payments within local and central government. One carer was sceptical that adequate resources would be allocated to Direct Payments within the local authority, which reduced its attractiveness:

"You're given a wee cake let's say, and you're wanting to cut it up so many ways right, but the size of the cake is decided by other people. Again we're still dependent on the local authority." (carer)

5.12   Users were also worried about the funding for Direct Payments and whether there would be transitional funding to move from services to Direct Payments and the resources to develop the support systems needed. The recent Scottish development project to promote Direct Payments announced by the Deputy Minister for Health and Community Care (Scottish Executive, 2001), which aims to develop existing local user-led support groups goes some way towards addressing this concern.

Cultural resistance to Direct Payments

5.13   One voluntary sector manager anticipated that not many people would want to use Direct Payments because they saw it as a state responsibility to provide public services, rather than individuals' responsibility to arrange services for themselves. He envisaged a "cultural resistance" to Direct Payments. While this may indeed be the case in some areas, no other participants highlighted this as a barrier.

DIFFICULTIES WITH PRACTICAL ASPECTS OF DIRECT PAYMENTS

Fears about handling money

5.14   All participants felt that a major potential difficulty with implementing Direct Payments for mental health service users was how they would cope with managing their finances and/or personal assistants when they became unwell or their condition worsened:

"People like us with forgetfulness right it would be the financial bit in the working out, that's the thing that would put me off. I would be put off by the technical bit, too much palaver you know" (person with dementia)

5.15   A recurring concern was about giving any cash payments to people whose judgement may be impaired either temporarily (examples given were manic depression), or in the case of a person with severe dementia, permanent impairment. Participants perceived mental health service users as being unlikely to be capable of managing a Direct Payment without a great deal of assistance, and as most research participants were unfamiliar with what form this assistance could take, were more inclined to rule Direct Payments out.

5.16   Although involving attorneys, accountants, circles of support, relatives, user-led trusts, a senior personal assistant etc in helping individuals to manage Direct Payments are all methods of support operating successfully in other parts of the UK, particularly for people with severe learning disabilities, and which have been well documented (e.g. Holman & Bewley, 1999), there was limited awareness of such options in the mental health field. This highlights a general need to provide information and raise awareness of the different options for supporting Direct Payments recipients.

Bureaucracy and paperwork

5.17 All participants were concerned that the paperwork involved in ensuring accountability for public money could impose added stress in people's lives when they were least able to cope with stress. Again, because there was limited awareness of Direct Payments, respondents tended to be unaware of the different ways that people can be supported so that this does not become an obstacle. The pen picture below illustrates the kind of support needs identified by research participants.

Pen picture 'Claire'

Claire is woman in her sixties who lives alone in a rural area. She has had mental health problems for many years. She has a care manager, a SAMH worker who visits twice a week, a CPN, a home help once a week, and she attends a day centre once a week for lunch. Claire is happy with the people who provide her services but she wants more support over particular periods such as Christmas and New Year as she often becomes unwell with the flu at these times. Claire wants someone to cook meals and do shopping for her, as she often struggles to do these things for herself. She also wants to get out more possibly with people from the day centre.

While Claire imagined using a Direct Payment to help her get out more, she wondered whether in reality it might be used solely to arrange much needed help about the house. At present, Claire pays her home help by going to the local Council offices and this means transport costs. For this reason she liked the idea of having a Direct Payment to pay her home help - 'It's not an effort, but I mean it would save a lot of walking or having to get into town by bus, but it all adds up, all these little things add up'.

Claire would need support with filling in forms and organising things and thought that her Social Worker would provide this. She was able to handle her money but would need support if she became unwell and unable to manage a Direct Payment. People with whom she had build up trust and a relationship were in her opinion the best people to explain Direct Payment schemes to her.

Claire's care manager was supportive of the idea of a Direct Payment and she was aware that Claire worried about paying her home help. It would also mean she could choose the provider and what services she wanted. The care manager could not imagine Claire being able to manage the scheme alone, because she often had problems remembering things, but there was support from her Care Manger, CPN or the SAMH worker.

Dynamics of the support relationship

5.18 It was suggested that the employer:employee relationship could be compromised in situations where, to be effective, an individual needs their supporter to be directive and authoritative:

> *"Some people with mental illness, for example someone with schizophrenia, may need the push from some sort of authority just to get out of bed in the morning and an employed carer wouldn't have that authority. A support*

worker employed by social work or health can be seen to have that authority and to gently push someone because it's in their care plan." (local authority manager)

5.19   There was also doubt about how some people might handle difficulties with personal assistants if they were directly responsible for them. Professionals could think of individuals who they felt would have a problem handling awkward or difficult situations with employees. This perhaps highlights a need for training not only on practical aspects of managing Direct Payments, but around individual assertiveness and negotiation skills.

5.20   Particular concerns were expressed about people with dementia becoming employers and how they would handle the relationship with a personal assistant:

> *"Depending on how their dementia develops, it is easy to dislike people so staff may change frequently. If they have multi-infarct dementia, they may not recognise staff coming in the following day. There would need to be good intensive training for any person becoming an employee to understand and become really au fait with the issues of dementia."* (voluntary sector manager)

Insufficient safeguards/fear of exploitation

5.21   Professionals were concerned about the potential for exploitation by relatives and by unsuitable personal assistants, and the importance of safeguards to be in place if users were to employ their own personal assistants.

IMPACT OF DIRECT PAYMENTS ON CURRENT SERVICES

5.22   There were general concerns about the impact Direct Payments might have on the workload of existing paid workers both in the voluntary sector and in social work departments.   One professional argued that encouraging people to use Direct Payments instead of agency-provided services would have a negative impact on the range and quality of specialist mental health services available to those who did not opt for Direct Payments:

> *"Ultimately current structures will be challenged. The dedicated team here is a good thing and we need to know that the funding is there to sustain it. There's an efficiency in aggregating a pooled pot of money and staff and using as directed. While I think Direct Payments is far more empowering it's problematic. There may be a critical point when we cannot manage services properly if they are not sufficiently funded if more people became employers."* (local authority manager)

5.23   Professionals in both the statutory and voluntary sectors feared that implementing Direct Payments would change the "balance of services" for the worse. Areas with well-developed specialist mental health services felt most threatened:

> *"I have concerns about how Direct Payments will affect the future of services. If people can choose private services and we lose income it could have an*

adverse affect on what we can provide or the local authority, which in turn
means that it could have a knock on affect on those who cannot afford to pay
for private services." (voluntary sector manager)

5.24   Users, on the other hand, suggested that one of the positive effects of increasing choice through Direct Payments could be that existing services would be forced to "smarten their act up" or go out of business. The previous chapter also highlighted the suggestion of one user that pooling resources between a number of users may be a cost-effective way of meeting needs, benefiting from economies of scale while also being user-led.

SUMMARY

5.25   This research identified significant attitudinal and practical barriers to the implementation of Direct Payments to mental health service users. As in the previous study by Witcher et al (2000), it found perceived threats to the funding or future of services provided directly by the local authority, anxiety about people's ability to manage payments, and concerns about the support available. Additionally, it identified issues with community care assessments; a lack of knowledge and understanding of Direct Payments among professionals, mental health service users and carers; and a perception that more guidance was needed on aspects of Direct Payments including the eligibility of mental health service users for Direct Payments. A particular gap was the lack of knowledge of the different ways that recipients of direct payments can be supported to manage.

5.26   None of the barriers identified in this research were new or insurmountable. The negative views of Direct Payments expressed were in marked contrast to research studies involving actual recipients of Direct Payments, which have found recipients identifying few, if any, disadvantages (Witcher et al, 2000; Heslop, 2001). This suggests that fears and anxieties are largely dissipated once people start using Direct Payments, or that ways can be found to overcome these barriers. The next Chapter explores the supports identified by participants that would enable mental health service users to have better access to, and to manage, Direct Payments.

CHAPTER 6: SUPPORTING MENTAL HEALTH SERVICE USERS TO ACCESS DIRECT PAYMENTS

INTRODUCTION

6.1   Research participants believed that most mental health service users and people with dementia would need some form of support to use Direct Payments. This Chapter presents the findings on the types of support they identified. It should, however, be remembered that participants were being asked about a hypothetical situation, not one they had direct experience of, and these responses should be considered with this in mind.

PERSON CENTRED ASSESSMENT

6.2   Professionals suggested that the cornerstone of Direct Payments was good assessment, which needs to involve the person being assessed centrally in determining what his/her needs are. Hasler et al (1999) suggested that assessment for Direct Payments requires a new relationship with users and a new approach to allocating community care resources, including provision for self-assessment.

6.3   Respondents to this study felt that there were deficiencies in the area of community care assessments for mental health service users, both in terms of access and the way assessments were carried out. Improving assessments has implications for the pre- and post-qualifying training of care managers in person centred approaches. As one local authority manager suggested – "we would have to train staff to look more imaginatively at people's needs".

6.4   Care managers are in a position to present Direct Payments as an option to mental health service users, and should be knowledgeable enough to be able to advise potential recipients. This research showed that mental health service users, including people with dementia, were not routinely told about Direct Payments. The Research Advisory Group suggested that the practice in Essex County Council of including a question within its community care assessment about whether Direct Payments had been considered for the individual, and if not, why not, was an example of good practice. It was suggested by local authority managers that an individual's care manager, or another care manager with greater knowledge of Direct Payments, had a role in offering general advice on Direct Payments.

PUBLICITY AND INFORMATION

Promote Direct Payments to mental health service users

6.5   The previous chapter reported the finding that awareness of Direct Payments among mental health service users, their relatives and families and among professionals in this field was low and in some cases non-existent. Promoting awareness would, therefore, be an obvious first step in making Direct Payments accessible to people with mental health problems or dementia. Participants suggested a number of ways in which Direct Payments

could be promoted to people with mental health problems. The main message was "tell mental health service users about Direct Payments". However, awareness raising would also require sensitivity as in the case of "people with dementia who had not acknowledged their illness".

6.6　　Participants suggested promoting Direct Payments through media campaigns, producing information on cassettes, leaflets, and organising a road show involving existing recipients of Direct Payments who were themselves mental health service users. Social work staff needed training about Direct Payments so that they can "spread the word". Road shows and generally disseminating information about Direct Payments to service users, groups and voluntary organisations supporting mental health services users and people with dementia would enable further dissemination by word of mouth. To an extent, it was felt the focus groups had contributed to this process.

6.7　　One care manager felt that "face-to-face contact is better than an advert", and that an "educative type of approach" was required. A relative/carer of a man with dementia agreed that speaking to recipients of Direct Payments who had similar difficulties as her husband might help them:

> *"Maybe just to speak to someone who has been through all that themselves, and maybe they can say to you 'it has worked out alright and everything is fine'". (carer)*

6.8　　Independent Living Centres were thought able to provide general information and advice on Direct Payments, but potential recipients also needed information about the local scheme and how it operated. The consensus from interviewees was that, at least initially, mental health service users would find it helpful for existing support workers, care managers and others whom service users know to discuss Direct Payments with them.

Provide accessible information

6.9　　There was a major gap in information about Direct Payments to mental health service users, not only the provision of general information but in providing answers to specific questions people had about eligibility and practical issues. For example, what happened to personal assistants when employers went into hospital for a significant period of time? What happened when employees were sick, what contingency arrangements could be made? What could Direct Payments be used for?

6.10　　Participants identified the need for information on the 'nuts and bolts' of Direct Payments. Once the concept of having a cash payment for services was grasped, people needed to know how the local system worked and what the processes of applying, assessment, receiving payments and accountability were, as well as the kind of support they might receive.

6.11　　Information was needed about aspects of hiring and firing staff and what was good employment practice. There was also a need for information about local agencies providing support if individuals choose to deal with agencies instead of hiring staff directly.

6.12   It was suggested that there was a need for an information structure. One voluntary organisation manager felt that local authorities should be provided with independent funding to enable them to do this. Most important of all, participants emphasised that information about Direct Payments had to be accessible and relevant to mental health service users, and should include the perspectives and stories of individuals with mental health problems or dementia who had made use of Direct Payments.

LEGISLATION & GUIDANCE

Eligibility

6.13   Low take-up by mental health service users is identified as a cause for concern in the Direct Payments literature (Heslop, 2001; Maglajlic et al, 2000), and indeed was the reason for undertaking this research. This study found only two mental health service users in Scotland to be receiving Direct Payments. The majority of mental health service users did not know about Direct Payments and if they had heard about it, they were unsure if they were eligible.

6.14   The practical interpretation and implementation of recipients being "willing and able to manage a payment, alone or with assistance", currently serves to exclude people who may be able to consent to changes in the way their support is delivered but may not understand the full implications of a Direct Payment. Holman & Bewley (1999) concluded that the legislation and policy guidance was not written with people with learning disabilities in mind. Nor does it appear to have had mental health service users in mind.

6.15   People needed clearer information about eligibility and who should be excluded from Direct Payments. Such criteria would need to be publicly available through accessible documents. Further, local authorities were felt to need more guidance about what managing a Direct Payment 'with assistance' might mean in practice.

6.16   Proposed changes in the Better Care for All Our Future White Paper (Scottish Executive, 2001), including making it a duty for local authorities to offer Direct Payments as an alternative to providing services, enabling recipients to purchase local authority services as part of their care package, and allowing attorneys or guardians (under the Adults with Incapacity (Scotland) Act 2000) to set up, vary and receive Direct Payments on behalf of a Direct Payment recipient, have great potential for addressing some of the difficulties identified by this research.

ACTIVE & INDEPENDENT SUPPORT

6.17   Supportive organisations had an important role to play in supporting mental health service users to access Direct Payments and in supporting local authorities. Support organisations could ensure the availability of good information about Direct Payments and the practical support needed to help individuals manage and maintain them. Engaging an agency to manage employment issues would resolve many of the concerns expressed by the research participants.

Getting ideas about how to use Direct Payments

6.18   The mental health service users who participated in this research had found it beneficial to have a co-facilitator in the focus groups who was a disabled person with experience of employing personal assistants and of independent living issues. By extension, they were attracted to the idea of having a "personal explanation", or "people in the same situation" with whom they could discuss Direct Payments and how they might be used. The preference was for a person with mental health problems to be involved who could confirm that "it worked for me and I've got the same problems as you." It was valuable to ask questions and discuss practical issues face to face with others, especially those with first hand experience of Direct Payment. It was suggested that central and local government could consider organising road shows and seminars involving recipients of Direct Payments:

> *"I think for someone who's actually experienced this, who's gone through it, the experience you have, I think is the person I would speak to rather than a helpline or read leaflets." (mental health service user)*

6.19   One of the most effective ways of promoting Direct Payments was felt to be through word of mouth and through involving recipients of Direct Payments speaking to other users about their experiences.

The need for training

6.20   Most aspects of Direct Payments are new to mental health service users and therefore many would be ill equipped to manage a payment or personal assistants, or to negotiate with service providers. Training needs were identified around staff selection and recruitment, hiring and firing and generally managing employees, working within employment law, good employment practice etc.

6.21   Specific training would be necessary on managing the money and how to budget and satisfy specific accountability requirements of the local authority. This training would therefore need to be local. In addition, there were other training needs: for example, assertiveness, decision-making, and negotiation skills.

6.22   One voluntary organisation felt that if Direct Payments were to be offered, the local authority should provide a training package or buy in a service to provide that information to users.

Support in handling the money

6.23   The research identified a major anxiety felt not only by professionals, but by users and carers, that mental health service users will have difficulties handling the money. One man with dementia said, "money and me don't mix well together now". There were concerns about whether the money would be spent on what it was intended for. It was recognised, however, that the level of support required in handling money would be largely dependent upon the individual and their ability to deal with money. While some people would need

help from the outset, others would need help only when they were ill. This suggests a need for clear systems of accountability and flexibility in how payments are made, and for considering indirect payment systems as the best option for some people. Contracting services through an agency may be a positive choice for mental health service users, including people with dementia, who are anxious about managing financial payments.

Importance of independent support organisations

6.24   This research identified a need for local support organisations to offer expertise on Direct Payments, including what it means to be an employer, providing training on the practical issues of Direct Payments, advice and advocacy and potentially to "step in when you're down and don't feel particularly able or capable to do things". In Authority B, a support organisation for Direct Payments existed and this was well placed to offer advice and support, but users had reservations about this agency's understanding of mental health. Most participants believed that organisations should be independent of service providers including the local authority but should have expertise in mental health.

6.25   For some mental health service users it would be necessary from the outset to designate another person/body or third party to take on all the practical responsibilities associated with managing a Direct Payment such as PAYE etc. This may or may not be the same support organisation providing general advice and support. Such an organisation would need to be independent of service providers if they were to administer the payment and advocate on the person's behalf. It would require negotiation and in one managers' words a "proper partnership between the client and the agency". There were also reservations about this idea:

> *"I'd have major concerns about agencies being given the money – having seen how some are run – too much money would be creamed off for charges for services used." (advocacy project)*

6.26   Although it was generally not thought essential that support organisations were solely user-led, it was vital that they understood mental health problems and that users played a key role in the organisation. It was essential though that this agency was not a service provider as this would compromise their advice. They should "have a person centred approach and be imaginative to 'independent living'".

6.27   One participant suggested it should be the government's responsibility to employ Direct Payment advisors. They would be similar to those who advise on setting up in business.

6.28   Local authorities still perceived a role for social work in "monitoring that everyone participating is involved in an equal partnership and that no one person is railroading how it is operating."

6.29   Support organisations might also take on a service brokerage role, although this was not discussed in any detail in the study. Independent advocacy services and service brokerage are not widely available in Scotland. Although it was expected that care managers should provide such information at assessment, local authority managers said that comprehensive information about agencies and what they provide "isn't readily available" to

them. Community care forums and other voluntary bodies in some areas had started to plug the information gap.

Development of support arrangements

6.30   There were clear concerns about exploitation and therefore about investing decisions in close relatives in some cases. There was interest in, though limited knowledge of, arrangements such as appointing an attorney, having a circle of friends/support, setting up a board of trustees etc. A circle of support ensured that "no one person involved in their care has a monopoly".

6.31   Several voluntary and user based forums were mentioned as having a role to play in supporting mental health service users in their decision to have a Direct Payment. Some of these organisations also offered payroll support and services in managing staff. In reality, it will be helpful to have a network of organisations offering advice and support on Direct Payments.

PLANNING

6.32   All participants identified the need for contingency or future arrangements whereby a designated person or group would be given permission to "take the reins if things get worse". Users were familiar with the concept of pre-planning in respect of treatment plans:

> *"There is a very useful form. It's where if you become unwell, and I don't think we can actually work out what that is, then you can write down what helps you recover beforehand when you have insight and that form can be referred to when you are ill, whatever that happens to be." (mental health service user)*

6.33   Having some form of advance planning or advance directive would be essential for many mental health service users and would ensure that when they were ill they retained as much control and choice as they were currently capable of exercising, and were able to regain full control when they became well again. Users wanted the flexibility for such arrangements to involve a friend or relative as well as an independent body. Heslop (2001) describes how advance planning with personal assistants can ensure that Direct Payments work for people with fluctuating illnesses.

USER FRIENDLY DIRECT PAYMENT SCHEMES

6.34   Research participants felt that if Direct Payments were made widely available to mental health service users there would need to be safeguards in place to ensure that the money was used for the purposes intended. However, it would be counter-productive if this were translated into overly bureaucratic procedures that were off-putting to users.

6.35   To be successful, there needed to be flexible ways of paying the money that truly addressed users' fears about the paperwork and bureaucracy while retaining the spirit of the Direct Payments Act. As Holman & Bewley (1999) maintain, to be helpful to users

procedures, whilst necessary, need to be accessible, easy to understand and straightforward. For this to happen, there would need to be proper consultation and involvement of people with mental health problems and dementia at local and national level advising on the setting up of schemes.

6.36   One professional felt it would also be helpful to put transitional arrangements in place effectively freezing agency-provided services while individuals tried Direct Payments and entitling them to return to receiving such services if, for whatever reasons, Direct Payments did not work out for them.

SUMMARY

6.37   Although it was difficult for participants in an abstract sense, to anticipate what the practical implications of Direct Payments might be, a number of concrete practical proposals for support to mental health service users emerged. The previous chapter identified some issues with community care assessments. It is not surprising therefore, that one of the proposals was to develop more person centred assessment as the necessary foundation for Direct Payments. Further publicity and information was needed so that mental health service users have a better chance of making an informed decision whether they want, and can manage, a Direct Payment.

6.38   In response to earlier research (Witcher et al., 2000) the Scottish Executive has committed £530,000 for a two year development project 'Direct Payments Scotland'. The project aims to put in place the support systems needed at a local and national level to help develop Direct Payments schemes for all client groups and increase take up.

6.39   Amending legislation and guidance, in particular clarifying the criteria for eligibility, could advance the inclusion of mental health service users. There is a need for active support for Direct Payments provided by independent organisations. Because of the nature of mental health problems and dementia, there is a need for planning for contingencies and for the future. Further, there is a need to set up Direct Payment schemes that are user-friendly and do not put people off with unnecessary bureaucracy and paperwork requirements.

6.40   Participants identified that most mental health service users and people with dementia would need some practical support both to agree to Direct Payments, to manage the payments, and to manage any employees. Active local support organisations would need to work closely with local authorities and user groups. Support organisations would be a source of peer support and advice, would help with ideas about how to use a Direct Payment, and provide training and support in handling the money.

6.41   Given that coping with fluctuating illness was a main concern of all participants, forward planning or agreeing a form of advanced directive to provide for decision-making in the event of incapacity, either of a temporary or a more permanent nature, was felt to be essential. Finally, procedures for Direct Payments need to be accessible, easy to understand and straightforward so that mental health service users were not put off by unnecessary bureaucracy and paperwork.

CHAPTER 7: CONCLUSIONS AND IMPLICATIONS FOR POLICY AND PRACTICE

INTRODUCTION

7.1   The purpose of this study was to examine how Direct Payments could be made more accessible to mental health service users including people with dementia. Mental health service users, carers/relatives and professionals supporting them, were asked what they thought of the idea and what the obstacles and solutions might be. In this final Chapter, the research findings are discussed and conclusions for policy and practice drawn.

DISCUSSION

7.2   The Scottish Executive (2001a) is committed to promoting more widespread take-up of Direct Payments, including take-up by mental health service users, and has proposed that Direct Payments should be available as a right. This research found that such wider take-up cannot be achieved without first overcoming a number of problems. The first of these is that most mental health service users have not yet heard of Direct Payments. Further, while service users and professionals did display an interest in the notion when it was introduced to them, the research also found very real and practical challenges that it would be short-sighted to ignore.

7.3   The majority of people whose views were sought through this research were being asked to think about Direct Payments for the very first time. It was therefore necessary to inform at the same time as exploring their perspectives. Even in the two authorities with a Direct Payment scheme, mental health or dementia service professionals knew little about the scheme apart from its existence: Direct Payments were not perceived as an issue that impacted on mental health services at all. In itself, lack of information and knowledge of Direct Payments is a fundamental obstacle, as well as being symptomatic of diverse attitudinal and practical barriers.

7.4   It seems prudent, before Direct Payment schemes become mandatory, to address the problems or obstacles to their use by mental health service users. One of the major concerns of all the research participants was around the ability of mental health service users to manage a payment given the fluctuating nature of mental illness and, in the case of dementia, the fact that it is a worsening condition. There was a general antipathy to the idea of mental health service users having direct control of money when there was the potential, in the eyes of the research participants, for misspending and mismanagement when individuals became ill. It would be discriminatory, however, to use this concern as grounds for a blanket exclusion of all people labelled as having mental health problems or dementia, given that the difficulties they experience are so diverse and individual.

7.5   The Adults with Incapacity (Scotland) Act 2000 and the review of mental health legislation will undoubtedly have a bearing in the future on the assessment of capacity and the arrangements, such as power of attorney, that enable others to take over when an individual is no longer able to make decisions, particularly in the case of people with dementia. However, as Holman & Bewley (1999) argued, it is important that assessment of capacity to consent to Direct Payments is clear about the choices and decisions involved, the level of change in someone's life that Direct Payments might bring about, and what the person is consenting to. Furthermore, those implementing Direct Payments need to be aware

that recipients can receive a great deal of help in managing a Direct Payment. The research findings suggest that mental health service users might be excluded by the prejudicial and judgemental attitudes of some staff who do not consider them 'able to consent' to Direct Payments, nor able to manage in the longer term.

7.6   The issue of consent and control continues to underlie the primary reluctance of local authorities to consider Direct Payments for mental health service users, as it does for others including people with severe learning disabilities (Holman & Bewley, 1999). In fact, the research on Direct Payments suggests that many of the core barriers to Direct Payments are common across all community care groups (Witcher et al, 2000; Dawson, 2000). The framing of current Direct Payments legislation and guidance does not take into account the implications for people with mental health problems or dementia in respect of how to respond to fluctuating or worsening conditions. As Dawson (2000) emphasised, care managers need to start from an assumption of competence rather than incompetence. This author has devised a useful competence checklist to help assessors give proper consideration to whether someone is unable to make a decision. The challenge for policy and practice is to work through the problems and to ensure that the spirit of the Act is implemented and that the legislation works for, not against, mental health service users.

7.7   Since research participants had limited knowledge of the potential support arrangements that can assist individuals to manage in these circumstances - for instance user-led trusts, circles of friends/support, involving relatives or friends and so on - being unable to manage either temporarily or permanently was perceived as THE major obstacle to implementing Direct Payments. Such arrangements have been more extensively explored in relation to people with severe learning disabilities and much of what has been learned should be transferable into the mental health field.

7.8   In the short term, local authorities and voluntary organisations supporting mental health service users who want to implement Direct Payments to mental health service users could do worse than to invest in a copy of the guide to local authority implementation and management of Direct Payments, "Direct Routes to Independence" by Hasler et al (1999) and "Funding Freedom 2000" by Holman & Bewley (1999). These should be read in conjunction with the widely available official guidance about Direct Payments (Scottish Office, 1997).

7.9   One way of addressing the barriers identified by this research could be through setting up pilot or demonstration projects. These would have the specific purpose of providing Direct Payments to mental health service users, working through any problems, evaluating the outcomes and providing a firmer foundation for the longer term. This could be undertaken with two or three willing and enthusiastic local authorities and would help identify circumstances where Direct Payments can work, and others where they definitely will not work, and thereby contribute to clarifying and sharpening the ways that eligibility criteria are applied in practice. The National Pilot to Promote Independent Living in England (Davidson, 2001) is a good example of this kind of developmental and action research model, and should provide valuable lessons on which to build demonstration projects in Scotland.

7.10   The National Pilot, which runs for 3 years and is managed by the King's College, has direct involvement of mental health service users as project coordinators, as well as local authorities, voluntary agencies and health services. The project aims to promote existing Direct Payments schemes, and assist local authorities to build on them with other client groups and to break new ground in implementing them with mental health service users.

While the new Development Project (Scottish Executive, 2001b) to promote Direct Payments in Scotland, 'Direct Payments Scotland', will actively promote and develop Direct Payments generally, the findings from this research suggest that it may be beneficial also to focus specifically on promoting Direct Payments to mental health service users, ideally through Direct Payments Scotland.

7.11   The importance of a clear context of choice, control and supported decision making as the foundation for Direct Payments cannot be emphasised enough. This research found that community care services in mental health presented traditional options and limited choice and availability on the whole. Participants felt that there were shortcomings in the range of services offered and how these services met individual needs, especially in the ways people were supported during the day. Direct Payments potentially offer individuals greater flexibility, choice and control and the experience of the few mental health service users in the UK who are recipients suggests that mental health service users can experience such benefits (Heslop, 2001).

7.12   Fundamental issues around community care assessment were raised. The research points to implications for the way community care assessments are carried out. The challenge for policy makers, perhaps, is in how best to support local authorities to make assessments more person-centred, to involve the service user in identifying his or her needs and generally make them more sensitive to the needs of this client group. Independent advocacy as envisaged in the recent Scottish Executive (2000) "Guide for Commissioners" has a clear role in supporting those who have difficulty expressing what they need, although it is usually a limited resource. Hasler et al (1999) provide useful guidance on self-assessment for Direct Payments and advocate consultation with Centres for Independent Living and the involvement of peer advocates.

7.13   The finding that mental health service users are not routinely told about Direct Payments when assessed for community care services reveals a gap in practice that needs to be challenged. Mental health service users in other parts of the UK testify to the positive benefits of Direct Payments (Heslop, 2001). One local authority in England, Essex County Council, has incorporated a question as part of the assessment proforma which asks whether Direct Payments are being considered and if not, why not. It may be worth considering duplicating this practice in the assessment procedures of local authorities in Scotland.

7.14   This research found that consent and ability to manage a Direct Payment was often interpreted as an 'all or nothing' concept. It was commonly assumed that recipients would need to become direct employers of personal assistants, as well as manage financial payments. Few participants, for example, had thought in terms of individuals exercising choice to engage in Direct Payments on an agency basis or of using indirect payments. The possibility of using Direct Payments in this way, or of using indirect payments to third parties such as a Council for Voluntary Service, should not be ruled out. Research participants were anxious about handling paperwork and the responsibilities of becoming an employer, and while indirect payments are not a substitute for Direct Payments they might be used as a legitimate option available to mental health service users, even if only as a temporary measure before accepting Direct Payments.

7.15   The benefits of user-controlled trusts (see Holman & Bewley, 1999) and other proxy arrangements could usefully be explored as part of the solution to anxieties over handling the financial and employee responsibilities of a Direct Payment. User-controlled trusts mean the

individual does not have to handle the money directly while retaining ultimate control on how it is spent. The individual can choose to appoint someone to act on their behalf. This would provide the in-built flexibility to take account of life changes and fluctuating conditions that were the main concern for mental health service users in this research.

7.16   To be considered a viable option, Direct Payments need to be easy to access and understand. This research found that to be supportive to mental health service users, Direct Payment schemes should avoid being overly bureaucratic or setting up complicated systems of accountability. Another flexibility that should be considered, given the hesitancy about trying Direct Payments, is the idea of freezing an individual's eligibility for community care services provided by the local authority or voluntary agency when he/she moves over to Direct Payments. Creating a probationary period between receiving community care services in the "normal" way and settling finally on Direct Payments would provide an opportunity for the user to make an informed decision as to whether Direct Payments were the right choice for them.

7.17   Many of the findings point to the need to plan and to ensure sufficient safeguards are arranged at the outset when a person starts to use Direct Payments. Mental health service users in this research had some experience of advanced planning for medical treatment, and this could be translated into setting up advanced directives for independent living support in the context of receiving Direct Payments. There is immense expertise which can be tapped within centres for independent living both in Scotland and England, especially in light of the National Pilot Project, which is working in conjunction with the NCIL, and within other networks such as the Scottish Personal Assistant Employer's Network. This could and should be brought together with that of existing mental health service user groups to ensure that support is relevant to people with mental health problems and dementia.

7.18   One of the barriers identified was a fear on the part of professionals that Direct Payments constituted privatisation by the back door and might change mental health services for the worse. The fear was that it might reduce the current restricted choice in local authority services even further, especially for those who were either not eligible for or chose not to have Direct Payments. The Scottish Executive's proposals to enable recipients to purchase local authority services would go some way to relieving this particular concern. However, as the Research Advisory Group pointed out, this would not address the particular concerns of the voluntary sector if local authorities were to choose to redirect existing funding, much of which is currently used to commission mental health services from the voluntary sector, to resource Direct Payments.

7.19   Another fear expressed was that mental health services would lose a valuable 'early warning system' if personal assistants were not part of the team of statutory and voluntary sector support. This fear seems to presuppose either that a personal assistant employed directly by a service user would not pick up or report warning signs, should the service user start to become ill, or that the statutory services could not intervene. In fact, such eventualities can be anticipated and planned for through addressing such issues in the training of personal assistants, and the use of advance directives and other means, but again neither professionals nor users seemed to be aware of this. Furthermore, of course, instituting Direct Payments does not mean total disengagement by statutory services; there should continue to be regular reviews by the care manager or equivalent in charge of the package of care, and both health and social services should be ready to step in with enhanced support if the person's health changes. Such gaps in awareness should be dealt with through educating

local authority and voluntary sector staff about Direct Payments, and the making of advanced directives should be encouraged.

CONCLUSIONS

7.20   The overall implementation of Direct Payments in Scotland was found to be disappointingly slow. It was also inequitable: mental health service users, for the most part, were not being offered the choice to opt for Direct Payments. In a small way this research has contributed to beginning a process of dialogue with users, carers/relatives and mental health professionals. A positive development would be to follow up with ongoing consultation and involvement of users, carers and the organisations that support them in the development of Direct Payments.

7.21   While Direct Payments potentially offer a way to facilitate more flexible service provision and to offer mental health service users greater control over their support, this research identified a number of barriers which first need to be overcome. At the heart of getting it right for mental health service users are person-centred assessment, proper support, advice and access to training, and sufficient flexibility in Direct Payment schemes to allow for different arrangements and to manage transitions. In other words, what is needed is community care assessment and support that are dynamic and person-centred.

7.22   More equitable and accessible implementation of Direct Payments that included mental health service users would contribute significantly to the effectiveness of national and local social inclusion strategies. In particular, the opportunity to gain access to support services at those times and in the specific ways sought by users would contribute appreciably to overcoming the wider barriers to inclusion that mental health service users often encounter.

Scottish Health Feedback
November 2001

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ANNEXES

ANNEX 1: DIRECT PAYMENTS LEGISLATION AND GUIDANCE - OCTOBER 2001

1.   The Community Care (Direct Payments) Act 1996 gives local authorities the power to make cash payments for community care services direct to disabled people. The Community Care (Direct Payments) (Scotland) Regulations 1997 and the 2000 Amendment Regulations identify those groups of individuals to whom direct payments may be made and the associated conditions.

2.   The legislation is enabling. Local authorities have a power to make direct payments. It is not a duty. People cannot be forced to accept them if they would prefer the authority to arrange the service. People can only receive direct payments if they would otherwise have received community care services.

3.   No maximum or minimum on the amount of a direct payment has been set, either in the amount of care that is needed or the amount of money that is given. It is up to the local authority to decide how much to give people.

4.   The definition of disability includes any type of disability, whether physical or learning disability; and people who are disabled by illness, for example, mental illness or HIV/AIDS.

5.   The 1997 Regulations allowed disabled people between 18 and under 65 only to participate; people who start to receive direct payments before the age of 65 could continue to receive them after that age. Since 7 July 2000 people aged 65 and over have been eligible to receive direct payments and since 20 December 2001 16 and 17 year olds and disabled parents who wish to purchase services for their children have been eligible to receive them.

6.   People must be able to manage direct payments alone or with assistance, but the disabled person must be the one in control, the one who makes the choices and who accepts the responsibility.

7.   People who are subject to certain mental health or criminal justice legislation will not be able to receive direct payments. These are people who are required to receive certain services as part of their treatment or rehabilitation and it would not therefore be appropriate to give them control over these services.

8.   Direct payments cannot be given for permanent residential care. They can be used to purchase temporary residential care subject to a maximum set down in Regulations.

9.   Direct payments cannot be used to buy local authority services, as local authorities cannot sell services in this way.

10.   Direct payments cannot be used to pay close relatives. The Regulations prohibit direct payments from being used to pay a spouse or partner, or a close relative living in the same household. In addition, the guidance says that direct payments should not be used to pay close relatives living elsewhere, or friends living within the same household unless this is the only way of providing the service required. This restriction was relaxed in 2000 to allow direct payments to be used to employ close relatives living in a different household where this is the most appropriate way of providing the service required.

11.   Local authorities can require someone to make a financial contribution to the cost of their care package, just as they can charge them for services. As with non-residential services, it is up to the social work department to decide whether they charge people who receive direct payments. The guidance reminds local authorities that they should ensure fair treatment between service recipients and direct payments recipients by charging both sets of people in the same way for equivalent services.

12.   Local authorities should monitor and review people receiving direct payments - as they do people receiving services - to ensure that needs are being met. Once a local authority has given a direct payment it still has an ongoing responsibility towards that person.

Community Care Division
October 2001

ANNEX 2: TYPE OF SCHEME BY LOCAL AUTHORITY

Table 1: Type of scheme by local authority

Local Authority area	1999 Survey			2001 Survey			Number	Past	Current	Plans
	Pilot	DP	Quasi	Pilot	DP	Quasi		MH users	MH users	MH users
Aberdeen City	yes	-	-	-Yes		-	4	yes	no	Yes
Aberdeenshire	-	yes	-		yes		7	yes	no	Yes
Angus	yes	-	-	- Yes		-	24	D/K	D/K	D/K
Argyll & Bute	-	yes	-	-	Yes	-	2	no	no	Yes
City of Edin.	-	yes	-		yes		50	D/K	no	yes
Clackmannanshire	-	-	-	-	-	-	-	-	-	-
Dumfries&Galloway	-	-	yes	-	Yes	-	8	no	no	yes
Dundee	-	-	yes	-	-	yes	17	no	no	no
East Ayrshire	-	-	yes	-	-	yes	19	yes	no	yes
East Dunbartonshire			yes			yes	19	D/K	no	yes
East Lothian	yes	-	-	-	Yes	-	5	no	no	Yes
East Renfrewshire	-	-	yes	-	-	yes	20	no	no	Yes
Falkirk	-	-	-	-	-	-	-	-	-	-
Fife	-	yes	-	-	Yes	-	37	yes	yes (1)	Yes
Glasgow	-	-	yes	Yes	-		15	D/K	D/K	D/K
Highland	yes	-	-	Yes		-	11	no	no	Yes
Inverclyde	-	-	yes	-	-	yes	50	yes	Yes (4)	Yes
Midlothian	-	-	yes	-	-	yes	11	no	no	Yes
Moray	-	yes*	-	-	-	yes	4	no	no	Yes
North Ayrshire	-	-	yes	-	-	yes	17	no	no	Yes
North Lanarkshire	yes	-	-	Yes		-	5	yes	yes(1)	Yes
Orkney Islands	yes	-	-	Yes		-	0	no	no	No
Perth & Kinross	-	yes	-	-	Yes	yes	5 (DP)	no	no	No
Renfrewshire	yes	-	-	Yes		-	3	no	no	D/K
Scottish Borders	yes	-	-	Yes		-	10	no	no	Yes
Shetland	-	yes	-	-	Yes	-	0	no	no	Yes
South Ayrshire	-	yes	-	-	Yes	-	20	no	no	No
South Lanarkshire	-	-	yes	-	-	yes	56	no	no	Yes
Stirling	-	-	-	-	-	-	-	-	-	-
WestDunbartonshire	-	-	yes	-	-	yes	6	no	no	no
West Lothian	-	yes	-	-	Yes	-	7	no	no	yes
Western Isles	-	-	-	-	-	-	20 in 'other'	D/K	D/K	D/K

*Although Moray Council was identified as having an operational Direct Payments Scheme in the previous survey, it came to light that this has always been a third party scheme.

ANNEX 3: RESEARCH INSTRUMENTS

Focus group topic guides

- User groups (mental health service users and people with dementia)
- Carers of people with mental health problems or dementia

Interview schedules

- Service user
- Carer
- Care Manager

Interview Guides

- Voluntary sector project manager/coordinator
- Local authority social work manager (mental health/older people) and Senior Care Manager (mental health or dementia)

RESEARCH INTO DIRECT PAYMENTS TO MENTAL HEALTH SERVICE USERS

FOCUS GROUP TOPIC GUIDE   -   USER   GROUPS   (MENTAL HEALTH SERVICE USERS/PEOPLE WITH DEMENTIA)

Notes to facilitator before starting: -

➢ *Go over the aim of the study – to explore from different perspectives whether people with mental health problems could receive cash payments instead of community care services, whether there'd be any particular problem or barriers and what support might be needed to make it work.*

➢ *Re-assure group re confidentiality, not answering questions not comfortable with, etc. etc.*

➢ *Encourage people to talk from their own experience but also to reflect if possible on how it might be for people with mental health problems generally.*

➢ *Go over the two main topics for discussion – first we want to explore your experiences of getting paid help to stay at home; second we want to talk about the idea of getting cash or direct payments instead of services and what you think of it, whether you have any concerns and what kind of support you or people in a similar situation to yourself might need to make it work.*

1.   EXPERIENCES OF PAID HELP TO SUPPORT INDEPENDENT LIVING

Preamble: First I want to understand something about your situation right now and the kind of paid help you get to live independently. I understand that you're users of mental health services/services for people with dementia is that right? I'd like to ask you a few questions about your experiences of services to begin with.

1. What kind of community care services are you getting to stay at home just now? Who from? (e.g. social work department, voluntary organisation -which one?)

2. What things do you need <u>help with at home</u>? Are you getting this, and who from?

3. What do you or would you <u>like to do during the day</u>? Do you need any support to do that? Do you get it and who from?

4. Do you need any kind of paid help/support at the<u> evenings and weekends</u>? Do you get it now, and who from?

5. *Have you ever thought you might like to change the help you get in some way? Or get a different kind of help?* (Prompts: change the person who comes, what they do, or the time they do it, get a different kind of help entirely? Can perhaps use examples from the variety of types of help described already by different participants)

6. Have you tried to get the kind of change you wanted? What happened? What do you think of that?

7. Do you face any other difficulties in getting the support you need?

2. Exploration of DP

Preamble: We've talked about your experiences of services to help you stay at home and some of the difficulties you face, now we want to move on to talk about another kind of community care option – cash payments or 'direct payments' to support independent living, and whether you'd be interested in this, what concerns you might have and what support could overcome or avoid such problems.

Input from Peter re explaining DP *– e.g.. instead of getting services, the local authority can make a cash payment instead for the individual user to buy the services or support they want. Only a few people get direct payments in Scotland but this is growing slowly. It gives users more control over the help they get and more choice in what help they get and who provides it. Some people choose to become an employer of staff while others choose to buy services. Outline 3rd party schemes and difference with DP. Talk about the issue of "willing and able" to manage a DP and who is eligible. Give time here for participants to ask questions about how schemes work. Facilitator is to make sure all participants are clear about the main features of the schemes before proceeding.*

1) Thinking about your situation now, would getting the money instead of services be a help to you? *(Prompt: e.g. to get the help you need at home, or during the day, or at evenings and weekends)*

2) Had you heard of DP before today? Who from?

3) Would you know how to get a DP if you wanted one and who to ask?

4) What do you think might be the advantages/attractions of getting money/cash instead of community care services? *(Prompt: more choice and control over eg who helps, when they do it and what they do, support to do the things you want to in life like get a job or go to college)*

5) What might be the disadvantages/drawbacks? *(Prompt: eg being worried about handling money; having to hire and fire staff; deciding between different services etc.)*

From speaking to people and from other research, we know that some people find it helpful to have particular kinds of support to manage a DP. I'd like now to move on to ask you about the kind of help and support you'd find useful.

6) Would you need any help to decide whether you were "willing and able to manage" a DP, and from whom?

7) What help might other people in a similar situation to yours (mental health service users or who have dementia) need to decide?

8) Would you need information or advice? What about? Format? *(Prompts: general leaflets, helpline, talking to people receiving DP about DP generally, employing staff, how to choose between different services)*

9) Would you need any training? *(eg. on managing the money, becoming an employer etc)*

10) Are there any organisations/individuals you can get this information or advice from now? Are these support organisations run by people with disabilities? Would that be important?

11) Is there any other kind of support that might be helpful, such as being able to talk with other people getting DP?

12) Would you need more intense help at any time – eg would you need someone or an organisation to step in if you became ill every so often/your dementia got worse? What is the best way to provide this?
(Note for the facilitator – in other parts of the country this has sometimes been provided by trusted friends/relatives, advocates, 'circles of support', trustees, attorneys)

13) Some people say DP should be publicised more to people with mental health problems or dementia, do you agree? What's the best way to do this?

14) Are there any other questions you would like to ask?

14/05/01

RESEARCH INTO DIRECT PAYMENTS TO MENTAL HEALTH SERVICE USERS

FOCUS GROUP TOPIC GUIDE – CARERS OF PEOPLE WITH MENTAL HEALTH PROBLEMS OR DEMENTIA

Notes to facilitator before starting: -

➢ *Go over the aim of the study – to explore from different perspectives whether people with mental health problems could receive cash payments instead of community care services, whether there'd be any particular problem or barriers and what support might be needed to make it work.*

➢ *Re-assure group re confidentiality, not answering questions not comfortable with, etc. etc.*

➢ *Encourage people to talk from their own experience but also to reflect if possible on how it might be for carers of people with mental health problems/dementia generally.*

➢ *Go over the two main topics for discussion – first we want to explore the paid help people currently get to stay at home; second we want to talk about the idea of getting cash or direct payments instead of services and what you think of it, whether you have any concerns and what kind of support people with mental health problems/dementia might need to make it work.*

1 EXPLORATION OF HOME CARE EXPERIENCES

Preamble: I want to understand something about your situation right now and the kind of help people get to live independently. I understand that you're caring for someone with a mental health problem or dementia - is that right? I'd like to ask you a few questions about your experiences of services to begin with.

1. What kind of community care services is the person you are caring for getting to stay at home? Who from? (e.g. social work department, voluntary organisation – which one?)

2. What are the things they need help with at home? Do they get this help from any services just now?

3. What do they like to do during the day? Do they need any support to do that? And are they getting this community care services now?

4. What kind of help/support do they need in the evenings and weekends? Are they getting this support right now?

5. *Have you or the person you care for, ever thought you'd like to change the help they get in some way? Or get a different kind of help?* (Prompts: change the person who comes,

A3 - 5

what they do, or the time they do it, get a different kind of help entirely? Can perhaps use examples from the variety of types of help described already by different participants)

6. Have you or the person you care for, ever tried to get the kind of change you or they wanted? What happened? What do you think of that?

7. What other difficulties do people with mental health problems or dementia face in getting the support they need?

2. Exploration of DP

Preamble: We've talked about experiences of community care services for people with mental health problems or dementia and some of the difficulties people face. I want to move on to talk about another kind of community care option – cash payments or 'direct payments' to support independent living, and whether the person you care for would be interested in this, what concerns you might have and how such problems could be overcome or avoided.

Input from Peter re explaining DP *– e.g.. instead of getting services, the local authority can make a cash payment instead for the individual user to buy the services or support they want. Only a few people get direct payments in Scotland but this is growing slowly. It gives users more control over the help they get and more choice in what help they get and who provides it. Some people choose to become an employer of staff while others choose to buy services. Outline 3rd party schemes and difference with DP. Talk about the issue of "willing and able" to manage a DP and who is eligible. Give time here for participants to ask questions about how schemes work. Facilitator is to make sure all participants are clear about the main features of the schemes before proceeding.*

1. Thinking about the kinds of help the person you care for needs, would getting money instead of services be a help? *(Prompt: to get the help needed at home, during the day, or at evenings or weekends)*

2. Had you heard of DP before today? Who from?

3. Would you know how to get a DP for the person you care for, and who to ask?

4. What do you think would be the advantages/attractions of getting the money rather than services?

5. What might the disadvantages/drawbacks be? *(Prompt: eg concerns/worries about person or carer having to handle money; having to hire and fire staff; choosing between different services etc.)*

From speaking to people and from other research, we know that some people find it helpful to have particular kinds of support to manage a DP. I'd like now to move on to ask you about the kind of help and support you'd find useful.

6. Would the person you care for need help to decide whether they are "willing and able to manage" a DP?

7. What support might other people with mental health problems or dementia need?

8. Would they need information or advice? What about? Format? *(Prompts: general leaflets, helpline, talking to people receiving DP about DP generally, employing staff, how to choose between different services)*

9. What kind of training might they need, for example to manage the money, as an employer of staff?

10. Are there any organisations/individuals they can get this information and advice from now? Are these support organisations run by people with disabilities? Would that be important?

11. Is there any other kind of support they might find helpful such as being able to talk with other people who are getting DP?

12. Would they need more intense support at any time – eg would they need someone or an organisation to step in because every so often they become ill/dementia gets worse? What is the best way to provide this? *(Note for the facilitator – in other parts of the country, this has sometimes been provided by trusted friends/relatives, advocates, 'circles of support', trustees, attorneys)*

13. Some people say DP should be publicised more to people with mental health problems or dementia, do you agree? What's the best way to do this?

14. Are there any other questions you would like to ask?

14/05/01

DIRECT PAYMENTS TO MENTAL HEALTH SERVICE USER STUDY

INTERVIEW SCHEDULE – SERVICE USER

Enter codes:

Case Study Number (1-1 to 3-4): ☐-☐

Age: ☐☐

Ethnic background: ☐☐

Date of Interview: ☐☐☐☐☐☐

Initials of Interviewer: ☐☐

Tick the appropriate box:

Sex: Male: ☐ 1
Female: ☐ 2

Mental health problems: ☐ 1
Dementia: ☐ 2

Area: Authority A ☐ 1
Authority B ☐ 2
Authority C ☐ 3

Domestic setting: Own home ☐ 1
Parental home ☐ 2
Living with a partner/spouse ☐ 3
Other relative's home ☐ 4
Supported accommodation ☐ 5
Supported living ☐ 6
Sheltered housing ☐ 7
Other ☐ 8

DIRECT PAYMENTS TO MENTAL HEALTH SERVICE USER STUDY

General points to cover at the start of the interview: -

➢ *Thank you for agreeing to this interview. We really do appreciate the time you are giving us. Explain that they will receive £10 for taking part at the end of the interview.*

➢ *The study is about direct payments and we want to find out what you think about the idea. Don't worry if you don't know much about them, the information we sent you should explain things and I'll try my best to answer your questions but remember I am not an expert on DP.*

➢ *We'd also like to speak to the person who helps you most like a close relative or friend and your care manager and you have given us your consent to contact them.*

➢ *Anything you say will be kept confidential and not passed on to anyone outside the research team. In the report no-one will be able to be identified but we will use some quotations from what people have said. Please feel free to pass on any of the questions I ask.*

➢ *Please remember that speaking to me will not get you a DP if you want one, you will need to contact your local authority to find out more.*

SECTION 1: COMMUNITY CARE SERVICES

1. Have you been assessed by a social worker/care manager? When was this and what did you think of it?

2. What happened after you were assessed? Were you happy with this and the support arranged for you? (*If not happy, probe for reasons and what happened)*

3. What support do you get to help you stay at home? (*this is referring to paid support not that provided by informal carers or networks*)

4. *Have you ever thought you might like to change the support you get in any way? Or get a different kind of help?* (Prompts: change the person who comes, what they do, or the time they do it, get a different kind of help entirely?)

5. Have you tried to get the kind of change you wanted? What happened? What do you think of that?

6. Do you face any other difficulties in getting the support you need?

SECTION 2: PROS AND CONS FOR CASH OR DIRECT PAYMENTS

Before starting on this section, ask the person if they have any questions to ask about DP.

7. Thinking about your situation now, would getting the money instead of services be a help to you? How would it help you? *(Prompt: e.g. to get the help you need at home, or during the day, or at evenings and weekends)*

8. Thinking about the support you need, what might you use this money for? *(e.g. choosing your support worker(s) or which services you want, help to go to work or college instead of a day centre, to visit your relative?)*

9. Would getting the money to buy community care services be an advantage to you? Why? (*if necessary* p*rompt: more choice and control over eg who helps, when they do it and what they do, support to do the things you want to in life like get a job or go to college instead of going to a day service)*

10. Can you see any disadvantages for you in getting cash instead of services? What are they? *(If necessary prompt: eg unsure about handling money; having to hire and fire staff; deciding between different services etc, what happens when you're ill, dealing with paperwork etc.)*

11. Did you know that you could get cash instead of services? Who told you about this?

12. Would you know how to get a cash payment and who to ask?

13. What information or advice could help you decide if this was for you?

SECTION 3: THE SUPPORT YOU MIGHT NEED TO MANAGE A DP

Explain briefly that a cash payment can be given by the LA to a disabled person who has been assessed as needing community care services, as long as they are not subject to special sections of the MH Act. (See Jim's briefing notes or booklets for more detail). These are called 'direct payments'. Sometimes local authorities give the cash to a third party to manage on the person's behalf – this is what's known as a third party scheme. (Authority B has 3rd party scheme; Authorities A and C both have DP schemes).

Also explain that the cash can be used to buy support workers often called personal assistants, and also can be given to an agency who will arrange the support on the person's behalf.

The next few questions are about the help and support you might find useful if you were to manage the money instead of services.

14. How do you feel about managing the money, and would you have any difficulties managing on your own? *(such as with managing the payment, the duties of being an employer including payroll, knowing what services different agencies offer if you want them to arrange the support for you, filling in paperwork for the local authority, having back-up if PAs are ill, something else?)*

15. Would you need help or support to manage the money, and who would you like to help you? *(e.g. a family member, friend, advocate, an organisation who manages payroll, an accountant, etc)*

16. Might there be times in your life when you're unable to manage a payment or support workers? What do you think should happen then? *(e.g. a family member, friend, a group of supporters like a circle of support or group of trustees, an attorney etc take over the duties of being an employer)*

17. How would you feel about that? (*advantages and disadvantages of someone else acting on person's behalf)*

18. What kind of information or advice do you need now? *(Prompts: general leaflets, helpline, talking to people already receiving the money, about the duties of being an employer, how to choose between different services etc)*

19. Are there any particular skills you would need to develop? What training courses might help you? *(e.g. courses about how to manage the money or being an employer, assertiveness)*

20. Would it be helpful to talk to other people who're getting the money instead of services now?

21. Are there any kinds of practical or other support that might be useful to you?

22. Do you think the people supporting you to manage this should be independent of services or family? Are there any organisations like this in your area now? *(e.g. user-led organisations Centres for Independent Living, self-advocacy groups, independent advocacy projects)*

23. There aren't many people getting cash payments just now - do you think this should be publicised more, and do you have any suggestions how this should be done?

24. Are there any other comments you'd like to make?

13/06/01

DIRECT PAYMENTS TO MENTAL HEALTH SERVICE USER STUDY

INTERVIEW SCHEDULE – CARER

Enter codes:

Case Study Number (1-1 to 3-4): ☐-☐

Date of Interview: ☐☐☐☐☐☐

Initials of Interviewer: ☐☐

Tick the appropriate box:

Sex of carer: Male: ☐ 1
Female: ☐ 2

In cared-for person's home ☐ 1
Other ☐ 2 (Please say where): …………………..

DIRECT PAYMENTS TO MENTAL HEALTH SERVICE USER STUDY

General points to cover at the start of the interview: -

➤ *Thank you for agreeing to this interview. We really do appreciate the time you are giving us.*

➤ *The study is about direct payments to mental health service users and people with dementia and we want to find out what you think about the idea for NAME. I'll try my best to answer your questions but remember I'm not an expert on DP.*

➤ *NAME gave us permission to interview you and his/her care manager. This interview is about them and the support they need, rather than about your situation as a carer.*

➤ *Anything you say will be kept confidential and not passed on to anyone outside the research team. Please feel free to pass on any of the questions I ask.*

SECTION 1: COMMUNITY CARE SERVICES

25. Has NAME been assessed by a social worker/care manager? when was this and what did you think of it?

26. What happened as a result of this assessment? Were you happy with this and the support arranged for NAME? (*If not happy, probe why and what happened*)

27. What support does NAME get to help them stay at home? (*this is referring to paid support not that provided by informal carers or networks*)

28. *Have you or NAME, ever thought you'd like to change the support he/she gets in any way? Or get a different kind of help?* (Prompts: change the person who comes, what they do, or the time they do it, get a different kind of help entirely?)

29. Have you ever tried to get the kind of change you or they wanted? What happened? What do you think of that?

30. What other difficulties do people with mental health problems or dementia face in getting the support they need?

SECTION 2: PROS AND CONS FOR CASH OR DIRECT PAYMENTS

Before starting on this section, ask the person if they have any questions to ask about DP.

31. Thinking about NAME and their preferences, would getting the money instead of services be a help? How would it help? *(Prompt: e.g. to get help needed at home, or during the day, or at evenings and weekends)*

32. Thinking about the support he/she needs, what might he/she use this money for? *(e.g. choosing a support worker(s) or which services he/she wants, help to go to work or college instead of a day centre, to visit relatives? etc.)*

33. Would getting the money to buy community care services be better than having services arranged by local authority? How? What might the advantages be? (*if necessary prompt: more choice and control over eg who helps, when they do it and what they do, support to do the things the person wants to in life like get a job or go to college instead of going to a day service)*

34. Can you see any disadvantages for NAME in getting cash instead of services? *(If necessary prompt: eg unsure about handling money; having to hire and fire staff; deciding between different services etc, what happens when the person is ill and unable to manage, dealing with paperwork etc.)*

35. Did you know about cash payments instead of services? Who told you about this?

36. Would you know how to get a cash payment for NAME and who to ask?

37. Do you think NAME could agree to having a DP? Would they need any support to help them decide?

SECTION 3: SUPPORT CARED FOR PERSON MIGHT NEED TO MANAGE A DP

Explain briefly that a cash payment can be given by the LA to a disabled person who has been assessed as needing community care services, as long as they are not subject to special sections of the MH Act. (See Jim's briefing notes or booklets for more detail). These are called 'direct payments'. Sometimes local authorities give the cash to a third party to manage on the person's behalf – this is what's known as a third party scheme. (Authority A has 3rd party scheme; Authority A and C both have DP schemes).

Also explain that the cash can be used to buy support workers often called personal assistants, and also can be given to an agency who will arrange the support on the person's behalf.

The next few questions are about the help and support NAME might find useful if he/she were to manage the money instead of services.

38. How do you feel about NAME managing the money? Would he/she have any difficulties managing this alone? *(such as with managing the payment, the duties of being an employer including payroll, knowing what services different agencies offer if they arrange the support, filling in paperwork for the local authority, having back-up if PAs are ill, something else?)*

39. Would NAME need any help or support to manage, and who could best help them with this role? *(e.g. a family member, friend, advocate, an organisation who manages payroll, an accountant, etc)*

40. Might there be times in his/her life when he/she is unable to manage a payment or support workers? What do you think should happen then? *(e.g. a family member, friend, a group of supporters like a circle of support or group of trustees, an attorney etc take over the duties of being an employer)*

41. How do you think he/she would feel about that? (*advantages and disadvantages of someone else acting on person's behalf)*

42. What kind of information or advice might he/she need now? *(Prompts: general leaflets, helpline, talking to people already receiving the money, about the duties of being an employer, how to choose between different services etc)*

43. Are there any particular skills he/she would need to develop, and what training courses might help them? *(e.g. courses about how to manage the money or being an employer, assertiveness)*

44. Would it be helpful to talk to other people who're getting the money now?

45. Can you think of any practical or other support that might be useful to them?

46. Would it be important for those supporting NAME to manage this to be independent of services or family? Are there any organisations like this in your area now? *(e.g. user-led organisations Centres for Independent Living, self- advocacy groups, independent advocacy project etc)*

23 Not many people are getting direct payments just now - Do you think this should be publicised more, and do you have any suggestions how this should be done?

24 Are there any other comments you'd like to make?

13/06/01

DIRECT PAYMENTS TO MENTAL HEALTH SERVICE USER STUDY

INTERVIEW SCHEDULE – CARE MANAGER

Enter codes:

Case Study Number (1-1 to 3-4): ☐☐

Date of Interview: ☐☐☐☐☐☐

Initials of Interviewer: ☐☐

DIRECT PAYMENTS TO MENTAL HEALTH SERVICE USER STUDY

General points to cover at the start of the interview: -

➢ *Thank you for agreeing to this interview. We really do appreciate the time you are giving us.*

➢ *The study is about direct payments to mental health service users and people with dementia and we want to find out what you think about the idea for your client.*

➢ *We got the permission first of your client to interview you and his/her carer. This interview is about them and the support they need to live independently.*

➢ *Anything you say will be kept confidential and not passed on to anyone outside the research team. Please feel free to pass on any of the questions I ask.*

SECTION 1: COMMUNITY CARE SERVICES

1. I'd like to get a general picture of this person's situation and the support they've been assessed as needing to stay at home. Without going into detail, can you tell me something about this?

2. Describe how this person's 'care package' helps him/her to a) live independently; and b) participate in the community?

3. Is he/she involved in making choices about his/her support? What kind of choices and how do you involve this person?

SECTION 2: PROS AND CONS FOR CASH OR DIRECT PAYMENTS

4. What do you know about the local Direct Payments Scheme (Authority B– 3rd party scheme)? *(ask them about who runs it, the recipients, support provided, eligibility, whether LA staff have received training about the scheme etc)*

5. Would having the money instead of services make any difference to the choices your client has and the ways their support needs are met? *(positives and negatives)*

6. Thinking about your client's support needs, what might he/she use this money for? *(e.g. choosing a support worker(s) or which services he/she wants, help to go to work or college instead of a day centre, to visit relatives? etc.)*

7. What do you think the advantages might be over arranging services for this client?

8. What might be the disadvantages for this client?

9. Where would the money come from?

10. Do you think he/she would be eligible for a DP? If no, why not?

11. How would you go about assessing whether he/she can consent to having a DP? What kind of support might he/she need to determine this? What criteria might you use?

SECTION 3: SUPPORT CLIENT MIGHT NEED TO MANAGE A DP

12. Before I ask about the support your client might need to manage a DP, I'd like to ask a) how you see your role in relation to DP; and b) what you see as the role of the local authority? (*ie in terms of assessment, deciding on levels of payments, monitoring, ensuring accountability etc)*

13. What difficulties might your client face in managing on his/her own? *(such as with managing the payment, the duties of being an employer including payroll, knowing*

what services different agencies offer if they arrange the support, filling in paperwork for the local authority, having back-up if PAs are ill, something else?)

14. Would your client be able to manage a DP alone or would he/she need help/assistance from other people? Who might this come from? *(e.g. family, friends, an independent advocate, peer advocacy, supporters like a circle of support/friends, board of trustees, an attorney or guardian, accountant, an organisation to manage the payroll, etc)*

15. Might there be times in his/her life when he/she is unable to manage a payment or support workers? What do you think should happen then? *(e.g. a family member, friend, a group of supporters like a circle of support or group of trustees, an attorney etc take over the duties of being an employer)*

16. What do you think about other people or a third party managing on the person's behalf? (*advantages and disadvantages of someone else acting on person's behalf)*

17. What safeguards might need to be in place to ensure that other people, or third party organisations were acting in the person's 'best interests'?

18. Are there any local support organisations for people with mental health problems or dementia who could advise and support people in this way? *(eg advocacy organisations, user-led groups such as Centres for Independent Living, support orgs like ASSIST in Authority A)*

19. What kind of information or advice might he/she need now? *(Prompts: general leaflets, helpline, talking to people already receiving the money, about the duties of being an employer, how to choose between different services etc)*

20. Are there any particular skills he/she would need to develop, and what training courses might help them? *(e.g. courses about how to manage the money or being an employer, assertiveness)*

21. Would it be helpful to talk to other people who are getting the money now?

22. Are there any kinds of practical or other support you've not already mentioned that might help them?

23. Do you think the people supporting clients to manage a direct payment should be independent of services or family? Are there any such organisations in this area? *(e.g. user-led organisations Centres for Independent Living, self-advocacy groups, independent advocacy etc)*

24. Not many people with mental health problems or dementia get a direct payment just now. Do you think DP should be publicised more and do you have any suggestions as to how this should be done?

25. Are there any other comments you'd like to make?

13/06/01

RESEARCH INTO DIRECT PAYMENTS TO MENTAL HEALTH SERVICE USERS

INTERVIEW GUIDE WITH VOLUNTARY SECTOR PROJECT MANAGER/CO-ORDINATOR

Before starting: -

➢ *Go over the aim of the study – to explore from a range of perspectives 'direct payments' to people with mental health problems, what the problems/barriers might be, and what's needed to make it work.*

➢ *Go over main topics for discussion –1) exploration of community care services to people with mental health problems or dementia to support people to stay at home; 2) an exploration of the cash or direct payments option instead of community care services; and 3) their reactions to the idea of direct payments to mental health service users or people with dementia and the support they may need.*

➢ *Main purpose of this discussion is to explore with local voluntary organisations supporting people with mental health problems or dementia, and advocacy organisations, the desirability and feasibility of direct payments to people to mental health problems (including dementia) and the implications for community care services.*

1. EXPLORATION OF SERVICES SUPPORTING PEOPLE WITH MENTAL HEALTH PROBLEMS/DEMENTIA TO STAY AT HOME

I want to understand something about the kind of services people with mental health problems or dementia get to stay at home and who provides them. That is, the support people get at home, during the day and in the evenings and at weekends.

1. Does this organisation provide support for people with mental health problems or dementia in this area? What kind of support – direct services, advocacy etc?

2. How many people with mental health problems or dementia locally are in receipt of community care services/advocacy support from you?

3. How is your organisation supporting people with mental health problems or dementia to stay at home? (during the day? in the evenings and at weekends?)

4. What do you know about local mental health service users' views of your services?

5. Are you aware of any gaps in community care provision for mental health service users or people with dementia locally?

2. EXPLORATION OF CASH PAYMENTS FOR COMMUNITY CARE SERVICES

Having talked about the community care services available locally to people with mental health problems or dementia, I'd like to move now to discussing with you the option of giving people a cash payment instead of services

1. Is there a DP scheme or a 3rd party scheme in this area? What do you know about it?

2. What do you know about and what training have you had on DP?

3. What do you think about the idea of giving people with mental health problems or dementia a cash or direct payment instead of community care services? Why do you say that?

4. What do you understand by the term 'independent living'? Is this a term used in respect of supporting people with mental health problems or dementia?

5. Thinking about people with mental health problems or dementia, what do you think might be the advantages/attractions of getting the money rather than services?

6. What might be the drawbacks/disadvantages?

7. How might cash payments compare with other ways of delivering services?

8. If people with mental health problems or dementia felt they could not for some reason self-manage the money, do you think paying the money to another agency on their behalf is a good idea? Why? What kind of organisation would this need to be?

9. To your knowledge, are people with mental health problems or dementia generally told about the DP option when they're assessed for community care services?

10. Do you provide support for recipients of DP, and what kind of support do you give?

3. SUPPORT PEOPLE WITH MENTAL HEALTH PROBLEMS OR DEMENTIA MIGHT NEED TO GET & MANAGE A DP/CASH PAYMENT

1. The legislation and guidance on direct payments says that recipients should be "willing and able" to manage a DP and to be in control of the payment – how would this apply to people with mental health problems or dementia?

2. What support might a person with mental health problems need to determine whether they are willing and able to accept a direct payment, and to manage a payment in light of any fluctuating problems/worsening condition? Can your organisation offer this support? Who does?

3. What kind of support might a person with dementia need to determine whether they are "willing and able" to consider and to manage a cash payment in light of what we know about the effects of dementia? Do you offer this support? Who does?

4. Do you know if people with mental health problems or dementia currently get any information about DP? From whom?

5. Have you any worries/concerns about people with mental health problems or dementia handling money? Employing staff? Being directly involved in choosing the service agency? Anything else?

6. If they didn't want to employ staff but wanted to choose the services that supported them, what kind of information might they need? Is this available now? From whom? If not who might provide it?

7. What sort of information and advice might they need to employ staff? Where would they get this now? In the future?

8. What kind of training might they need?

9. What persons or organisations could and should provide the practical support for payroll, recruitment/selection, advice on employer roles and responsibilities, etc?

10. Are there currently any local voluntary organisations that could undertake these tasks for people with mental health problems or dementia, and what support might they need from Social Work to do so?

11. Do you think there is a role for independent brokerage or advocacy? What role?

12. Should the supporting organisations (i.e those offering payroll, help with recruitment and selection of staff, peer support, advice on being an employer, brokerage etc.) be user-led or does that matter?

13. What might encourage people with mental health problems or dementia to take up direct payments?

14/05/01