

Older People's Perceptions of Direct Payments and Self Operated
Support Systems

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Summary

This study provides a broad insight into older people's perceptions of Direct Payments and self operated support schemes.

It suggests that on the whole elderly people are unfamiliar with the idea of Direct Payments and, although critical of local services, are generally unenthusiastic about the prospect of individuals running their own support systems.

This is due to a variety of factors; notably, a general suspicion that any proposals for change invariably result in a reduction in local services .

In contrast, a minority -mostly women, some of whom lived in rural areas - with personal experience of direct/indirect payment schemes, are enthusiastic advocates of these systems particularly for people living alone or in areas where support services are thin on the ground.

It is important to note too, that all the participants in this study were quite adamant that the Direct Payments option should not be limited to those below retirement age. Age alone was not seen as a barrier to the skills needed for running a self operated support system.

It is evident, however, that considerable work needs to be done for elderly disabled people to view the Direct Payment option with confidence.

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1.0. Introduction.

On July 4th 1996 the British Parliament passed new legislation: The Community Care Direct Payments Act. This law allows local authorities to make cash payments directly to disabled individuals who need help and support to live independently within the community. Thus, enabling them to buy in help and support rather than depend on that provided by others. Hitherto, these people have had to rely on services provided by local authorities, voluntary organisations or receive cash indirectly through semi-autonomous bodies such as the Independent Living Fund.¹ However, although subject to review sometime in 1997, the Direct Payment option will not be available to disabled people over 65.

With this review in mind, on October 1st, 1996, Help the Aged commissioned the British Council of Disabled People's (BCODP) Research Unit at Leeds University to conduct research into older disabled people's views on Direct Payments and self operated support schemes. The research was completed over the following 3 months and the Research Report submitted to Help the Aged on January 6 1997.

2.0. Methodology.

Due to limited resources, notably time and funding, it was decided that the research would be based around a focus group format. This involves bringing a group or groups of people together to discuss and explore the various issues relating to a particular topic. Focus group discussions may be structured, semi structured, or free flowing. This research employed a semi structured strategy: here the discussion is shaped by the research team, but participants are free to explore and develop relevant topics and issues as they so choose².

It is a technique which enables researchers to uncover a lot of general information on key issues and debates pertinent to a particular topic area. But it is limited in the sense that it cannot accommodate detailed and sophisticated evaluation. In short, focus group discussions provide an informed overview rather than a comprehensive analysis (2). Findings, therefore, should always be treated with caution.

¹ For a comprehensive discussion of the issues surrounding Direct Payments and disabled people see ZARB, G and NADASH, P. (1995) *Cashing in on Independence*, Belper, The British Council of Disabled People

² Due to the limited time available and the general flow of the discussions, researchers were unable to explore issues relevant to Direct Payments and minority ethnic groups although there were participants from minority ethnic backgrounds in two of the focus groups.

The findings of this project then are based on material from three focus group discussions in three different locations: Leeds, Shropshire and London. The sites were chosen to ensure that the study would harness the views of people living in different parts of the country; both urban and rural. Two of the groups, Leeds and London, were organised through contacts provided by Tessa Harding of Help the Aged, and the third, Shropshire, with the help of a BCODP member organisation: Shropshire Disability Consortium.

In all 60 people, 36 women and 24 men, took part in this project; 40 of whom defined themselves as disabled people. A more detailed breakdown of the composition of the three focus groups follows .

2.1 The Leeds group.

There were 19 participants in all, 16 of whom were women. Five of these were from minority ethnic backgrounds. Their average age was 71 years; 5 people were over 75. Fifteen of the group defined themselves as non-disabled but, of these, only 10 said that they were not receiving any kind of help or support. Thirteen people said that they did not use services of any kind, but 3 of this group were regularly helped by relatives and friends.

It may be that this group is somewhat untypical of the elderly population as a whole because they all were involved either as users or volunteers with recently established local voluntary support networks. Although these groups are dependent mainly upon voluntary help they were set up with local authority funding. The services offered by these organisations were highly rated although those provided by the local authority were not.

Participants particularly liked the low cost of these services (for example, 50p for a weekly bathing service) , their range (examples include night sitting services, 24 hour emergency call out), and their flexibility. As a consequence they were very wary of any proposed changes to the present set up.

2.2. The Shropshire group.

Thirteen of the 24 participants were men. In contrast to the other two groups they were seen as more 'middle class' by the researchers, and all described themselves as 'White British' .They all came from small rural

villages and towns like Telford. The average age of this group was 68-less than half, 10 were over 70. Twenty two considered themselves to be disabled people. Of these, there were 4 women wheelchair users who were already in receipt of some form of indirect payments and were buying in their own help. Overall, the youngest of the three groups but one with a relatively high level of assistance needs and very concerned about recent cuts in local authority services.

2.3. The London (Hounslow) group.

The space available³ limited the number of people able to attend this group discussion. Consequently, there were only 17 participants including 8 men and 9 women. Only 2 of the group identified themselves as from a minority ethnic background; 1 man and 1 woman. The oldest of the three groups, the average age was 78, 7 people were over 80, and the least vocal. Only 3 participants said that they had no impairment/s. Seven of the group lived alone. Nine said that they did not use services although they all attended Heston Day Centre - the site where the discussion group was located. Two of the group were already receiving Direct Payments of some sort.

2.4. Focus group format.

The focus groups were held in accessible locations and all participants were provided with refreshments and, as and where appropriate, suitable transport. The discussions were facilitated by a research team of experienced disability consultants and personal assistants users: Jane Campbell, London, Liz Carr, Leeds and Shropshire, and Sue Croshaw, Shropshire.

Briefly, the focus groups took the form of a brief presentation on Direct Payments and self operated support schemes, the content of which was determined by the facilitators, and a series of questions design to stimulate discussion. These were asked at appropriate times during the ensuing dialogue. The questions were based on those in the research brief supplied by Tessa Harding of Help the Aged. These are listed below.

2.5 Research Questions.

³ The room available was only big enough for twenty people. The research team included a researcher, a personal assistant, and a notetaker

What do older people think about the prospect of receiving Direct Payments for services if and when they are extended beyond the age of retirement?

What are older people's perceptions of the potential advantages of Direct Payments for personal assistance?

What are older people's perceptions of the problems associated with Direct Payments.

What would the circumstances need to be for older people to feel confident about using Direct Payments?

Each of the three discussions lasted no more than 2 hours and the entire proceedings were taped and subsequently transcribed. The transcriptions along with the completed report were then submitted to Help the Aged and the BCODP for approval.

The remainder of the report is divided into 4 sections, each of which summarises the various issues raised by each of the questions .

3.0. What do older people think about the prospect of receiving Direct Payments for services if and when they are extended beyond the age of retirement? .

Findings suggest that apart from those with personal experience of the Direct Payment option the overwhelming majority of elderly people know very little about this type of provision. In Leeds, apart from one woman whose sister was already employing personal assistants through a third party scheme ⁴, most of the group were completely unaware of what Direct Payments actually were. One woman thought it was money awarded to the personal assistant or helper rather than to the disabled person themselves:

'Instead of paying the social services, they give you a certain amount of money and you do what you think's best with it for the person you you're caring for?'

Similarly, in Shropshire most of the group were not aware of the campaign for Direct Payments, and they were very wary of any changes

⁴ Briefly, third party schemes allow the disabled person to employ a personal assistant or helper through an independent agency; they will take responsibility for the recruitment and formal administration of staff, but the disabled person has control of what they actually do and how they do it.

to the current system. This was also the case in Hounslow, the majority were familiar with the type of services they were getting and were sceptical of change.

Much of this can be explained with reference to recent cuts in local authority services. Participants in each of the three focus groups talked about the limitations of local provision. The situation was particularly acute for people who live alone.

'At the moment, social services are saying that their priorities are not cleaning or ironing, They will only do the shopping, make us some lunch and collect your pension' Leeds man of minority ethnic origin.

'For those of us who live on our own; there's lots of things that we honestly cannot do in the way of housework. The home helps aren't allowed to do it and so at the moment we have to buy in ourselves to get the things like the floors and the things that have got to be done to be decent. Existing services do not and are not allowed to provide these things' Shropshire woman.

'They don't do curtains, they won't get up and do the curtains' Hounslow woman.

The following statement by a black woman living in Leeds shows how the limitations of local provision encourages people to look to alternate sources of support.

'I had home help but it wasn't worth while the woman coming because she came to iron and she had one hour and in that hour she only ironed about 6 things - including two table cloths. Then one week they sent a young lad and I said to him have you come to the right house? I said have you come here to iron? I let him in and he ironed. When he'd gone I had to put everything back in the basket, and I rang my friend to come over and iron. So I said to the them, it's not worth it; don't bother'.

The question of who enters your home is an important one and was raised by a number of people within each of the discussion groups.

However, as the following comments from a disabled woman in Shropshire illustrate, many recipients of services feel that they have little choice in the matter.

'You've got to have anyone that they want to send round to your house. You've got to let them in if you want their help -you can't turn around and say "I'm sorry I don't like her" .

Moreover, as might be expected, many of the participants, particularly in Leeds and London, were dependent on relatives for the things that they were unable to do for themselves. For example:

'My son lives with me and does everything I can't do, shopping hoovering, reaching up and all that type of thing'. Hounslow woman.

This was the preferred option for most of the people in the group.

However, following a brief presentation on Direct Payments by the researchers, people were still very cynical about the whole idea.

'It's confusing' Hounslow woman.

'It's not going to be like the pension is it? They don't realise we need more. They just give you something but don't seem to realise that it needs to go up because prices go up' Leeds woman.

Some people were unclear about the distinction between Direct Payments , social security benefits and their own money.

'I can't see any difference between Attendance Allowance and Direct Payments -I though your Attendance Allowance was meant to pay for care' Shropshire man.

'The money would be coming out of the individual's pocket instead of the council's. If you take £3 per day, that's £3 which has got to come out of your pocket' Hounslow man.

Generally participants were worried about the implications of receiving money in lieu of community care services; some were fearful of

additional personal cost implication. It was explained that the cost to the local authority would be no more or less than they receive already and that the Council were already charging them for services, but their fears were not allayed.

Moreover, they viewed any alteration to the present system with deep suspicion; several seeing it as just another cost cutting exercise by an unsympathetic Government.

'Money, money, money. ...it's all about money. A lot of people over 65 see this is as just back door privatisation. They're not very happy about it' Leeds man.

'People's needs are not being met now The local Council, the social workers are stopping us now from getting the equivalent hours; they're making sure that we don't get enough hours to qualify for independent living now, and they're trying to cut our hours down. So with us getting the money to pay our own carers we'll be no better off. We'll still be stuck with no care package and. ...they'll refuse you the money' Shropshire man.

Some, particularly in Shropshire, were fearful that the receipt of Direct Payment might result in a reduction in other benefits or in the quantity and quality of existing services.

'Direct Payments.. sounds very grand but if all disabled people's needs in Shropshire were met it would be fantastic. ...but that's going to cost a tremendous amount of money. And where's the manpower going to come from to serve everyone if they want a hot meal at lunchtime everyday? I mean it's difficult now, I know people at home who don't get their meals when they want them -meals on wheels don't turn up 'till 4 o'clock sometimes. It all sounds very grand but I'm afraid I don't think it's going to work.

Personally, I can't see any advantage to having Direct Payments because there's only so much money and whatever your needs are, at the end of the day, they'll say they're sorry but we've spent all the money.

...approach your local voluntary organisation instead, Shropshire man.

In Leeds, although the group were generally critical of social services staff there was agreement that there was a need for an expansion of services generally; particularly with reference to day centres. As one woman pointed out:

'I think we need more day centres. My sister has had a few years of being very low and depressed, and she's been shut up at home, on her own. Now she's become disabled, she's getting a life because she's going to a day centre 3 times a week; her life seems full. Before she became disabled there was nowhere for her to go and so I think there's a gap there -need for more day centres'

However, following further discussion in each of the groups many people said that they thought that the Direct Payments option was a good idea for younger disabled people.

'Young people will probably think it's better because they're far more independent, but for older people it's strange and new' Leeds woman.

Moreover, all the participants in this research were clear that if Direct Payments was to be an option for younger disabled people, then it should be available to older disabled people too. The following statements reflect the views of the groups as a whole.

'It would be nice to have the option' Shropshire woman.

'Whatever your age, over 65 or not, you should be allowed the choice of having this money. People are quite capable of managing their own affairs as they get older' Leeds man.

'It's over 65 when you need help, they've got it all mixed up' Hounslow man.

Moreover, many people were angry that the Direct Payment option was currently restricted to people below retirement age. Examples of the range of views expressed include:

'Do they think we're going senile and can't control our own affairs'? Leeds woman.

'If it's good enough for the under 65s; it's got to be good enough for the over 65s' Shropshire woman.

'You can get someone who's 20 who can't add up! You can get someone who's 20, and they're so thick it's unbelievable; and you can get someone who's 70 or 80 and they're so bright... My mother is nearly 100 and she's as bright as a button' Shropshire woman.

'Its disguising How many of them in Government are over 65, if they are capable of running the country why are we not capable of doing this' Hounslow woman.

'Because it's the Government that's making the rules, 99% of them have enough money to do what they like' Hounslow man.

It is important to note here that all participants in each of the three groups were adamant that the introduction of Direct Payments should be an option and not a substitute for services.

3.1. Some initial worries about Direct Payments.

Apart from those with experience of the system, there was some uniformity in each of the three groups with regard to initial worries about using Direct Payments. These included concern about personal security, the idea of 'strangers' as helpers, the assessment process, insurance, the administration of support systems -recruitment, vetting, tax and National Insurance (NI) etc. - monitoring, and the availability of alternatives should the system break down or the individual is no longer able to use the money effectively.

3.2. Strangers as helpers.

The idea of employing strangers as helpers worried many people. This was particularly the case for personal needs, and included people providing support to others and those needing help themselves

'I have to do everything for my husband whose disabled, to call someone else in would be so strange' Leeds woman.

'I don't fancy the idea of a strange woman coming in and giving me a bath -thank you very much. I've still got a little bit of self respect left. I prefer family to give me my bath and wash my hair, and say "come along mum, you need your clothes changing" , not some stranger telling me' Shropshire woman.

'If it's a stranger it's going to take some time to get an association up so that they don't mind if you say something you don't agree with and they are not going to get up and say "I'm not working for her anymore"' Hounslow woman.

3.3. Personal security.

The idea of strangers as helpers soon led to discussions of security. Several people expressed concern over personal safety

'Wouldn't that (Direct Payments schemes) be putting old people at risk? I mean you don't know who you're letting into your home these days do you? We're so aware of that these days -we have to be aware of it' Leeds man.

'The thing is that a lot of older people don't want strange people in their houses, and you don't know who you're getting through your door' Shropshire man.

'No, you could get anybody into the house couldn't you? Anybody at all.. No' Hounslow woman.

3.4. The assessment process.

Many people in each of the three groups were wary of the assessment process for access to the Direct Payments option. Some people were concerned about who will actually be doing the assessment while others were more concerned about 'means testing' and its consequences for personal resources.

'What happens if the disabled person has money in the bank? Like everything else will that be taken into account? If you've got money in the bank. ...you can forget it? Leeds woman.

'Will the money be taxed' ? Leeds woman.

'I'm getting worse and I can't get any help because my husband works. In another 2 or 3 years time when I'm over 65 I might need more help but I'm not going to get it -I'm going to have to be assessed allover again' Shropshire -woman.

Based on previous experience a number of people in each of the groups raised the question of form filling when accessing services. The following statement from a woman in Leeds reflects the views of many.

'What kind of form filling will there be to get this money? because to get Mobility Allowance you need a GCSE to fill it in' .

3.5. The administration of self operated support systems.

The administrative problems associated with employing people worried the majority of participants in the group discussions; many of whom had no previous experience as an employer. In Hounslow, for example, only 3 of the 17 participants were employers during their entire working lives .

Several people felt that recruitment could pose major problems. Indeed, In Hounslow everyone said they would be worried about recruiting their own staff. Although it was pointed out by some individuals, notably in Leeds and Shropshire, that they were not foolproof, in general, people felt that local authorities and voluntary agencies were far better equipped than individual disabled people to deal with these issues.

'At Least Home Care are vetted' Leeds woman.

'Whereas the local authority can check the character of the person they're employing, and you can't. And it may put you in a vulnerable position' Shropshire man.

'These people (paid helpers) go through a very strict test with the Council. They know what they're doing' Hounslow man.

However, a Leeds man noted that voluntary agencies should be subject to some form of regulation to safeguard users' interests.

'It will be essential that voluntary and private agencies are controlled. They should have to register and be inspected like residential and nursing homes because there's a great danger of people being abused and exploited'.

The bureaucracy associated with employing staff was also a major concern for many people .

'All the forms you get are couched in such language, it can make you feel ill' Leeds woman.

'If you do it for yourself, you'll have to take on board things like income tax and National Insurance. Now I know personally that income tax is very complicated and if you have to take on board that, it will be extremely difficult and certainly for people with no experience. It will be practically impossible because the forms are so complicated, Shropshire man.

'If you're going to employ people like that you'll have to have an accountant to make the returns to the tax office, you'd have to have an accountant, they re not going to accept your word for it' Hounslow man.

Several people in each of the three groups were unhappy about the idea of employing and paying people in a formal sense, and suggested that if the system was to work then users should have the opportunity to pay people on a casual basis.

'If you can get someone in, say a neighbour, to make you a meal, how would you go about paying them' ? Leeds woman.

'Occasionally I pay my neighbour to do my ironing, but if she's got to pay tax and insurance out of it, it won't be worth her while' Leeds man.

3.6. Monitoring and misuse.

Clearly, the idea of some kind of monitoring process was a major concern for many people. But several, especially in the Leeds group where many of the participants considered themselves helpers rather than users, believed that accountability was essential. They felt that paying money directly to individuals was risky and could easily be misused either through choice or necessity. For example:

'Supposing the person who isn't a good manager, will someone come in to monitor. ...to see how they are using the money. I mean they could be buying all sorts of trash, how will they know' ? Leeds woman.

'Don't you think that some of the people who would get this money would think 'I'm going to save this. I'm not going to spend it on what I need'? Because some people do tend to do that don't they? They do it with their central heating -they won't put it on because they're afraid of how much it's going to cost. Don't you think that giving people money would encourage them to do that sort of thing' ? Leeds woman.

3.7. General Insurance.

A man with experience of employing people raised another important consideration which needs to be taken into account when employing personal assistants: namely, the question of general insurance.

'What about insurance? if someone works for you and they have an accident are you liable? That's something else to worry about. You'd have to have insurance to cover that. At the moment all home helps and any council workers that come into your home are covered' Shropshire man.

3.8. Flexibility and the availability of alternatives.

As mentioned earlier people were adamant that Direct payment schemes should not replace existing services, and that any new system

should be flexible so that people can opt out and back in as the need arises.

'How will they do it? Are they going to do it on a 12 monthly basis, because people's circumstances can change so quickly' ? Leeds man.

'Will there be an opt out and opt in clause? So if you're getting some care and you decide you'd like to try these Direct Payments, is there some sort of clause built in so you can do this? Or if you decide that you didn't like direct payments, is there an opt out clause'? Leeds woman.

As the following testimony illustrates this was a particular concern for people who had direct experience of caring for someone with debilitating conditions.

'Suppose you're looking after someone with Alzheimers disease when you get this money; is it that person who will have to sign for it? I mean if someone hasn't got their full faculties, how do you go on then'? Leeds woman.

Setting aside the groups' initial worries over the introduction of Direct Payment schemes for the moment, the following section looks at their perceptions of the advantages for elderly disabled people and their families which might arise from this particular option.

4.0. What are older people's perceptions of the potential advantages of direct payments for personal assistance?

Despite the reservations cited above participants were quite clear about the potential advantages of Direct Payment schemes .

4.1. Helps maintain a sense of independence.

As the following statements show, several people pointed out that having Direct Payments would maintain the individuals' sense of independence.

'It gives people independence' Leeds woman.

'You can keep your own independence' Shropshire woman.

4.2. Enhances user choice.

Others focused on the question of choice, and the ensuing freedom which flowed from it.

'It's a matter of giving choice and extra options. It gives people more choice; choice as to what things they think are important rather than what someone else thinks is important' Leeds man.

'Choice.. to have the choice -about what you want to eat, who you want to help you, when you want to go shopping' Leeds woman.

'It's people over 65 that really need help; it would be nice to have a choice You can choose who you want' Shropshire man.

4.3. Enables users to live independently in areas without appropriate support services.

As the following statements from disabled women living in Shropshire show, the freedom to control your own support network is particularly important in rural areas .

'Those of us who live way out in the more rural areas and who don't have transport, often don't get the service we would like from social services. I feel abandoned at times' .

'If you have your own money you can pay the carer and the carer's got to come when you want her. With your own money you can say I want to eat when I want to eat, and if she's not there you can say you don't want her again' (This particular woman was 70 years old and had been a P A user for several years).

'There are so many things that local authority home care workers are not allowed to do that I want them to do. I mean they can't put your curtains up for you. If you have someone of your own, you can work out with

them the things that you would like them to do'
Shropshire woman.

4.4. Gives better value for money.

One Shropshire man with some experience of paying for services out of his own pocket felt that the Direct Payment option would enable disabled people to shop around, and get better value for money than they can from social services.

'You can get more hours for your money' Shropshire man.

4.5. Enhances the quality of the helper/helped relationship.

Potential users in Hounslow were particularly concerned about the quality of the relationship they had with their helpers. For instance, when asked about the preferred characteristics of paid helpers, people spoke of the importance of , 'reliability', 'understanding' and 'respectfulness' .

'They must be reliable' Hounslow woman.

'I want somebody that understands. ...someone who is careful putting you in the bath I Hounslow man.

'I think if you've got someone coming in like that it would be nice if they did not say like -" it's 12 o'clock we must go ". If there was a job which you desperately need to do and they are rushing off. ...someone who understands' Hounslow woman.

'I want someone to tidy up generally, and be respectful' Hounslow man.

Although the consensus across each of the three discussion groups was that informal networks of relatives and friends were probably the most effective and reliable support system available, it was generally overlooked that the enforced reliance on others sometimes results in family tensions and strained relations between the helper and the helped. With this in mind a Leeds woman with personal experience in this area pointed to the fact that self operated personal assistance schemes often help eliminate such problems.

'All this talk about families, but when my sister got the money to employ people, the first thing she said was "Oh good I don't have to rely on my daughter and I can feel that if she comes to see me she doesn't have to do anything; I can pay someone". In the past the family took over, in fact they had to go every day and they went through love ... Why should you have to rely on family? Paying someone takes the burden away, and the pressure off the family' Leeds woman.

Another Leeds woman suggested that self operated support schemes might be particularly beneficial' for people who lived on their own' Indeed, for the Hounslow group, several of whom lived alone, the 'friendliness' of support workers was a very important issue.

Hounslow women in particular felt that this was more likely because users of Direct Payment schemes could:

'control the friendship too. ..you can choose the person you like'

Another woman extended the point further:

'If you're paying them it wouldn't matter to you if you said stop and have a cup of tea with me. If your paying it doesn't matter that they think they should be working, but if you're paying them it doesn't matter if they sit down and have a chat' .

4.6. Gives users a greater sense of control.

The idea of controlling or' fixing' the number of hours people worked or , indeed, what they actually did while they were working was seen as a major advantage for many people in each of the groups. One woman in Hounslow, for example, was particularly keen to stop people smoking while they were working in her home: something which, hitherto, she had clearly felt unable to do.

'I think you should be able to say "smoking" or "non-smoking" ... Well because if you don't smoke and someone comes into your house that smokes a lot it clings to everything ...' .

As will be evident from the above, the idea of not employing or dismissing helpers who were in one way or another considered unsuitable had a general appeal to everyone involved. As one man from London put it:

'You can tell them straight out you don't want them' .

5.0. What are older people's perceptions of the problems associated with Direct Payments.

As noted in Section 2.1 the older people in our sample have a number of worries about the introduction of Direct Payments and self operated support systems, it is inevitable therefore that they foresee a number of disadvantages stemming from such schemes.

5.1. Not allowed to employ relatives as helpers.

Clearly the most significant issue to emerge from the discussions concerns the choice of helper. Following on from their general uncertainty about employing strangers, the majority of participants, in all three groups, felt that not being able to pay relatives was a, if not the, major problem with the Direct Payment option.

There were at least two main reasons for this. First, relatives were considered far more 'trustworthy' than strangers :

'My dad wouldn't let anyone in the house except me. That's why I think you should be able to employ relatives - they know the person better than anyone else, why shouldn't they be paid'? Leeds woman.

'You can trust your family' Shropshire man.

Second, people felt that because family members often provide informal support for older they should be paid accordingly.

'I can't understand them not letting you pay your relatives. I'm just thinking of my sister and her daughter - she comes over to take her shopping and then she takes her washing home every week, washes it and irons it all. Instead of getting a little job for two days a week she does all this for her mum. I

can't understand why she couldn't pay her daughter'
Leeds woman.

'80 per cent of the people who need care get it from their families. It's the sons and daughters who come round and wash up, Hoover, make the beds and various other things. The cheapest way out as usual, the Government expect your family to look after you for nothing , Shropshire man.

5.2. Not being able to pay people on a casual basis.

Similarly, not being able to pay friends and neighbours on a casual basis was seen as a major disadvantage of the Direct Payment option.

'A lot of people would like to employ a neighbour or someone informally and give them a couple of pounds now and again - that sort of arrangement might work'
Shropshire man.

5.3. The responsibility of administering a Direct Payment scheme.

As noted earlier the bureaucracy involved with self operated support schemes was seen as a significant problem by people without personal experience of the Direct Payment option.

'Say you are 70, what if you're not able to do all this? You're going to need someone to do it for you; someone to advertise and interview a person. A lot of older people are frightened of all this and don't want just anyone turning up on their doorstep Older people don't want all this it's too much trouble' Shropshire man.

'Whichever way you look at it, if someone lives on their own they're isolated, and a lot of older people don't want to go through the trouble of doing their tax and insurance and all that' Shropshire man.

Besides recruitment, tax, and National Insurance, some people from Hounslow felt that organising a helper's daily routine might pose something of a problem.

'You've got to work out the most important jobs obviously if you are going to pay £4 per hour they (the helpers) are not going to spend all day with you ... you would have to work out which jobs are really important' Hounslow woman.

It is important to remember, however, that those with experience of running their own system did not view the general administration of Direct Payments as a problem. With reference to the difficult issue of recruitment, for example, the following statements from a woman in Shropshire tell a quite different story.

'I find no problem at all. I live in the country and you find that somebody knows someone who can give you a hand with the housework and the next day they will ring you up and say "I hear you're looking for someone" I find that word of mouth works every time for me. Then you can see whether you can work together. I live in a very rural area and I live on my own -I'm virtually isolated but I don't have any problems in that way at all. I just say to people that I know around the village "Do you know of somebody" and the next day somebody will ring up'.

'I think that because we're in a rural area, that's where there are advantages because I think everyone who lives in a village or near a village knows that there are people that they could trust and take on through word of mouth' Shropshire woman.

It is also the case that some people were aware that these problems could be resolved through the use of independent living support networks. This was certainly the case in Shropshire.

'There is an organisation in Shropshire called SDC (Shropshire Disability Consortium) that helps people who choose to pay their own carers. They help by explaining all the problems there are and this group would be available, and I think essential, if older people needed help' Shropshire man.

5.4. Direct Payments and self operated support schemes will be easily exploited by service providers.

Several male participants, particularly in Shropshire, were very cynical about the whole idea of Direct payments, indeed, one man seemed convinced that the new system was open to exploitation.

'At the end of the day someone, somewhere is going to make a lot of money out of this and it won't be for the good of older people. When agencies get to know that there's this money about and people have these Direct Payments; they'll aim services at these people and overcharge' Shropshire man.

5.5. Direct Payments will inevitably lead to a reduction in other support systems such as benefits or services.

As mentioned earlier, many people, particularly in the Leeds and Shropshire groups, see change of any sort as a further erosion of current provision; Direct Payments are no exception.

'Thinking about this, one of the reservations may be, if a lot of people opt for this, could it undermine what we've already got going for us now. Because if I thought it was going to undermine the whole body of Community Care, I wouldn't want it' A Leeds man of minority ethnic origin

'I think they're going to rob Peter to pay Paul. They don't give anything out without taking something back from somewhere else. I reckon they'll try and stop some of the benefits we get already' Shropshire man.

'Won't this mean that people working for social services will be made redundant' Shropshire man.

It's worth noting here that at the conclusion of the Hounslow discussion group participants were asked if they would like to try Direct Payments if they were available to people over 65. Four of the 17, less than a quarter, raised their hands

6.0. What would the circumstances need to be for older people to feel confident about using Direct Payments?

Findings suggest that the following measures would need to be firmly in place for elderly disabled people to use Direct Payment and self operated support schemes with confidence.

6.1. Appropriate information and training.

There is clearly an urgent need for the widespread dissemination of appropriate and accessible information explaining in clear language what Direct Payments involve. This information must be in concise, jargon free language, and available in a variety of accessible formats and minority ethnic languages.

Back up training in the use of Direct Payments and self operated support systems must also be available for those who want it. Experience shows that this training can best be provided by organisations of disabled people which specialise in work in this area.

6.2. People should be able to pay relatives and friends.

Many of the people in this study were supported by their families. They felt strongly that users of Direct Payment schemes should be able to pay relatives as helpers.

It is also evident that many of the participants would be happier with self operated support systems if they could use Direct Payments to pay relatives and friends for occasional but specific services on a more casual basis.

6.3. National and local registers of paid helpers.

To enable people to feel confident about employing strangers, as helpers there would need to be some form of national and local registration system for experienced support workers.

Some agencies and organisations of disabled people already keep registers of personal assistants. There is an urgent need for some nationally recognised body with relevant experience to collect and collate this material and disseminate it in appropriate formats to local authorities, voluntary organisations, and other service providers.

Information about the register and how to contact the people on it could then be made available along with the other information about Direct Payments mentioned above.

6.4. Help with administration.

This study suggests that many older people will be put off the idea of Direct Payments because of the bureaucracy involved when employing someone on a formal basis. Consequently, they would need someone to help with the formalities of recruitment, tax, and national insurance.

Currently in many areas of the country these services are being provided for Direct Payment users under 65 by a variety of agencies including organisations of disabled people. Similar services must be available to people over retirement age interested in self operated support systems.

6.5. Peer support networks.

Similarly, peer support networks like those developed by personal assistance users under 65 would need to be established. These should include telephone links and advice lines for people living alone or in isolated rural areas.

6.6. Self operated support schemes must be flexible.

All self operated support systems must be flexible and include clearly defined 'opt in' and 'opt out' Clauses. This would give those unfamiliar with running their own support the opportunity to try it out for themselves.

6.6. Direct Payments and self operated support systems must not be a substitute for services.

For older people to feel safe with the Direct Payment option it is essential that they are secure in the knowledge that there is appropriate and well resourced back up services available should their self operated system break down.

It is essential, therefore, that the introduction of Direct Payments should be one of a range of service options, and not a substitute for other services nor a signal for local authorities to withhold or cut spending on those services.

7.0. Conclusion

This study has provided a broad insight into older people's perceptions of Direct Payments and self operated support schemes. It suggests that on the whole elderly people are unfamiliar with the idea of Direct Payments and, although critical of local services, are generally unenthusiastic about the prospect of individuals running their own support systems. This is due to a variety of factors; notably, a general suspicion that any proposals for change invariably result in a reduction in local services.

In contrast, a minority -mostly women, some of whom lived in rural areas - with personal experience of Direct/indirect Payment schemes, were enthusiastic advocates of these systems particularly for people living alone or in areas where support services are thin on the ground.

It is important to note too, that all the participants in this study were quite adamant that the Direct Payments option should not be limited to those below retirement age. Age alone was not seen by anyone as a barrier to the skills needed for running a self operated support system. It is evident, however, that considerable work needs to be done for elderly disabled people to view the Direct Payment option with confidence.