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**THE ROYAL BANK OF SCOTLAND CENTRE
FOR THE OLDER PERSON'S AGENDA**



**DIRECT PAYMENTS: THE VIEWS OF OLDER PEOPLE
FROM RURAL COMMUNITIES AND ETHNIC
MINORITY GROUPS**

**THE ROYAL BANK OF SCOTLAND CENTRE for the
THE OLDER PERSON'S AGENDA
QUEEN MARGARET UNIVERSITY COLLEGE**

THE SCOTTISH OFFICE CENTRAL RESEARCH UNIT

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Background

The origins of the direct payments scheme lie with the Disabled People's movement and the revolutionary idea of providing disabled people with cash to pay directly for their assessed care and support needs. Authorisation was given in 1997 to local authorities in England to offer cash payments to purchase care and support services through the implementation of The Community Care 1996 (Direct Payments) Act.

This scheme was initially restricted to those aged between the ages of 18-65 years. However since February 2000 (July 2000 in Scotland) this has been extended to include disabled people aged 65 and over, and further expanded in 2001 to include young disabled people between the ages of 16 and 18 years.

Prior to the implementation of the Community Care Act, procedures following a community care assessment placed the local authority in complete control regarding arranging and coordinating an individual's care package. The local authority arranged when and where services were provided, and who would provide them. The direct payments scheme could offer an alternative, more flexible approach, with the potential to empower individuals choosing to opt into this scheme. Individuals in receipt of direct payments have control in making arrangements for the provision of services that work *with* their lifestyle as opposed to their lifestyle *'fitting around'* local authority organised care and support services. Direct payments position the individual at the centre of control for their own service provision.

Initially, direct payments as a scheme was relaxed and local authorities were not obliged to offer direct payments as an alternative to everyone. However, since April 2003 (June 2003 in Scotland), local authorities are now obliged to offer direct payments to all those eligible. Key criteria for eligibility to opt into this scheme are that direct payments in the form of cash can only be offered to those deemed able to consent and manage the direct payment, either alone or with support.

In a brief review of the literature on direct payments, two important studies informed this project. In the first of these studies 'It Pays Dividends' (Clark, Gough & Macfarlane, 2004), commissioned by the Joseph Rowntree Foundation, the experiences of older people in receipt of direct payments in England were explored. Key findings were that older people experienced an improved quality of life, raised motivation and increased happiness and sense of satisfaction with their lives stemming from being in control of their own service provision. Most older people used their direct payment to employ a personal assistant (PA) to meet their social care needs. Previous career experience was seen to enhance the ease of taking on the role of 'employer', however the importance of access to support services was seen as essential in assisting older people to manage their direct payments. However, funding for support services is dependent on the budget allocation of local authorities and therefore variations in provision between local authorities exist.

Somali older people were also interviewed in this study and reported that a PA aided in securing culturally appropriate services, and support services were seen as vital in overcoming language and literacy barriers. Although most older people used their direct payments to employ a PA, there appeared to be difficulties finding a 'good' PA and it was suggested that a register of PAs would perhaps assist with this.

A general lack of awareness and utilisation of the direct payments scheme was identified. Older people commented that there was a need to raise the profile of direct payments as an option, possibly through television and radio. Care management teams acknowledge a need to embrace this scheme, and often overlooked direct payments as an option to pay for care packages. There also seemed to be difficulties arising from translating care packages into direct payments. A commitment was made to change this culture by raising awareness and enhancing knowledge regarding direct payments and creating a positive view of the scheme. Care managers who had experience of successful outcomes in relation to clients utilising direct payments reported immense job satisfaction. A separate study by Hasler & Stewart (2004) found that direct payments worked best in local authorities where a supportive local authority infrastructure was combined with both an understanding of the principles of independent living and a commitment to partnerships with users.

Health related services, such as chiropody, were seen as essential to older people maintaining their mobility and therefore important to meeting their social care needs. However these are health related needs and not social care needs, and fall outwith the remit of direct payments (although the context in Scotland is different because of the provision of free personal care).

Service users moving from adult to older people's services found restrictions placed on social and leisure activities implying ageist perceptions of older people's life styles. The Independent Living (extension) Fund, set up and financed by central government, was found to be discriminatory, excluding older people and therefore taking no account of increased costs related to being older.

A second study based in Scotland explored inhibiting factors which prevented the uptake of direct payments and looked at how these could be overcome. Main issues from the perspective of mental health service users and older people with dementia were explored (Ridley and Jones 2002). 'Direct What?' reflects the responses of service users and professionals' concerning direct payments. A key finding was that the implementation of direct payments within Scotland was slow, and additionally, the uptake in Scotland was reported as low. The main factors inhibiting uptake were identified as issues relating to the format of the community care assessment, whereby people not in receipt of community care services, having not been assessed, felt they were perhaps not eligible for direct payments. There was also suspicion that the outcomes of community care assessments were service-led rather than being person-centred.

The study further identified a lack of knowledge and understanding about the direct payments scheme. In general there were concerns regarding mental health service users and older people with dementia and their ability to manage the demands and responsibilities of a direct payment. Issues regarding anxieties concerning jobs were also highlighted and direct payments was viewed by some to be "backdoor privatisation" (Ridley & Jones, 2002). This concern has been echoed in a later study by Riddell et al. (2004) which highlighted the fact that ten of Scotland's thirty two local authorities (just under one third) have no direct payment users (however, the most recent figures indicate that all local authorities, except one, have at least one direct payment user – see <http://www.scotland.gov.uk/stats/bulletins/00370-00.asp>). It

was suggested that this low uptake may in part be accounted for by resistance from some Labour-controlled local authorities, who may feel that direct payments undermine other services and threaten public sector jobs.

The study by Ridley & Jones (2002) can be seen as a start to the opening up of debate and discussions regarding the way forward for the direct payment scheme. They suggest that “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 user, carers, and the organisations that support them in the development of direct payments.” (Ridley & Jones, 2002, p. 60).

It can be seen from the above that although direct payments have been in existence since 1996, there is by no means a nationally available, universally functioning scheme. Wide variations exist in relation to, for example, the extent of provision and promotion of the scheme; the amount and type of support for users; the individuals and their type and level of need(s) who are offered the scheme; the availability of personal assistants; and uptake of the scheme.

The Scottish Executive commissioned the Royal Bank of Scotland Centre for the Older Person’s Agenda, to work in partnership with Age Concern Scotland and Direct Payments Scotland (DPS), to carry out a short investigation as to how direct payments could work for older people aged 65 and over, and the ways in which future provision of direct payments with this group could be encouraged. The intention was to add the studies outlined above by focusing specifically on groups who are potentially hard to reach in these consultation processes. This project sought to explore the views of older people from remote and rural areas, and from black and minority ethnic groups. The research was intended to inform the Scottish Executive Direct Payments Working Group, who are currently revising guidelines for direct payments due to be launched in April 2005.

Overall aim

To explore how direct payments could work for older people from remote and rural areas, and/or black and ethnic minority groups, and the ways in which future provision of direct payments with these groups could be encouraged.

Objectives

- To establish current or potential support needs for the older people in their day-to-day living;
- To assess the extent to which there is already knowledge and understanding of direct payments;
- To explore participants’ perceptions of direct payments;
- To identify ways in which direct payments to older people can be encouraged and facilitated; and
- To identify the nature of the support that is required in order for direct payments to meet the needs of older people

Methodology

This project took place between August and October 2004. Due to the short timescale, it was agreed to set up a number of group discussions with older people from the

following four groups; people living in rural and remote areas in the north of Scotland, and from South Asian, Polish and Ukrainian communities in the Lothian region. Advice was sought from Age Concern Scotland about which groups to include in the project. They felt it was important that older Polish and Ukrainian people were given the opportunity to participate because the first generation do represent majority numbers in their upper 70s, 80s and 90s. (Efforts were made to set up a group comprising older members of the Chinese population. However, due to holiday commitments within this group, and the short timescale of the project, it was not possible to elicit views from this minority ethnic group. Given the fact that they are the second largest ethnic minority community in Scotland, it would be important to consider involvement of this population a priority in any further development of direct payments).

The findings from the project are presented thematically. It was possible to do this because there were common themes expressed by members of all groups. Where issues and concerns were specific to a particular group, this is stated in the report. It should be noted that, in the course of the report, we discuss and present several issues and concerns raised by participants, which the DPS presenter was able to answer, clarify and address – they are however mentioned as part of the process of obtaining views and exploring opinions about using direct payments, and inclusion of these issues and concerns does not imply a lack of information provision on the part of DPS at each event.

The Discussion Group Sessions

Staff at the Royal Bank of Scotland Centre for the Older Person's Agenda were keen that participants who were invited to the sessions could experience the event as an opportunity to gain knowledge and meet with other older people, as well helping us to gather information concerning their views relating to direct payments. The format of these group discussions was therefore constructed in the following way:

- A short overview by member of Direct Payments Scotland about the nature of direct payments, with the opportunity for a brief question and answer session;
- A personal account of the experience of receiving direct payments (this was only carried out in Inverness; there were difficulties in organising this for the groups in Lothian); and
- A series of questions designed to trigger discussion and debate around the use of direct payments (see appendix).

The series of questions were derived from existing literature and from brief consultation with the Scottish Executive, Direct Payments Scotland and Age Concern Scotland.

Care was taken to select a suitable venue with which, where possible, people were familiar and comfortable, and/or was accessible from a range of locations. Overnight accommodation was offered to participants from remote and rural locations who were unable to travel to and from the venue in one day.

Preparatory Meetings

A brief meeting was held with Direct Payments Scotland, to enlist their help in disseminating the invitation to people in remote and rural areas in northern Scotland

to participate. Approximately 120 letters of invitation, with details of the event in Inverness, were sent out via existing DPS networks.

Preparatory meetings were held with two support agencies, one for members of the South Asian community, and the other for Polish and Ukrainian elders in Lothian. A member of DPS attended both meetings. Prior to these meetings, the draft questions had been sent to a representative within each agency for comment. This representative had agreed to recruit participants on behalf of the Centre for the Older Person's Agenda. Issues addressed at the preparatory meeting included:

- agreed ways of working
- translation of materials (DPS had arranged for their general information leaflet regarding direct payments to be translated into six languages - Urdu, Punjabi, Hindi, Bengali, Polish and Ukrainian)
- roles and responsibilities of the interpreters
- reviewing the questions to ensure they were culturally relevant and sensitive, and could be translated accordingly
- practical issues such as catering, transport, access and any special needs
- methods of feedback to participants, Direct Payments Scotland, and support agencies

All stakeholders who attended these meetings expressed their appreciation that time had been given to explore the above important issues prior to the event. One of the interpreters commented that from their experience, this preparation was not usual. In one case, the translated Direct Payments Scotland leaflet was found to be inaccurate, and further changes had to be made. It does raise the question of agreed practice regarding translated material, and a recommendation would be that any such literature is always checked by another translator, prior to distribution to its intended audience.

In addition to the preparatory meetings above, the British Sign Language interpreters who were required at the Inverness event were sent in advance the questions to be used in the discussion groups, and a short meeting took place prior to the event to establish agreed ways of working.

It was explained to the agency support workers that the facilitators would like to tape record the group discussions (purely to aid with report writing), and to take a few photographs, for inclusion in the report to the Scottish Executive, and the next Centre for the Older Person's Agenda's newsletter. We checked with them whether they felt this would be appropriate, and if so, to ask participants prior to the start of each meeting whether they were in agreement. Nobody objected to the tape recording, and only one participant who attended the Inverness seminar declined to have their photograph taken. The group discussion was not taped in Inverness as owing to the room layout, the two groups were in too close proximity to permit clear recordings of the two separate discussions.

At each event, with the exception of the South Asian discussion group, three facilitators from the Royal Bank of Scotland Centre for the Older Person's Agenda were present. As the number of participants attending the event in Inverness was over 20, they were divided into two groups, and the representative from Direct Payments Scotland agreed to assist with one of the groups. One facilitator welcomed everyone to the event, gave a brief outline of the event and background to the project, and

introduced the presenter from Direct Payments Scotland. The facilitator then led the questioning, while the other facilitator(s) made detailed notes, and put summary messages on the flip charts. The facilitators also were on hand to ensure that all the practical requirements were met. At the South Asian discussion group, one agency representative acted as a facilitator as well as a translator, which was essential as four different languages were being used.

It had been hoped that participants at all group discussions would include some older people in receipt of direct payments. However, with the exception of the Inverness discussion, where one participant was a user of this scheme, this did not happen, as agency support workers did not know of anyone attending their agency who used a direct payment. It is important to note that currently in Scotland, there is a total of approximately 900 people in receipt of direct payments, of which around 300 are aged 65 years plus (<http://www.scotland.gov.uk/stats/bulletins/00370-00.asp>), and although this represents an increase, it remains a small pool of people from which to recruit existing users.

Characteristics of the Discussion Groups

The remit for this project was to recruit older people aged 65 and over, some of whom were service users, and possibly in receipt of direct payments, and some who were non service users. The majority of the people who attended the discussion groups were not service users, and had little knowledge or experience of community care. This meant that in response to some of our questions around previous knowledge of direct payments, participants' responses indicated a lack of awareness. In addition, participants found it difficult to envisage how direct payments could relate to them, either now or in the future. It is therefore important when interpreting these findings to place them in the context of exploring the views of people who had very little knowledge and awareness of direct payments, and to recognise that issues expressed may already have been addressed.

Although the majority of participants attending each of the group discussions were aged 65 years plus, there were some who were not over 65, but who expressed a real interest in attending the event for other reasons, for example, two of the people attending the Inverness event were carers. We included these people and valued their contribution to the discussions.

Inverness event:

A total of 21 people attended, two thirds (n = 14) of whom had not heard of Direct Payments prior to the seminar. One person was in receipt of direct payments. Just over half of the participants (n=11) lived in rural and/or remote areas. Two people were Personal Assistants, paid for by Direct Payments. Four of the participants were men, the remaining 17 were women. Three people required British Sign Language interpreters, one was hard of hearing and required the use of a hearing loop, and one participant was partially sighted. One person was in a wheelchair, and several others had mobility problems.

Four participants were already in receipt of services, seven were carers, one was both a carer and service user, and the remaining nine were neither carers nor service users.

We experienced difficulty recruiting people for this event, and are unsure why this was the case. We did recruit one person from Stornoway, two people from Caithness, two people from rural and remote Argyll, one from north Speyside, and two from the Black Isle region. Although this event was specifically for older people from remote and rural areas, it could be that the intricacies and difficulties of arranging transport, to attend an event about a topic which was not familiar, deterred people from attending. People welcomed the fact that travel expenses were covered. It was important that as a research team we did not feel we were just gleaning information from these people to feed back to policy makers. We wanted them to genuinely feel that they got something out of the day. Feedback from individuals at the end of the seminar indicated that they felt they had got more knowledge about Direct Payments, and many had enjoyed meeting other people.

South Asian Discussion Group

There were a total of 19 older Asian participants, who between them spoke four languages – Hindi, Urdu, Punjabi and Bengali. There were 8 men, and 11 women. No-one had heard of Direct Payments, and very few were in receipt of services. There were no participants who had requested assistance for special needs. More people attended this event than had been anticipated, as the initial request was for between 10-14 participants. This illustrates the benefit of using familiar support workers to recruit participants, and arranging culturally appropriate refreshments and providing transport to and from the event.

Three project workers assisted with the running of the event. The presentation was given in English, and translated into Bengali and Punjabi concurrently, by two of the project workers, and the answers translated back into English. The same approach was taken with the discussion group questions.

Polish Discussion Group

Eleven older Polish participants (3 men, 8 women) attended this event. None had heard of Direct Payments prior to the discussion. One participant had a visual impairment, and had been in receipt of some support to meet his needs.

The participants were familiar with the venue, and the high attendance reflected the involvement of the project workers. Two support workers, and an interpreter took part in the event. As with the South Asian group, the presentation and discussion questions were conducted in English, translated into Polish, and answers to questions were translated back into English.

Ukrainian Discussion Group

Seven older Ukrainian participants, 4 men and 3 women attended this event. None of the attendees had ever heard of Direct Payments. All presentations and discussion took place in English, with only occasional explanation/clarification in Ukrainian. One project worker and one translator attended the event.

In general, people came along for the purposes of information gathering, and that was their expectation. This does raise questions about how easy it is to carry out focus group research within a short space of time on a topic about which people have very little, or no previous knowledge.

A key issue in planning for events which require translation/interpreting services is that of time and resource.

Issues emerging from the discussion groups

When we refer to “several participants” in the following discussion, this includes participants from all discussion groups. Where an issue has been raised by a specific discussion group, this will be indicated.

Lack of awareness about direct payments

In general, with the exception of a few participants at the Inverness event, most people had not heard of direct payments prior to the event. Indeed, there was confusion about what the term actually referred to. None of the participants who were in receipt of services had been given the option of considering direct payments (except the one participant who is currently using direct payments who attended in Inverness). Although Direct Payments Scotland have done a great deal of awareness raising amongst professionals, e.g. social workers, offering direct payments as an option when undertaking community care assessments does not appear to be part of regular practice. Several participants had recently heard about ‘direct payment’, as referred to by the scheme offered by the Department for Work and Pensions (DWP), and thought this was what the event was going to focus on. This then raised discussion about the name given to direct payments, and whether this really reflected the essence of the scheme. There was a recommendation that this should be reviewed, and one suggestion that a less confusing, and more appropriate term might be ‘self-directed services’.

This lack of awareness raises questions about the most appropriate and effective means of dissemination. Direct Payments Scotland run a number of awareness raising events, and produce a regular newsletter. It was interesting that all participants had heard of the direct payment related to pensions (DWP), and had learnt about this through the media of television and radio. Participants from the Ukrainian discussion group felt that a similar approach would work well for direct payments. However, as was evident from presentations given by DPS staff, direct payments as a concept is complex and cannot be explained in one easy ‘soundbite’. Indeed, previous media coverage has diluted or misinterpreted the concept of direct payments, with the result that many people have misconstrued direct payments as being extra money or benefits (personal communication, DPS).

Other methods that were suggested by participants regarding dissemination of information included publicising in existing local authority directories targeted towards, or sent out to older people, and even in communications relating to council tax. A suggestion from participants at the South Asian discussion group included advertising and disseminating information regarding direct payments on culturally specific television programmes, such as Asian channels Zee-TV and Starplus. They also felt that in addition to leaflets, information could be produced in the form of videos and tapes, in appropriate languages. Each group was given a copy of the excellent ‘Living Life to the Full’ video produced by DPS. However, for those participants for whom English is not their first language there is a need to have this translated into a variety of different languages.

Lack of knowledge regarding services and support in general

During the course of the discussions, several participants indicated that they were not aware of services and support they could access, such as what a local authority was, or how to contact it, what a community care assessment was and how to obtain one. The majority of the people who attended the discussion groups were not service users, and therefore this lack of general knowledge around support and services perhaps is not surprising. This has implications for literature and materials publicising such schemes, which may assume prior knowledge of such concepts.

Sustainability of the direct payment scheme

Several participants voiced concern as to whether the scheme was 'just a fad', and would disappear in two years' time. Participants had not heard of direct payments previously (despite it being in existence since 1996, with around 13000 current recipients in England and Wales), and were not aware of any feedback, which raised questions for them about the maintenance of such a scheme. This has implications for any publicity material related to direct payments in that people do not want to feel they are being used as guinea pigs, but that they are taking up a scheme that has been carefully thought out and evaluated. Research shows the direct payments scheme has the potential to transform people's lives on a long term basis. It is these stories and examples that can best be used to illustrate the tremendous impact direct payments can have, and to allay concerns and fears.

Many participants raised questions about the sustainability of the funding for this scheme – one participant expressed a fear “*that the money will run out, if more and more people apply for it, and that this could have a knock-on effect on Local Authority service provision, if carers leave them to work for direct payments*”. The government has not allocated additional monies in order to implement and support this scheme, and any direct payment services are provided from existing community care budgets.

Equality of the direct payments scheme

Participants in all groups raised the issue about the potential for fraud within this scheme. The concern was partly related to a lack of awareness of how the scheme operated, such as having a separate bank account and rigorous accounting procedures in place, but in addition, some participants feared that even with these systems in place, that some recipients could use the money inappropriately. This is a common concern for people, and the issue is adequately addressed in “A Guide to Receiving Direct Payments” (Scottish Executive).

There was also a concern that there might be inequity amongst local authorities, particularly in relation to the assessment process, and the readiness (or lack) of a particular local authority to promote and support an individual to use the direct payment scheme. Although legally the local authority has a duty to offer direct payments to all those eligible for them, it does raise questions about how this offer is made, and the level of detail and information provided in order for the individual to make an informed choice.

A specific concern for people living in rural communities is the inequity that may arise because of the geographical distances and proximity of facilities. For example, one participant made an important observation that if one of the agreed tasks was for

her PA to assist with shopping, as the facilities are further away (the corner shop is not an option), this may take longer, and therefore use up more of the direct payment funds. Whilst an accurate community care assessment would build time in for this, people need reassurance this would be accounted for. People in remote areas could see potential benefits of using such a scheme, when, despite services being in existence, they still feel disadvantaged. One example given was where a community taxi existed but for times when it was not available, there was no other means of transport.

Mismatch between support needs of people and ability of payments to meet these

In the discussion groups we asked people to tell us about the things that are important to them, that they would like to be able to continue doing, and the support they may need to continue these in the future. It was interesting that all of the groups highlighted aspects related to maintaining their homes or gardens, and activities that could counteract social isolation, such as getting out and about and meeting people. Very few people mentioned basic needs such as personal hygiene or being able to fulfil nutritional needs. This may be because people felt the latter could be considered so fundamental as to not merit debate regarding whether an appropriate service would be available. Furthermore, this may reflect the fact that none of the participants we spoke to was in need of that basic level of support. It was highlighted that there are other forms of support that could meet some of the needs, e.g. Care and Repair, Handy person service, as direct payments are not designed to cover home maintenance. In relation to the support that could help to counteract social isolation, there may be scope for direct payments to meet this, but given the complexity of this concept, it would be important that any community care assessment was sensitive enough to thoroughly explore with an individual their needs in relation to this.

Direct payments as a way of celebrating choice and individuality

Some participants could quite clearly see the difference that direct payments could make to the service(s) they were currently receiving. This difference related to more choice, and respect for individual needs. One participant, who was in a wheelchair, and required help with personal hygiene, stated “*I could have a shower more than twice a week. If somebody invited me out spontaneously, I might be able to have a shower before I go – I can’t do this just now*”. This participant is currently dependent on help to get out and feels there is a lack of spontaneity in her life. She not only saw the direct payment as being useful to assist with her personal hygiene needs, but saw the potential of this scheme for meeting other needs, such as being able to go down to the shops.

Another person in receipt of a service talked about the flexibility that employing a personal assistant might offer. They related a particular incident, concerning a ‘Tuck-In Service’, whereby a home help who had been booked for an hour period had actually completed the task within 15 minutes. When the husband had asked if she could sit with his wife while he went to get milk, the home help refused, which meant the couple were unable to have a cup of tea with milk that evening.

An issue which emerged from two of the discussion groups related to culturally sensitive services, such as catering for language and culinary needs. One participant envisaged employing a PA who could cook Asian food. Another participant would

welcome the opportunity to have his needs met by a PA who could speak his language.

The ability to choose who is going to meet your needs was met with enthusiasm by all groups, particularly those currently in receipt of services who stated that often they have a series of different workers, whom they may not necessarily have met previously.

Participants in all groups felt that the scheme would enable them to have more choice about when, and how often, their support is provided. People felt that having this choice and individuality could greatly benefit their health, as can be seen in the following comments:

“It would give me back my independence”
“I wouldn’t have to rely on family so much”
“It would increase my wellbeing and confidence”
“It would save the worry for me”
“It would improve my quality of life, in particular, by reducing stress”
“By getting to know the carer, I would gain confidence”
“It would give me a sense of achievement, because I could do it myself, and not be relying on the local authority to do it for me”

People wanted to feel, however, that they would continue to have a choice about whether they could buy their own services, or have them delivered by their local authority.

Direct payments as means of giving control to older people

One participant described her individual circumstances, whereby currently, she is supposed to get half an hour of personal support. Because her carer has approximately 10 other clients needs’ to meet in one day, the visit is always rushed, and in fact the participant only gets 15 minutes. She feels an advantage with direct payments would be that the carer may have fewer clients in the one day, and she could judge how long the carer would stay and so would give her some choice about the length of time. She also felt this would lead to increased job satisfaction for carer.

“I would get the help I need, not what somebody else thinks I need, and what my husband needs. We would have more control, and it wouldn’t be more than we actually need”.

Some participants talked about feeling very dependent on family and friends, and not necessarily having the control to change the situation. They felt direct payments had the potential to give them more control in relation to who was going to assist them, and would afford them more independence. This could potentially remove some of the tension that may occur when a family member or friend feels obliged to give support, but does not have sufficient time to do this.

Using direct payments to be creative in meeting service needs

Participants hoped that direct payments would create the opportunity for support to be more creative, for example, people talked about the possibility of using direct

payments in collaboration with others, to help more than one person or a group of people (a sort of pooling of resources).

One participant who was in receipt of direct payments was able to give examples of the creative ways in which he used his PA: *“I was going for surgery, and wanted to get fitter. My Personal Assistant helped me to get fitter for the operation”* and *“I wanted to get new floor covering, so my Personal Assistant helped measure up and went to the shop with me”*.

Participants from the South Asian and Polish discussion groups talked about the potential lack of skilled personal assistants to meet their needs. For example, people talked about how much more effective support would be if they could communicate in a shared language, and wondered whether the direct payment system could be used to employ a relative or friend from their native country to move to Scotland to become a personal assistant. Another suggestion was that instead of employing someone from abroad, there could be value in identifying individuals from second (or even third) generation families, who would probably be bilingual, and have the advantage of an understanding of legal and social systems in the UK.

Personal responsibility and management of direct payments

The responsibility and management involved in using direct payments was a major concern for participants in all groups. They were informed of the support available, for example through the Lothian Centre for Integrated Living, but it was recognised there is currently inequity of support throughout Scotland, where some local authority areas do not have an identified agency. An addition, concern was raised regarding the experience of support agencies of working with BME older people, and their awareness of lack of literacy, either in English or their own language, amongst this group.

Despite knowledge of this support, participants felt that the responsibility and management of direct payments was a “massive task”, and were unsure whether they felt willing or able to take this on. Several participants from all the discussion groups expressed concern about taking on the task of managing the administrative and legal facets of direct payments, such as national insurance, tax, health and safety, holiday pay, sick pay, hiring and firing of personal assistants, and monitoring their work. There was a comment made about the appropriateness of taking on such responsibility and management at a time in life when some older people are looking to relinquish these types of tasks from their day-to-day living. A few participants felt that direct payments could be seen as the government transferring the burden/responsibility back to older people.

The responsibility discussed above seemed to be heightened for those people whose first language was not English. These individuals talked about the increased difficulties in asking questions, getting their point across, and receiving information, relating to this complex scheme, when they were not using their native language.

The responsibility of being an employer was felt to be onerous. One participant from a remote highland village did not want to be an employer, and have the responsibility of hiring and firing. She commented that *“this could be particularly difficult within a small rural community, where people could get to know what happened”*.

Specific issues related to Personal Assistants

All groups expressed concern regarding the potential pool of personal assistants they would need to draw on in order to cover for planned or unplanned periods of absence, such as holidays or illness.

Of particular concern for older people living in rural and remote areas was the limited availability of personal assistants, and the lack of anonymity afforded to those living in small communities.

People discussed the issue of availability of PAs to cater for people with specific needs, such as hearing or visual impairment, complex medical conditions, and language other than English. People from minority groups felt that if they could employ a PA who had knowledge of the British social care system, they would feel more secure. Personal characteristics that people would value in a PA included honesty, a sense of humour, commonsense and *'someone who really knows me'*.

The profile of the role of a personal assistant needs to be raised, and training and education provided, so that becoming a PA could be seen as a career opportunity. Indeed, many stressed the importance of nurturing PAs, and involving them in developing the whole scheme of direct payments, and make use of their first hand experience. There was also a suggestion to make younger people aware of such opportunities, perhaps by raising awareness in secondary schools of the potential to work as a personal assistant.

The issue of not knowing service providers, who may be working in their home, was a concern raised by participants in all groups. Participants talked about feeling unsafe when a stranger comes into their home, and speculated about the potential for 'taking advantage'. Even though currently unfamiliar care workers may attend people's homes, because these people are employed by the local authority, participants felt that this offered some feelings of security. To lessen the responsibility of appointing a suitable, trustworthy person, participants felt they would like a support agency to help them with hiring and ongoing monitoring of the PA's work. They felt it may at times be difficult for an older person to comment on the working relationship, and that there may be a real need for an advocate to feed into the monitoring process. In addition, people felt that they would want somebody to monitor the working relationship to ensure the PA's rights as an employee were being upheld.

Assessment

People raised concern about whether the assessment was sophisticated enough to pick up the wide range of needs. They felt that the assessment should focus more on actual needs, rather than on what is currently available or offered. In addition, there were concerns about being rejected, or turned down, or not being eligible for a direct payment. Some support organisations work with individuals to assist them to identify their own needs, i.e., a form of self-assessment, and this can give the individual a much better idea of what they can use as a platform for negotiation, with, for example, the care manager. Using this approach may enhance the appropriateness and sensitivity of the assessment.

Participants from minority groups, where the involvement of extended family was very much a part of their lives, expressed a concern that there might be an assumption on the part of service providers that their needs were being met by family members. They felt that this may have implications for receiving a community care assessment, and actually receiving appropriate direct payments. This point highlights the need for culturally competent assessments as one means of addressing concerns about the assessment process itself. (One of the critical readers of this report noted that this is a requirement of the guidance for the Community Care and Health Act 2002).

Support

The majority of participants indicated that they wanted one-to-one support, as opposed to information giving over the telephone, and that ideally, they could receive more intensive support through the first month of using a direct payment.

Several participants also indicated that they would require support in filling in the forms, particularly participants whose first language was not English. We would recommend that forms are reviewed by older people themselves to ensure that they are relevant and appropriate.

A plea from across the board was for support to be coordinated, as older people did not want to deal with 5-6 people to get the information required.

Any support provided needs to be culturally appropriate, and participants from minority discussion groups would like support to come from their existing group(s), however, this has large resource implications for project staff, with concomitant funding issues.

Anxieties relating to how receiving direct payments might impact on other benefits

A general concern of several participants was whether being in receipt of direct payments would have an impact on existing benefits and allowances, such as attendance allowance, carers allowance and disability living allowance. The DPS representative was able to clarify for participants that direct payments is independent from any benefits, but that it is means-tested.

Key issues to consider

- It is evident from this piece of work that the findings generated mirror those of previous explorations of direct payments. Whilst this is of validatory use, there is now, more than ever, a need to move the debate forward, and begin to implement and evaluate the recommendations highlighted in all of this research. It is interesting that many of the conclusions from this piece of work reflect those of Witcher et al. (2000), who looked at the impact of direct payments on choice and control for disabled people. This raises the question as to whether older people should be considered as a group who pose a different set of challenges and requirements for direct payments, and if so, what these differences might be.
- It is difficult to carry out research in a ‘one-off’ format when people have had no experience of the topic, in this instance, direct payments. People may only have knowledge of services if they, or a friend or relative, use them. This has implications with regard to asking people to explore their views about service

provision, both now and in the future. Using case studies as a prompt in discussion groups would enable people to become more engaged with the actual process of using the scheme, and may therefore encourage more responses that relate more directly to how they feel. This methodology, however, requires time for preparation, planning, and execution.

- It became clear following the DPS presentations that direct payments could be a pretty daunting prospect for some older people. Evidence to date shows that a key factor in uptake of direct payments is the availability of one-to-one support. This was also identified by participants in this study as being key, and older people felt that without support, the scheme could not be successful. In addition, this short study has shown us that support needs to be culturally sensitive and be available in all geographical areas. It would be appropriate to consider using existing and established support mechanisms, for example, agencies which already have a role in supporting older people from minority ethnic communities, or people living in remote and rural areas. For example, the possibility of dedicated BME workers could be considered, perhaps on a regional basis, to support the development of direct payment schemes with BME older people. Such organisations would need to be provided with requisite resources (time, training, staff) in recognition of this support. Any support should be monitored to ensure advice provided is independent and impartial.
- Evidence from our discussions indicated that there is still some way to go in securing the commitment of all local authorities in Scotland. There is a need for local authorities to commit to direct payments both financially, and philosophically, and to have a key person to contact in each local authority area who has expertise on direct payments.
- Participants indicated that having an identified local point of contact (place/person/phone number) would make them feel more confident about making an enquiry.
- Continuing work that encourages professionals to both be aware of direct payments, and feel competent to implement the scheme is a priority.
- Literature, including videos and leaflets, and support, needs to be made available in a range of languages, and efforts need to be made to address the needs of those older people for whom literacy is an issue, in whatever language.
- A careful assessment of all the guidance literature available to ensure that the key issues identified from the substantive body of research are adequately represented.
- Promote career opportunities for PAs that includes consideration of appropriate education and training.
- In relation to awareness raising, DPS to date have taken the view that demand from service users is the best way to achieve uptake, and the focus of their approach has been to work directly with special interest groups, who can in turn negotiate with councils to implement the scheme. More debate and discussion needs to take place to decide which approach to awareness raising is most appropriate for older people, and who might best serve their interests.
- Careful consideration of the new single shared assessment criteria is required to ensure that they match up with the needs of service users that direct payments has been set up to meet (for example, issues specific to rurality, such as increased costs relating to travel, and time).

- Build on and incorporate work and research already conducted – for example, the study by Hasler & Stewart (2004) describes a planning tool which was developed by the project, called ‘Smooth Routes to Direct Payments’. This outlines ten practical stages for developing an independent direct payments support scheme. In addition, a close analysis of a local authority where uptake of direct payments has been successful, such as Orkney or Fife, could give key information about important drivers for future implementation.

In addition to the points raised above, important issues relating to the process of holding discussion groups with people from different cultures and backgrounds should be taken into account. This includes the preparation time – establishing contacts and relationships, setting up preparatory meetings, determining needs and requirements in order to hold the groups (e.g. interpreters, accessibility, travel expenses and remuneration), and this should not be underestimated.

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APPENDIX

Questions/issues arising from Group Discussions

The groups raised a number of questions relating to direct payments about which they wanted more information. **A large number of these questions were answered by the Direct Payments Scotland representative(s).** We have included them as part of this report, however, as they form a useful part of the data collection process, and highlight particular questions that older people want addressed. These questions in turn can provide valuable data in the shaping of guidelines, and the production of any further literature that is directly targeted to inform older people about direct payments.

What if someone is not assessed properly?

Assessed need relating to leisure and therapeutic activity and travel – is this covered?
Confusion about disability versus frailty – e.g. if someone has arthritis, would they be classified as frail, or disabled? (interestingly, the group of older people agreed they would classify that as disabled)

How does Direct Payments affect a Crossroads budget?

Does Direct Payments affect benefits?

Is it means tested?

If we can't get local authority carers, where would the carers come from?

Do you get the carers yourself?

What about backup services?

Where are we going to get the labour force required?

What happens if you are not happy with the person you have employed as a PA?

Is the DP system monitored from time to time, and is the evaluation open to fraud?

Who monitors the quality of work of the personal assistant?

Is the community care assessment carried out every year?

Is there enough budget in the pot to keep DP going?

What amounts of money are available to provide service? What is the range of provision?

Do Direct Payments rise every year with the cost of living? Is it index linked?

What is the average amount of money people on direct payments can receive, and the frequency, whether monthly or weekly?

What did the Scottish Executive hope to achieve by introducing DP?

How do you initiate the service? Who do you speak to?

Can Direct Payments pay for education/training of carers/PAs?

Is there advocacy support for personal assistants?

Is there any distinction with regard to age (e.g. 50+, 65, or 80+)?

Who pays for the travel costs of the personal assistant?

Is there a directory or a network of available PAs and other support services?

What do you want to say to politicians?

We asked participants to give us one or two comments they would like to be fed back to the policy makers. Below are some examples:

Could the Scottish Executive please think of another name for the scheme, as it is currently confused with another government scheme (DWP)?

Ensure adequate funding, regardless of uptake.

Lack of joined up thinking!

If direct payments are to pay for lifelong learning, is there a cut-off in relation to age?

If the Scottish Executive want people to use the scheme, there needs to be a more concerted and open campaign.

A proper analysis of the cost-benefit of introducing direct payments needs to be carried out, i.e. has the government saved money by not putting people into care homes.

People at the top don't actually know what is happening at grass roots level.

Information should be in plain English and people should find out from other direct payments users what to put in this information.

If direct payments do not meet the needs that an older person has, is there another scheme that is being developed that will do this?

Need to look at other countries, UK lagging behind – for example, go to Copenhagen.

They (Scottish Executive) need to be congratulated for introducing the Act – well done.

More information. Not everybody can come to events – think of other ways to disseminate information. Suggestions included GP surgeries, health centres, places of worship, and shopping centres.

Everyone needs to know about this, including professionals – doctors, social workers, ward managers, hospital discharge staff.

Concern that might turn into a 2-tier system: those that can manage Direct Payments, and those that can't, so therefore continue to receive Local Authority care.

In England, the rules have recently changed such that individuals can employ people living at the same address - does Scotland plan to follow suit?

Why bring out a system when there is not adequate support to implement it?