

# **Implementing direct payments for disabled people in the UK: initial findings from interviews with purchasing authorities**

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There is now considerable quantitative data revealing the uneven take-up and implementation of direct payments policy for disabled people across the UK. Rates of take-up vary considerably between different countries and regions and between different localities. Our purpose here is to explain the key generative mechanisms underlying these differences. This working paper presents preliminary findings from 102 telephone interviews, with key informants in purchasing authorities, conducted as part of the ESRC-funded project 'Disabled People and Direct Payments: a UK comparative study'. These included representatives of 43 English Authorities, 17 Welsh Authorities, 30 Scottish Authorities and 12 Health and Social Service Trusts in Northern Ireland. The telephone interviews were semi-structured in format, and involved lead officers on direct payments (e.g. senior managers with responsibility for direct payments as part of their wider job role), or designated officers working with direct payments (e.g. direct payment coordinators or project workers). In almost all cases, interviews were tape recorded and transcribed for subsequent analysis. In this preliminary working paper, we summarise the key findings from each section of the interview schedule.

## **Roles and responsibilities**

The interviews began with discussion of the respondent's role in relation to direct payments for disabled people within the Authority or Trust concerned (e.g. job title, responsibilities and previous experience). As the findings reveal, responsibility for and involvement in direct payments differs considerably between localities and across different regions of the UK. Sixty-five percent (28) of those from the English sample were in designated full-time direct payment posts but in the Welsh sample it was just one out of 17 (6%). The remainder worked on direct payments part of the time. The time spent on direct payments for this group averaged between 10-20%, although there were exceptions, with some clearly spending more time than this. In the English authorities there was a clear shift towards designated full-time direct payment posts (e.g. by comparison with details listed for direct payment in the NCIL database, developed from 1999 onwards). The reasons for this were partly related to the designation of direct payments as a key performance indicator in England.

In Scotland, 7 out of the 31 interviewees (23%) had designated direct payment posts. These had mainly emerged in response to policy changes in 2003 and included posts such as a Senior Social Worker with sole responsibility for policy, a Team Leader for direct payments and a Senior Resource Officer covering both direct payments and Independent Living Fund referrals. Throughout the remaining 24 authorities, roles were integrated into

more generic posts in community care or areas of disability services. Where designated roles had not been developed, respondents found that direct payment roles were increasingly taking up a lot of time. By contrast, none of the respondents in Northern Ireland held designated posts for direct payments. Responsibilities were held at Assistant Principal or Director level (community care or social work) or through service manager roles within disability services. However, it was clear that direct payments formed only a small part of much larger workloads. Across Scotland and Northern Ireland, many of those without designated posts spent around 25 per cent of their time on direct payments, whilst others conceded that direct payments took up only a very small fraction of their workload.

## **The use of direct payments**

The successful implementation of direct payments policy in the UK will ultimately be judged by the extent to which disabled people (and others) are enabled to live more independent lives. A key factor in achieving this will be the degree of choice, control and flexibility that purchasing authorities are able to support through local mechanisms of assessment and care management. Publicly reported data on the receipt of direct payments, together with initial findings from the Direct Payments Survey Group, suggest considerable diversity in this respect. For this reason, it was important to discuss with local informants how direct payments are currently being used, including the opportunities and restrictions that may face disabled people when they choose this option.

All of the interviewees said that direct payments gave users greater choice, control and flexibility, and there were many innovative examples of the uses that direct payments could be put to in order to promote independent living. These included support for alternative forms of respite, travel options, and support for diverse social activities. In the main, direct payments were used positively to provide greater flexibility towards independence in everyday living. However, there were substantial differences in the degree of flexibility and choice available to users in different localities.

All of the purchasing authorities organised their assessments for direct payments through the community care system, and therefore in relation to a generic framework for the assessment of needs. However, this did not always mean that needs met through services would be equivalent with need met through a direct payment. For example, in three English authorities, respondents suggested that assessed hours for direct payments could be higher than the equivalent for directly provided services (due to extra time for administration and PA recruitment, or because half-hour allocations were rounded up).

There was evidence that packages involving a direct payment are often subject to additional tiers of assessment and checks than those consisting only of direct service provision (in Scotland, around half of local authorities indicated that they had different procedures). In some cases, this simply involved a contract stating that users take responsibility for their payments. Others required a more stringent examination of the package by senior staff than would otherwise be imposed. One trust in Northern Ireland indicated that where a home care package would require one layer of checks, a direct payment could be subjected to as many as five. Fair Access to Care (FAC) criteria were also noted by several interviewees in England and Wales as a restriction on access to direct payments for some disabled people.

In terms of the allocation of direct payments for assessed needs, the bulk of resources were devoted to personal care. Purchasing authorities tended to fall into two camps – the majority focusing resources on support for personal care and a significant minority adopting a more open approach to meeting any assessed need. For example, around a third of Scottish authorities were clear in asserting there were no restrictions on the needs that might be met using a direct payment (assessed on a case-by-case basis) while two thirds focused resources on personal care. Packages were sometimes ring-fenced for different areas of assessed need. For example, in three English authorities needs for housework or gardening were not funded through direct payments (although in two of these money from the personal care packages could be used for these activities if the user ‘had cash left over’). Similarly, one authority would not fund respite breaks through direct payments (in this case the restriction aimed to ensure equity between users of direct payments and directly provided services). In some cases, direct payments were being used simply to buy in agency support for personal and home care that was similar or identical to that provided for ‘service users’. While the majority of direct payments packages focused on personal care and domestic tasks, there was evidence of change in eligibility criteria to accommodate greater flexibility and innovation across all user groups.

The value of direct payments as an alternative to direct service provision was most clearly demonstrated in reported outcomes for users at the individual level. There were specific examples of disabled people who had used direct payments to achieve major gains – to leave residential care, to avoid going into residential care, to maintain family contact, to move house, and to gain employment. Respondents were keen to emphasise creativity in the use of direct payments to support independent living outcomes, and numerous examples were provided to illustrate this. At least six authorities allowed direct payments for user-defined alternatives to respite care (including short breaks, holidays and rental of holiday cottages). Two authorities allowed payments for ‘pay as you go’ mobile phones to mental health users. One allowed gym membership (including membership for the PA). Two cited users who had been allowed the cost of satellite TV channels. One had allowed support for attendance at an international conference. Innovative usage was also demonstrated in positive outcomes where, for example, individual users were seen to go shopping, to the pub or to community meetings rather than to a day centre. There were however some who were more sceptical about flexibility and choice, perceiving more ‘creative’ usage, such as attending football matches, as an inappropriate use of funds.

To summarise, there was a general feeling that direct payments allowed greater options for independence when compared to directly provided services. Those with dedicated direct payments roles were more likely to champion the creative use of direct payments. However, difficulties in defining ‘needs’ and quantifying them through the community care system meant that practitioners were often unclear about the boundaries of eligibility for direct payments. Some interviewees felt that, while alternatives to directly provided services were welcome, there should be other options (e.g. embracing alternative mechanisms such as vouchers). There were fears within purchasing authorities that direct payments policy represented a government strategy for the privatization of social care. It was strongly argued that direct payments should remain a choice for existing service users, rather than being imposed, and there was some concern that direct

payments users received more favourable treatment than service users (this concern appeared particularly marked in Scotland). However, direct payments were enthusiastically applauded throughout the UK where they could be evidenced by success stories of real positive change in people's lives.

## **National guidance and local interpretation**

The successful implementation of direct payments policy requires creativity, and those responsible for implementing direct payments policy (at either managerial or operational level) faced challenges in interpreting policy guidance during the emerging and largely enabling policy framework following the 1996 Act. Consequently, it was important to discuss the utility and interpretation of national guidance at the local level. This included guidance from the Department of Health, the Scottish Executive, the Welsh Assembly and the Northern Ireland Assembly.

Implementation guidance from national and from regional governments was broadly welcomed. More specifically, more recent guidance appeared to provide more clarity and generate more positive responses from respondents at the local level (e.g. guidance from the Scottish Executive in 2004). Clearer guidance provided a more sure foundation for the establishment of new service structures and helped to challenge reluctance amongst some staff. In Northern Ireland, consultation and guidance by the Assembly, in 2003, appeared to have provided a positive 'turning point' in policy implementation.

However, respondents throughout the UK also identified considerable issues of uncertainty and clarity that adversely affected the implementation of direct payments at local level. Many welcomed the scope for interpretation, allowing local policy development to be adapted to local conditions, local politics and local strategic plans. Yet this flexibility became a 'double edged sword' when implementation relied heavily on the interpretation of frontline staff, resulting in some individual and ad hoc decision-making that may have denied potential users a direct payment. Continued ambiguity was perceived as giving some social workers reason to limit or delay the roll-out of direct payments to certain user groups.

The biggest concern amongst the English sample was a perceived contradiction between the incentive to expand usage of direct payments and the requirement to maintain a 'duty of care'. Seventy percent (30) of English interviewees saw problems or ambiguities in Department of Health guidance in relation to their responsibility to users and the potential for litigation. Such concerns centred on questions around Criminal Records Bureau checks, the vetting of PAs, and the potential liability for instances abuse. In Scotland, there was also widespread confusion over the legal position on disclosure and police checks for potential PAs employed via direct payments. Many interviewees felt that the guidance was too vague, leaving local authorities unsure as to how to proceed. The proportion of those with major concerns in this area appeared substantially lower in Wales, with 7 out of 17 (41%) citing such issues as a major issue, whilst in Northern Ireland there appeared to be much less critical engagement with the specifics of policy guidance (perhaps due to the relative lag in take-up and implementation more generally).

A second, and related, area of interpretation concerned guidance on the condition that users should be 'willing and able' to manage a direct payment. This was the most frequently mentioned concern for those in the Welsh authorities, and was cited by almost

half of the interviewees in England. Lack of clarity at the local level in defining capacity and consent had created problems in implementing robust and equitable direct payments policies. Many of the interviewees viewed lack of clarity on consent issues as impeding the choices of those with mental health needs, dementia or learning difficulties (three English respondents also noted confusions over ‘power of attorney’ issues). Almost a quarter of English interviewees felt that such concerns might have been avoided if promised guidance on indirect payments had been provided by the Department of Health (at the time of the interviews, additional guidance on indirect payment schemes was not available).

Specific concerns with guidance on children’s services were prominent amongst the Scottish authorities. Indeed, 12 out of 30 (40%) raised children’s services as a key area of concern, and there was some frustration with a lack of clarity from the Scottish Executive, following requests for specific guidance in this area. Similarly, several interviewees in England and Wales noted concerns over direct payments for disabled children. This was especially the case in the need to clarify support during a child’s transition to ‘young person’. Lack of clarity on consent and carers’ entitlements, coupled with the fact that many children were described as having ‘severe disabilities’, resulted in concerns that such children might lose their direct payment during transition.

To summarise, concerns and ambiguities over ‘grey areas’ in policy guidance focused primarily on the relationship between capacity, consent and duty of care. These ambiguities were viewed as inhibiting take-up and equity amongst vulnerable user groups (including children and young people with complex impairments, users of mental health services, people labelled as having learning difficulties, and older people with dementia). In addition, both the DOH and the Scottish Executive were criticised for not always responding to requests from local authorities for clarification on specific issues associated with the implementation of direct payments policy. A minority were concerned that national or regional governments might wait for litigation at the local level before intervening to help resolve some of these complexities. Additional areas of concern related to the provision of aids and adaptations (in terms of ownership, cost and user contribution), joint working between health and social care, and to the employment of relatives.

## **The impact of mandatory duties and targets**

During the interviews, respondents were asked about the impact of subsequent policy changes since the initial implementation of the 1996 Act. In particular, the discussion focused on the impact of a mandatory duty to offer direct payments to those eligible to receive them, and this introduction of performance indicators or targets. It was clear from the responses that the use of performance indicators and local targets for direct payments implementation varied dramatically between the different regions of the UK, and between different localities where national/regional requirements were not in place.

Our quantitative review of initial direct payments implementation had revealed a generally low take-up, and uneven implementation, by purchasing authorities across the UK, particularly in the early years after the Act. This raised questions about the effectiveness and equity of a national policy that was ultimately discretionary or enabling in character. Consequently, the introduction of mandatory duties to offer direct payments provided an important focus for discussion of more recent implementation.

The impact of a mandatory duty to offer direct payments in England and Wales was considered very high, especially in convincing strategic and upper management to move forward with implementation where there had been prior reluctance. There was less impact in those authorities that had been implementing direct payments for some time, although change was seen as reviving flagging growth rates in some of those authorities. However, in Wales, compared to England, there appeared to be a greater reluctance by some senior managers to move forward with implementation, despite the changes.

Amongst the Scottish authorities, 19 out of 30 (63%) viewed the introduction of mandatory duty, in 2003, as the main impetus for policy development (rather than the 1996 Act). Even in those authorities where efforts had been made to implement policy during the discretionary period, planners had often experienced a lack of clarity on how to proceed, which led many to lose impetus. In other areas, where there may have been fewer initial users, the absence of compulsion meant that there was little incentive for anyone to take on a direct remit for driving forward implementation or establishing a local direct payments scheme.

The original 1996 Act had been poorly received in Northern Ireland, with only 2 of the 12 Trusts interviewed indicating that they had developed policy as a consequence of the original legislation. The shift to mandatory implementation from April 2004 was therefore central to developing local implementation strategies. Leading on from this, interviewees also indicated that the policy review led by the DHSSPS in 2003-04 had been vital in promoting policy and enabling change at trust level.

A second key factor had been the introduction of performance indicators or targets for direct payments implementation. Broadly speaking, whilst in England there had been a strong steer from the Department of Health in establishing targets, elsewhere in the UK their use had been much more varied and localised.

There was little doubt that key performance indicators in England, together with the mandatory duty, had a significant effect on strategic and upper management in those authorities that had previously been reluctant to pursue direct payments under the enabling framework of the 1996 Act. In some authorities, the number of direct payments users had trebled since the introduction of targets. Key performance indicators for direct payments were welcomed by the majority of respondents, for their value in convincing management to take direct payments seriously. Yet there were also criticisms that they focused on the quantity rather than the quality of provision.

No performance indicators had been set by the Department of Health, Social Services and Public Safety (DHSSPS) in Northern Ireland, and 7 out of the 8 Trusts interviewed did not have any targets of their own in place. Respondents in Northern Ireland generally viewed target measures as largely irrelevant because direct payments policy was at such an early stage of implementation. However, the general feeling from the interviewees was that recent changes, and a review of policy led from within Northern Ireland, had been significant in adding momentum to implementation.

In Scotland, performance indicators and local targets for direct payments were used in only 6 of the 30 authorities interviewed (20%) and varied considerably (for example, in the time period covered or in projections for growth). Almost all the Scottish authorities without set targets were resistant to them. Instead, respondents emphasised the need to focus on ensuring that users were fully informed about service and support choices. There was also some concern that the use of targets might result in service users being pushed

to take on a direct payment when this might not be the most appropriate support option for them. Several of the 17 Welsh interviewees were also sceptical about key performance indicators, and felt that their introduction in Wales would have potentially negative effects on the value of direct payments as an elective alternative to directly provided services.

To summarise, the introduction of mandatory duties, performance indicators and local targets had a significant positive impact on policy implementation in terms of take up (although there were reservations about the absence of quality indicators). This effect was evident in all parts of the UK where such initiatives had been taken. However, the influence was more apparent where targets had been led nationally or established clearly at a senior local level. There was also some significant scepticism or resistance to the use of targets in those localities or regions where implementation was still at a very low level, or where there was a lack of focus on the place of direct payments within strategic policy development.

### **Extending direct payments to ‘new’ user groups**

Since initial implementation of the 1996 Act there have been significant changes to the profile of eligibility for direct payments. This began with the removal of the upper age limit of 65 in 2000 and was followed by extension to parents or guardians who looked after disabled children, to 16-18 year olds and to carers. In Wales the extension to these groups began in March 2005. Additional changes in Scotland extended eligibility to all those assessed as having ‘community care needs’. Although originally planned for April 2004, phased implementation began from April 2005. It was therefore relevant to discuss with all interviewees the extension of direct payments to new user groups, although the implications were different in the different countries and regions of the UK.

In England and Wales, all interviewees saw the extension of eligibility to as a positive and welcome move. Issues of consent, noted above, appeared to impact negatively on implementation for people with learning difficulties and users of mental health services. Most interviewees from England and Wales noted an overall improvement in uptake by new user groups (with the exception of mental health service users). In Northern Ireland, there was relatively less development and the focus tended to be narrower, with the main emphasis remaining on people with physical impairments (in one Trust, people with learning difficulties were still described as a ‘new group’).

There had been widespread concerns about the more general extensions in Scotland (leading to delayed implementation). However, just under half of the Scottish respondents indicated that they had framed local policy development to accommodate new groups, or would be able to do this without too much difficulty. The decision to instead pilot extension with specific target groups (beginning with frail older people in April 2004) caused some frustration. The possibility of extension to groups such as homeless persons and those recovering from drug or alcohol abuse raised a number of concerns (e.g. in relation to the financial implications and the need for clearer guidance from the Scottish Executive).

Clearly then, some authorities were much further ahead in implementing take-up amongst additional user groups than others. Those authorities that had offered direct payments to a wider range of groups before there was a mandatory duty to do so had clear advantages in implementing specific support arrangements. Yet, even here, there was

recognition that considerable work and investment would be required to fulfil policy objectives. There was some frustration amongst those authorities whose early inclusive local policies had been curtailed by the eligibility criteria of the 1996 Act, only to be extended subsequently. Key areas of concern were apparent in relation to mental health users and those with learning difficulties, partly due to the general concerns surrounding consent and sometimes in relation to the specific eligibility of individuals covered by section 117 of the 1983 Mental Health Act.

It was clear that considerable advances were being made where there were good direct payments support structures, free payroll services and development funding for innovative work (70% of our English sample authorities had received DoH development funding). Development funding in English authorities targeted older people, children, young disabled people, people with learning difficulties and users of mental health services. This gave many English authorities considerable advantages, while the additional practical support for direct payment users and improved outreach created a positive impact on the development of best practice more generally.

## **Training and publicity**

Information plays an important role in the take-up of direct payments, raising awareness and increasing knowledge. Publicity and training are likely to impact both on potential users and on staff involved in assessment, commissioning or care management within the purchasing authority. Consequently, the interviews included a discussion of local initiatives and activities in relation to publicity for direct payments and the provision of training to further policy implementation.

There was no standardized model for publicity on direct payments, with different authorities engaging in different forms of activity. Publicity strategies were important in alerting and orienting potential users, and those authorities with varied and effective training models appeared to have a higher take-up of direct payments. Publicity strategies included leaflets, presentations, local press and radio articles, networking with voluntary organizations, and the production of videos or DVDs. There were clear differences in the resource base for such activities in different parts of the UK.

In England, the majority of authorities had some form of publicity drive. Only one reported that this was an area requiring development (in another, publicity was provided exclusively by the support organization). The large number of full-time direct payment posts within the English sample appeared to have a positive effect on capacity for publicity. Cash resources were also important, with 70% of the English sample having received DoH funding for additional outreach to targeted user groups. More than a third of English authorities carried out leafleting in conjunction with events, presentations and networking opportunities (e.g. involving voluntary sector organizations). One interviewee, a direct payments advisor, had carried out 43 presentations during a six month period. Four authorities had organized publicity slots on local radio and five were using local papers or local council newspapers for publicity purposes along with 'success stories' of direct payments users. In addition, many used council or support organization web pages to promote direct payments. In addition, six had produced, or were in the process of producing, a video or DVD on direct payments for potential users. All of the English authorities had developed training for direct payments users at some point (one admitted that this needed to be developed).

In Wales, 2 of the 17 authorities had no training in place. One had organized an intensive training initiative and increased direct payments usages by 50% (although it was unclear whether this was a direct effect). The majority of Welsh authorities used information leaflets, produced either by the authority or the support organization, although two were only just beginning to develop promotional materials. Five had used newspapers or magazines, and two others were planning promotions at local sites or events. Several authorities shared the same support organization or provider and this provided opportunities to collaborate on publicity. In one case there was a jointly produced information booklet; another group were organising the production of an All Wales video with combined funds from four authorities. Although the Welsh Assembly had provided £4,000 to each authority to develop promotional materials, there remained some concern amongst respondents who felt they still lacked sufficient information on direct payments to push forward with publicity.

In the majority of Scottish local authorities, information leaflets and frontline staff provided the most common publicity route for potential users. Voluntary sector organisations for and of disabled people were also used as main points of contact, alongside support organisations. However, some concerns were expressed about proactive publicity policies and the potential impact these might have on service budgets if demand increased. There were examples of some innovative practice and targeted approaches, such as the production of a video specifically targeted at people with learning difficulties in one authority (this was felt to have had a significant impact on take-up locally).

Although all of the Scottish authorities had been involved in staff training on direct payments to some extent, approaches and intensity varied considerably. In those authorities where there were designated direct payment posts, training strategies were far more ingrained in mainstream social work practice. Dedicated officers were able to spend time with colleagues and teams, and to champion training initiatives across the authority. Elsewhere, training had been less intense with input limited to one-off or ad-hoc information events (sometimes with the local support organisation or finance department taking the leading role). Integrated approaches were apparent where direct payment training had been incorporated within wider moves towards single shared assessments and the Supporting People initiative. Direct Payments Scotland also facilitated local training events, particularly in some of the smaller Northern and island authorities. There was some evidence of staff resistance and certain groups were still lacking in training on direct payments, with community mental health practitioners and children's services often cited as more difficult to involve.

In Northern Ireland, the Regional Review Sub-Group on Training for Direct Payments had been established to provide a training framework for all trusts in the Province from early 2005. Most of the interviewees were involved in this initiative, although individual trusts also had their own approaches. A number of diverse interim approaches were in place, but concerns were raised over existing arrangements and the lack of overall training in making staff aware of policy changes in some areas. In one trust, for example, the only training had been at the time of initial implementation in 1997 and was restricted to the 'physical disabilities' team. Again there was some evidence of staff resistance to the underlying principles of direct payments provision.

Four out of the 8 trusts conceded that they had not been particularly proactive in their publicity on direct payments. Whilst some attempts had been made to produce leaflets at the time of the original legislation, these had rarely been updated in light of more recent changes. As in Scotland, partnerships with local voluntary organisations had been used in two of the trust areas, but neither viewed this as a particularly successful strategy. There was also a suggestion that staff awareness would be most effectively raised by increased demand from potential direct payments users.

To summarise, the interviews revealed considerable unevenness in capacity and activity associated with training and publicity to support the implementation of direct payments policy. Across the UK there were regional disparities, for example in the extent to which national or regional government had invested in development activity. Purchasing authorities with dedicated direct payments posts were more likely to engage in systematic and proactive training and publicity and this impacted positively on demand and take-up from potential users. There were a number of examples of innovative practice, including collaborative initiatives between authorities. There was also some evidence of low level resistance to training amongst some staff groups, particularly in Scotland and Northern Ireland.

## **Local labour markets and the recruitment personal assistants**

The successful implementation of direct payments policy, and sustainable extension to a larger and more diverse client group, is contingent upon the recruitment and retention of directly employed staff from local labour markets. Questions of market capacity, training, and working conditions have been raised by researchers in the past. Consequently, the interviewees were asked about their experiences of the availability and employability of personal assistants to support disabled people as direct payments users.

Half of the authorities in Wales reported difficulties in recruiting PAs. This was often related to the geography of large rural areas, or to the age demographic of localities with a high proportion of retired residents. In England, PA recruitment was also identified as problematic by around half of the respondents, and interviewees noted that recruitment had become more difficult in recent years. Although many Scottish authorities reported a general difficulty in recruiting home care staff, more than half indicated that this difficulty did not extend to direct payments. In Northern Ireland 7 out of 8 Trusts acknowledged general problems with social services staffing but, as in many Scottish authorities, there was a sense that the recruitment of personal assistants was drawing on a different pool of labour, and with potential advantages for some potential employees.

Recruitment difficulties were clearly apparent where direct payments users had very small packages of hourly support, or where requested hours were ‘unsocial’ for the employee. In Scotland, recruitment difficulties were linked to low number of users, and to continuity of employment (when compared with home care jobs). There were several examples of specific local recruitment difficulties in more affluent areas and commuter belts (e.g. where casual and part-time domestic support work was available) and in localities where service sector or retail employers had recently established new large-scale job opportunities (e.g. new call centres or supermarkets).

In response to difficulties, several Scottish authorities had raised hourly rates of pay to make personal assistance employment more attractive. In England and Wales, there were also concerns about low rates of pay and lack of travel expenses in some authority

areas. A small number of English had reviewed, or were considering increasing, the number of hours awarded in a package in order to make recruitment for personal assistance more attractive to potential employees. Recruitment was considerably easier where a disabled person in receipt of direct payments was able to identify or headhunt potential employees (either through informal networks or from agency staff known to them). The employment of friends and relatives was acknowledged as one way to address recruitment difficulties, especially in rural areas, and 3 of the Trusts in Northern Ireland had considered relaxing rules on the employment of relatives to address recruitment difficulties. On a positive note, a small number of respondents noted recent improvement in recruitment where employees were leaving agency and residential care jobs to become PAs because the work gave them greater satisfaction, or because they felt more valued in the work role.

In addition to the discussion of general recruitment factors, interviewees were also asked to comment specifically on provisions for the employment of relatives. At the time of interviewing (November 2004-April 2005), policy guidance differed between Scotland and the rest of the UK. In England, Wales and Northern Ireland, guidance implemented in 2003 relaxed the ruling that relatives could be employed only in 'exceptional circumstances' and allowed family members *not* living in the same household to be employed. From April 2005, the situation in Scotland has subsequently been brought into line with the rest of the UK.

In the majority of areas, the employment of relatives continued to be viewed with some caution whether they lived in the same household or not. There were perceived problems regarding the changing distribution of power within family relationships, issues that might arise if a family member was not acting in the best interests of the user and questions around what would happen if the relationship broke down. There were also concerns about the feasibility or implications of 'sacking' a family member if problems arose. A further concern was that large numbers of unpaid carers would come forward asking for direct payments, and that this would have considerable financial repercussions for authority budgets. Exceptions were also made where the direct payments user had a particular condition which meant that new people coming into the household would impact negatively.

However, the employment of relatives was seen as one way to tackle difficulties in recruitment affecting particular communities (e.g. within some urban black and minority ethnic communities and some sparsely populated rural communities). The exceptional circumstances rule had also been applied to allow people in the same household to work as PAs when there was no available alternative. In Scotland, the majority of local authorities welcomed the 'exceptional circumstances' condition as a general principle, since it allowed relatives to be employed but not to be advocated as a mainstream option. Most found that this arrangement was adequate to meet exceptional needs (such as support from family members during terminal illness). There were widespread concerns, in a significant minority of authorities, that relaxation of eligibility would result in spiralling costs associated with the employment of previously unpaid family carers.

## **The impact on local services and commissioning**

The implementation and extension of national direct payments policies, especially in the context of mandatory duties and performance targets, has clear implications for the

allocation of budgets and resources within purchasing authorities. Any substantial increase in the take-up of direct payments will necessarily impact on existing service provision and commissioning strategies. This theme was raised in the interviews by asking respondents about the impact at the local level.

Across Scotland, Wales and Northern Ireland, despite unease over the principle of direct payments, the reported impact on existing services and future commissioning was minimal. Direct payments remained a 'minority service' and, in most cases, authorities and trusts suggested that the numbers of users was not high enough to prompt any significant restructuring of services. There had been some anxieties about 'opening the floodgates' but little noticeable impact as yet (although the award of large individual packages was sometimes seen as more influential than large numbers of users). Concerns appeared more tangible in England and Wales, with around 35% (16 and 6 respectively) reporting management concerns about the financial impact on block contracts and the potential decommissioning of local services. Overall, interviewees conceded that services which were not working well might be lost.

In England, where take-up has been higher, there was evidence of some resource transfer from services for people with physical impairments and learning difficulties (and potential for impact on children's services and respite care). At the same time, in areas where there had been pressure on existing services to begin with, higher take up of direct payments had eased problems. All of the English interviewees thought that direct payments would impact on existing services over time (one authority already had 50% of users with physical impairments on direct payments). Only one Welsh authority suggested that services (for people with learning difficulties) might decline, although several others suggested a potential impact on respite services.

Taking a longer term view, there was more widespread concern, particularly where service provision was organised through block contracts. Although widespread, such concerns remained, by and large, hypothetical at the time of the interviews and authorities were generally coping with demand. User groups with smaller service budgets were seen as more vulnerable to the potential for cuts in service provision. When coupled with broader political resistance to direct payments, apparent in some authorities, concerns over existing services meant that direct payments implementation for new users was being funded from additional budgets rather than from centralised service allocations. For example, where a large 'home care' budget was tied up in a block contract, personal assistance for direct payments users had to be funded from elsewhere. In the main, it was services such as day centres and respite that were considered to be most at risk, should significant numbers of their user groups switch to direct payments. Several authorities also implied an actual or potential impact on residential care as residents took up direct payments as a means to live independent living. High risks to services were particularly apparent when there were small numbers of users accessing a service (e.g. children's respite services). Conversely, several authorities mentioned that lack of services in some sectors had encouraged people to choose direct payments.

To summarise, the current take-up of direct payments amongst disabled people in the UK remains low compared to the number of those eligible to receive them. However, there is great variation within this small numbers, and between different user groups. Although the impact on existing services and commissioning strategies has so far remained minimal there are clear concerns at the local level about future implications.

Many view future transfers of resources from traditional services, like day centres and residential care, to direct payments as a potentially liberating influence for disabled people and their families but many also fear the threat to locally valued service options. There are particular concerns about the potential impact on some service areas with small budget allocations or client groups. Commissioning strategies based on block contracts for traditional modes of delivery raise particular barriers to flexibility in the allocation of resources to meet increased demands for direct payments.

## **The role of local support organisations and disability activism**

The development of appropriately skilled and resourced direct payments support organisations has frequently been identified as a key factor in the successful implementation of direct payments for disabled people. Moreover, there is evidence that early take-up of direct payments was closely correlated with the existence of local user-led support organisations. As implementation has proceeded there has been a diversification of support roles, and an increase in the number of authorities using in house or voluntary sector providers more distant from the local disabled people's movement.

Only one quarter of the authorities in our English sample had a user-led support organization and 14% (6) were authority led (two of these were sub-contracted to social service departments in another authority). The remaining 61% of authorities (26) were contracting with voluntary sector organizations (such as Rowan, Pendralls or the Shaw Trust). In some cases, such schemes employed disabled staff and at least one authority retained an overseeing board of disabled people. One authority retained a local support scheme run by disabled people as well as a charitable organization, based outside the area. By contrast, interviews in Wales revealed only two local user-led support groups (one of which was suspended pending a re-tendering process).

In Northern Ireland, all support offered to direct payment users had been arranged through the Centre for Independent Living in Belfast. In 6 of the 8 trusts this was organised formally, with designated workers covering trusts in Eastern and Southern Board areas. In each case this arrangement was said to work extremely well, with the CIL offering flexible support to both users and staff. In the two Northern Board trusts, no formal support arrangements had been developed. In one area, partnerships with local voluntary organisations for disabled people had been utilised, alongside informal contact with the CIL, and negotiations were underway in the other trust to secure a more formal arrangement.

From the descriptions of support roles given during the Scottish interviews, 13 out of the 30 local authorities were user-led (43%). This included larger established organisations (like the two centres for independent/integrated living in Edinburgh and Glasgow) and smaller local groups developed in more recent years. A further 13 were non-user led. Within this group, services were often run by local voluntary organisations and were described as having 'user involvement' or, in three cases, were in-house services run from within the local authority. Four areas had yet to establish a support service. A third of authorities stated that they hoped to develop a user-led ethos, with a view to user control but there were also reported difficulties in engaging interest from local disabled. Geographically dispersed populations made it difficult to get an

organisation established or to take on the support role (in some of the island communities the notion of collective support by disabled people was questioned).

The majority of support organisations were contracted to provide a wide range of services and roles (from promoting interest in direct payments, to the provision of advice and guidance, staff recruitment and payroll services). Where support roles were outsourced to a third party or retained by the authority this was most likely to be in the area of payroll services. In the main, interviewees were happy with the work that local support organizations were doing and saw them as invaluable in supporting the implementation of direct payments policy. There was some concern over actual or potential decline in user-led support organizations in the UK. Some described user-led support organizations as struggling to cope with rapidly increasing demand and at least two of the English authorities were reviewing tenders with a view to engaging an alternative voluntary sector provider. One English authority, currently providing in-house support, was considering funding for its direct payment user group to take on the support role. Development funding had been significant in supporting or developing local organisations and many trusts in Northern Ireland complained that Department of Health funding, available for tender in England, had not been an option for them. In areas without user-led support organisations, respondents often commented that disabled people's organisations did not apply when contracts were put out to tender, or that they simply awarded the tender to the organisation that could do the best job.

Preliminary research suggested that the effective self-organisation of disabled people has had a considerable impact on the development of local direct payments schemes and the provision of appropriately resourced support organisations. Disability activism was clearly significant in pushing forward the early development of direct payments, and in generating user demand for this option at local and national level. However, it is also clear that the mobilisation of activism and claims for direct payments has varied considerably across the UK. It was therefore important to include a discussion of these factors in the interviews with local informants from purchasing authorities.

Local organizations of disabled people were instrumental in pushing forward the early direct payments agenda in England, although our interviews did not include those well-known authorities with the longest standing disability activism (or the largest numbers of direct payments users). Even so, a quarter of English interviewees (11) noted the significance of early pushes for direct payments from local disabled people and from local champions working within their authorities. Five gave specific examples of locally based disability groups who had lobbied for the development of a local direct payments scheme. Overall, 18 (42%) of the English sample were aware of some form of activism and early demands from potential direct payment users. In the Welsh sample, the situation was strikingly different. One authority had worked in partnership with a group of disabled people and there was just one example given of an individual who had pushed forward local authority thinking on direct payments (on behalf of her son).

In Scotland, three levels of involvement were apparent. In 22 of the local authorities there appeared to have been some input from disabled people in securing policy change. However, in most cases this viewed as relatively low key and coming at a time when change was on the agenda anyway. Although it was commonplace for individual users to have requested service change, such claims had rarely been facilitated through collective voice. A second group of 7 respondents noted that disabled people had no input into the

development of direct payments policy. Indeed, in some cases the local authority had found it difficult to generate interest from users. The third group of responses suggested a lack of awareness of any role for grassroots disability activism.

In Northern Ireland, a different history of policy development and the role of collective disability activism has been far more limited than elsewhere in the UK. Here there was a conspicuous absence of local or regional ownership over direct payments policy development, including a perception that legislation had been imposed on the Province from Britain. Indeed, one Trust representative described a meeting with users where direct payments were viewed with considerable suspicion, suggesting that the Trust was merely seeking to implement a cost saving strategy. However, in two other areas respondents reported positive changes of attitude as disabled people gained greater knowledge about proposed changes.

To summarise, support organisations play a key role in the implementation of direct payments for disabled people, and user-led organisations linked to the disabled people's movement have been particularly important. Across the UK, provision and capacity has been extremely varied. User-led organisations took an initial policy lead in parts of England and the major Scottish cities but were largely absent elsewhere. Following the 1996 Act there was some increased capacity as local organisations took on contracted support roles. However, as implementation has moved forward, expanding eligibility to new groups and increasing the numbers of potential users, some of these organisations struggled to mobilise the financial and human resources to cope. At the same time, new providers of direct payments support have emerged from the voluntary sector and from within purchasing authorities themselves. There is now some concern that the initial link between direct payments and disability activism is coming under strain.

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