

CHAPTER 9

The Implementation of Direct Payments: issues for user-led organisations in Scotland

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Introduction

Since the implementation of direct payments in April 1997, there has been a concerted drive to increase the number of disabled service users across the UK. Having been initially introduced as enabling legislation, local authorities in Scotland, England and Wales are now required to offer direct payments to all eligible persons. Recently this was extended to include older people, 16 and 17 year olds, parents of disabled children and 'carers' in England and Wales. Over the next few years in Scotland, implementation of the Community Care and Health (Scotland) Act 2002 will see direct payments broadened to cover children's services and all persons defined as community care users. These include persons who are: frail, receiving rehabilitation after an accident or operation, fleeing domestic abuse, a refugee, homeless, or recovering from alcohol or drug dependency (Scottish Executive 2002). Such a move clearly marks an important policy shift and has significant implications for the disability movement, which has fought a long campaign to secure direct payments for disabled people.

Whilst in many areas of England and Wales, there are increasing numbers of direct payment users (Department of Health 2002), six years after implementation in Scotland policy remains largely marginalised (Pearson 2004). The first major study into direct payments in Scotland carried out by Witcher et al. (2000) confirmed this limited availability with only 13 out of the 32 local authorities having fully operational or pilot schemes and a total of 143 users. Although more recent figures show a rise to 534 users (Scottish Executive 2003a), this represents only a fraction of the total in England and Wales (Pearson 2004). The reasons for this delay centre on an anti-market discourse (Pearson 2000) whereby many local authorities view direct payments as a privatisation tool to erode key social services. In addition, weak disability activism has

also contributed as an important constraining factor. As such, the basis for policy expansion in Scotland differs from England and Wales in that direct payments have been far less popular as a mainstream service option for disabled people across many areas.

Throughout this time, the role of support organisations has been identified as being critical in the successful development of direct payments across the UK (Hasler et al. 1999; Witcher et al. 2000). Whilst Centres for Independent/ Integrated Living (CILs) have traditionally been viewed as the main centres of expertise for user support, there has also been a growth in other local support groups over the past few years. However as Morgan, Barnes and Mercer (2000) have observed, these services have assumed a number of different forms, many of which have not developed from a 'user-led' framework promoted by the disability movement. Drawing on a small study of support organisations in Scotland, this chapter explores some of these challenges. It is argued that the shift to widen direct payments raises both a series of concerns and challenges for CILs and the wider disability movement. On one level, as the move to integrate new users gathers pace, CILs are increasingly seen as the main centres of expertise. Alternatively, they could be left in an increasingly precarious position, whereby there is an assumption that they are willing and able to support these new groups without additional resources. At the same time, the increasing presence of direct payment support services with limited user involvement and affiliation to local authorities may equally serve as a threat to the longer-term role of user-led support for disabled people.

The research study

This chapter reports on a small study carried out for Direct Payments Scotland (DPS) over summer 2003. The research was designed to provide DPS with information on how support needs could be best met as new changes in Scotland are implemented. With this in mind, the study set out the following objectives:

- To explore the current roles of user-led organisations in supporting the needs of direct payment users.
- To examine the capacity of these organisations to provide additional support for a more diverse direct payment user population.
- To examine the capacity of representative organisations of new user groups to offer specialist direct payment support.

For the study, fifteen semi-structured interviews were carried out with

a range of groups representing current and new direct payment user groups (as determined by the Community Care and Health (Scotland) Act 2002). Discussion in this chapter focuses primarily on interviews with organisations undertaking an existing support role for direct payment users. This covered the two main CILs in Edinburgh and Glasgow, the Scottish Personal Assistance Employers Network (SPAEN) and two other (non user-led) direct payment support services. However, additional commentary is taken from interviews with personnel with responsibilities for direct payment planning from five local authorities (selected to reflect geographical diversity and including two urban and three rural areas). The views of three new user groups, covering the parents of disabled children, homeless persons and drug users are also referred to, together with three groups from minority ethnic communities, where direct payment take-up has been particularly poor. Interviews were semi-structured, lasted between 20 and 40 minutes and were carried out between May and July 2003. Questions were framed around the role and remit of the organisations and their capacity and willingness to adapt to changes in response to the new legislation. Data from the interviews were analysed with the aid of NUD*IST through a framework of themes developed from the interview schedule.

Direct payments and the independent living movement: issues in Scotland

Since the campaign for independent living began over twenty years ago, direct payments have represented an integral goal for the disability movement. Over this time, the emergence of CILs in the UK has helped instigate the shift in realising this goal through the development of community based support controlled by disabled people. An important basis for the transition to direct payments came in the mid-1980s from the demands of small groups of disabled people in areas such as Hampshire, Essex and Edinburgh. This began with the emergence of indirect payment schemes, whereby cash is paid through a third party (usually a local voluntary sector organisation) to the individual (Pearson 2000). These early cash payments represented an important initial challenge to rigid and paternalistic modes of service provision offered by local authorities to disabled people.

As mentioned earlier, since the initial implementation of direct payments in April 1997, there has been a marked difference in take-up across the UK. Figures released by the Department of Health (Department of Health 2002) for England and Wales show a total of 7882 users. (It should be noted that this figure represents a combined total, although in practice the overwhelming majority of users live in

England, with less than 200 direct payment users in Wales.) Whilst numbers in many areas still remain relatively low with fewer than 50 users (Hasler 2003), individual authorities like Essex and Hampshire have over 600 users. This is in marked contrast to the overall total of 534 users in Scotland.

Since 1997, the more widespread use of direct payments in England has also been supported by a faster pace of legislative change (Pearson 2004). This began with the extension of direct payments to older people from February 2000 in England and Wales (Department of Health 1998) and six months later in Scotland (Scottish Parliament 1999: col. 1119). Subsequent changes south of the border also included those set out in the Carers and Disabled Children Act 2000, which gave payment access to parents or guardians who look after disabled children, 16 and 17 year olds and carers. A later announcement in the Health and Social Care Act 2001 made direct payments mandatory in England and Wales from 2003, although by this time most areas had schemes in place.

In response to the limited use of direct payments in Scotland highlighted in Witcher et al.'s (2000) research, the Scottish Executive has promoted a number of measures in an attempt to encourage greater uptake. In line with the rest of the UK, the enabling feature of legislation has now been removed so that from June 2003, local authorities across the country have been obliged to offer direct payments to all disabled people requesting them. In addition to the expansion of user groups through the Community Care and Health (Scotland) Act 2002, a focus has also been made on the role of information access and service support through the establishment of DPS in 2001. An initial allocation of £530,000 was made by the Executive to set up the project, with renewed funding to support work until 2006. The remit of the project covers three main areas. Two of these include increasing awareness of direct payments amongst users, local authority staff and service providers and identification of training needs amongst key personnel. The third area focuses more specifically on establishing and developing user-led support organisations. Consequently, DPS has worked closely with the two Centres for Independent Living in Edinburgh and Glasgow and has sought to promote their approaches to direct payment support as a model for service development across the country. Indeed, the importance of this type of organisational support was underlined by DPS in their 'Five Steps' guide to implementing direct payment schemes (DPS 2002). This has also been acknowledged by the Scottish Executive and highlighted as good practice in their policy and practice guidance published in June 2003 (Scottish Executive 2003b). As DPS

suggests to potential organisations, the type of structure promoted is one that should be flexible enough to incorporate a range of user interests within each organisation's constitution:

You should ensure involvement in your support organisation of people from client groups to whom direct payments will start to become more widely available – e.g. people with learning disabilities, or housing support needs, mental health users, people from ethnic minorities (DPS 2002:3).

As the discussion so far has suggested, for the two main CILs in Scotland, the emphasis on user-led support has been a key goal from the outset. In 1991, the first Scottish CIL opened in Edinburgh followed by the Glasgow CIL in 1995. Both the Edinburgh and Glasgow centres offer a range of services focused around the independent living needs of disabled people and together with Scottish Personal Assistants Employers Network (SPAEN), form the major centres of user-led expertise for direct payments north of the border. Whilst support for direct payment users through training and advice work forms a key part of CIL work, their remits extend to include far wider aspects of independent living through which a range of additional training opportunities and peer counselling services have been developed.

Given the symbolic importance of direct payments in the history of the independent living movement, it was unsurprising that concerns were raised by CIL representatives over the policy shift in Scotland to include other groups as defined by the 1990 NHS and Community Act. As one respondent commented, there remained anxieties over the wider position of CIL control through the extension of direct payments and the expectations of providing service support associated with this change:

We wouldn't ever lose ownership of the organisation. Direct payments and independent living came out of the disability movement and we wouldn't sell out on that (CIL representative).

Yet despite this unease, each of the interviewees acknowledged the importance of making direct payments more widely available to other groups. As another respondent commented:

Everything has a history and something that has preceded it. If direct payments have come out of the disability movement and [they're] going to benefit lots of people in the long term then it

must be a good thing (CIL representative).

In contrast, for one local coalition of disabled people involved in the development of a new direct payment support service, the extension to new groups was seen as largely unproblematic. However, it was important to focus on the social model as a basis for inclusion and not rigidly categorise individual identities:

Direct payments are primarily given to disabled people but looking at the social model [of disability] that's going to widen out – disabled people can also be refugees, homeless, drug users or whatever. You can't draw a hard line and say it's only disabled people (Local coalition of disabled people representative).

Keeping up with demand: shifting patterns of support for CILs

Underpinning these broader philosophical concerns relating to the 'ownership' of direct payments, however, was a more practical concern from the CILs with regard to meeting new demands within their budgets. As one of the CIL respondents commented, 'we are willing to work with anyone as long as we have the experience and resources to cope with their demands'. To date, both CILs and SPAEN have already experienced an increased workload, as more local authorities have referred users to their service. This has extended their service provision over a much wider geographical area and has put considerable pressure on staff as they have sought to meet the needs of an increasingly dispersed user population. Indeed, one case was described where staff based in Glasgow had been supporting users in the north of the country since the local user-led support service had folded six months earlier. Whilst the local authority was seeking to tender for an alternative service provider, in the meantime no payment was made for this role.

As the respondent outlined, the reasons for this increased caseload stemmed from the limited pool of expertise around direct payment support in the country:

Because of the lack of user-led support groups in local areas, we have been approached by numerous local authorities [for direct payment support] and we've said, 'we can't do it' and then they're approaching [the other main CIL] who say 'we can't do it either' (CIL representative).

As Morgan et al. (2000) reported from their study, funding for CILs is a major problem with most income short term and limited to particular

services. Moreover despite the widespread recognition of the importance of support organisations in facilitating direct payment packages, local authorities are not obliged to meet these costs as part of individual assessments. Indeed the CILs and SPAEN reported considerable variation in local authority willingness to cover payments for these services. These ranged from councils who core funded support services to those which made limited or no contributions. One instance was described where one of the CILs discovered that a local authority had been advertising their services on information leaflets despite only making token annual payments. Other examples were cited where, despite attempts to contact the local authority and formalise an agreement, no response had been made and the council continued to spot purchase services as and when they required them.

This type of sporadic funding basis is clearly unsustainable in the longer term. Given that CILs and other user-led support services rely on this income as a key part of their funding, the variation in local authority funding clearly makes service planning very difficult. Even with local authorities that had made more substantial payments, there remained difficulties in defining longer-term goals:

We were trying to anticipate demand and draw up a business plan for ourselves that looked at the increase in the client group and extra staff we need. But the social work [department] are saying 'we have to look at what's needed just now'... there's just no forward planning (CIL representative).

Developing new support networks: user-led or user consulted?

Whilst CILs have been widely seen as the main providers of independent living support and expertise around direct payments, over the past few years a number of designated support organisations for direct payments have been established across the UK. In promoting these, key proponents such as DPS and the National Centre for Independent Living (NCIL) have emphasised the importance of developing these as user-led (DPS 2002). However, it is clear that many of these organisations have promoted only a limited role for users – which to date have mainly been disabled people.

Indeed, this difference was clearly reflected in the organisational structure of the two direct payment support services interviewed for this study. In both cases, support services were staffed mainly by non-disabled, local authority employees. Although each organisation stated that they had disabled people on their management committees, it was

clear that the overall direction of the services remained outwith the disability movement. Moreover in contrast to the CILs and SPAEN, both respondents generally welcomed the extension of direct payments to a wider user population as a positive move and envisaged no conflict of interests with their existing roles. In terms of future funding, the picture was perhaps more optimistic than the CILs, where one of the support services thought that any requests for additional funding from the local authority would be unproblematic. However, like the CILs there was a sense that they would have to prove the need for increased resources for specialist training as demand from new users emerged, rather than having new structures in place prior to change.

Likewise for local authority planners seeking to develop direct payment support services, concerns appeared to focus primarily on offering users choice and for them to adapt and include any new user group. Indeed in one area, this issue had come to a head in the planning stages of the support organisation. Whilst the local coalition of disabled people had taken a leading role in drafting the constitution, the remit proposed was considered to be too narrowly defined and was subsequently redrafted. As the planner described:

It [the constitution] was very focused on disability and so I said 'you've got to widen it so that regardless of who comes in on a direct payment has the option of being user-led and is able to be involved in the service' (Local authority policy planner).

Accommodating new user groups

So far, discussion has highlighted two main concerns for CILs, firstly, the increasing work-load for direct payment support without adequate resources being made available and secondly, the increasing popularity of non user-led direct payment support services amongst many local authority planners. It is, of course, unclear whether in the long-term these type of support services will emerge as a real challenge to CILs as service providers, but there appears to be evidence at this stage that some local authorities may favour service support outwith the disability movement. As local authorities in Scotland move to widen policy access, the next section of this chapter explores some of the support options under consideration and questions the impact on CILs and user-led organisations within the disability movement.

As detailed, CIL support for direct payment users forms part of a network of independent living services offered by the centres. Faced with the extension of direct payments, staff interviewed for this study had

been considering how this role might develop over the longer term. Given the concentration of direct payment expertise in the CILs, the idea of offering consultancy to new user groups and local support organisations has been raised as a possible framework for proceeding with change. Through this approach, new groups would be invited to work with the CILs to develop their skills and training for support until they are able to establish their own support group. This would encourage the development of more locally based user-led services but without altering the overall management and control of CILs by disabled people.

However, questions were raised about the appropriateness of providing direct payment support to other groups. Whilst it was acknowledged that individual identities do not fit easily into unitary categories, there remained unease about the relevance of the experiences of disabled people as a basis for wider support:

I think we should prepare ourselves for people saying ‘well your expertise is as a disabled person and the difficulties experiences by other disabled people, but what do you know about being an asylum seeker or drug user?’ (CIL representative).

Another option raised was to employ specialist workers for the new user groups within the CILs. In doing this, direct payment support would be specifically framed around the different user groups and would provide a ‘one-stop shop’ for all groups. However although this would perhaps provide a more specialist level of knowledge for more diverse user needs as part of CIL structures, concerns were raised over the implications of this type of shift for the management and constitution of CILs. Indeed, this pushes CILs further towards the designated direct payment support service model favoured by some local authorities.

Discussions also took place with three organisations representing users from minority ethnic communities. These included two groups from the Chinese community and one from the Jewish community. One of the groups – representing the needs of older Chinese people – conceded that they had never heard of direct payments. In the case of the group representing the children and families, also in the local Chinese community, the development worker said that she had some knowledge about policy but suggested problems such as language and bureaucracy had acted as the main barriers to publicising direct payments and had therefore prevented any potential users coming forward. Likewise for the worker representing the needs of the Jewish community, knowledge

about direct payments was fairly limited although there was said to be some interest from individuals. However, none of the groups interviewed had had any contact with the local CIL and were unaware of its existence. As such, each of the organisations stated that both service provision and/or support would be organised through their groups if users came forward in the future. Whilst it is acknowledged that this only presents the experiences of two communities in one Scottish locality, findings mirror some of the broader problems surrounding basic information access for direct payments highlighted by other black minority ethnic groups in the UK. This is illustrated in studies of, for example, the experiences of young black disabled people (Bignall and Butt 2000), and of Asian disabled people (Vernon 2002). Furthermore, the concentration of both provider *and* support roles within these organisations also suggests that there is a clear need to provide culturally appropriate direct payments support.

Groups interviewed for the study representing new users (as defined by the 2002 Act), also reported a lack of knowledge about the forthcoming changes. Indeed, in one case a major organisation representing refugees turned down a request for an interview because it was stated that 'direct payments will not affect our services in any way'. For the others although there was some awareness of forthcoming changes, the issue of support had not been addressed. However, the work of the local CILs was generally acknowledged and welcomed as a possible framework for service development. As the respondent from a group representing drug users commented:

Many of the barriers faced by disabled people are very much the same as those with drug problems...I think we could learn a great deal from them in terms of person centred services and human rights (Drug support group representative).

This type of partnership was also broadly welcomed by the group working with homeless persons. However for staff working with parents of disabled children, the appropriateness of the CIL in its current form was questioned in that its focus to date has centred on adult needs. As such, this underlined the need to develop more specialised training in order to meet new support needs.

Indeed, it was evident from the interviews undertaken with local authority planning representatives for direct payments that very little had been done in the way of preparatory work for taking on additional roles. Moreover, concerns remained over the impact of policy extension and

clearly this type of change in the culture and organisation of services needs to be made in reasonable time to ensure good access and continuity across all user groups. At the time of interviewing (July 2003), no guidance had been produced by the Scottish Executive. However in light of the type of concerns outlined in this chapter around the capability of local authorities to diversify policy at this stage, the Executive announced a deferment of policy expansion until April 2005 (Scottish Executive 2004). Whilst planners remain committed to expanding policy to new user groups and therefore changing the pattern of uptake, there seems to be some recognition that this will need to be done gradually.

Review

As highlighted in this discussion, direct payments are about to move into a new era as they become more extensively used and accessible to a more diverse user population. For CILs and the wider disability movement, this clearly has important implications both in terms of practical support and representation of disabled people at a local level and through the overall policy direction. It was argued in an earlier study (Pearson 2000) that direct payments should be viewed as an appendage to the 1990 NHS and Community Care Act. In these terms, policy was promoted initially by the Conservative Government through a market discourse. Central to this idea has been the use of direct payments as an instrument for accessing choice and diversity in service provision.

Seven years on from its initial implementation, it is clear that this route has also influenced the Scottish Executive in its decision to extend policy to all user groups defined in accordance with the Community Care legislation. At the same time, although some elements of the social justice origins of policy (Pearson 2000) remain in evidence, as an increasing number of people gain access to direct payments, there remain fundamental concerns. Indeed for the disability movement, a prerequisite for social justice rests on the premise that individuals should not be passive recipients of services, but in control of when and how they are delivered. As support services are recognised as being central to successful direct payments schemes, it is clear that the experiences of disabled people need to be drawn upon in this area of service provision. At this transient stage, it is vital that CILs gain appropriate recognition for their expertise in this area and are utilised as the framework for user-led support. But in taking on this enhanced role in providing knowledge and expertise for new direct payment users, adequate resourcing must be made available in order to allow centres to employ more staff and maintain other interests.

However, it is clear from the wider pattern of direct payment support services developing in Scotland (DPS 2003) that many local authorities are favouring use of generic support services with limited user involvement and close affiliation with social service departments. Whilst many of these organisations promote an active role for users in their constitutions, interpretations of this involvement vary considerably and often include almost any kind of engagement. As a recent study into user involvement in voluntary organisations found (Robson, Begum and Lock 2003), users only really value 'user-centred involvement' where service users objectives and priorities become the focus of the organisation's work. Any shift away from this framework will inevitably push direct payments away from its independent living roots and towards a more welfarist model of service provision. Indeed, the failure by some local authorities to invest in support services serves to underline the on-going gaps in understanding about the role of direct payments. Furthermore, findings reported in this chapter replicate earlier research in highlighting gaps in providing information and support for direct payment access to black and minority ethnic communities. It is evident, therefore, that work still needs to be done to emphasise the function of policy as a means of promoting independent living and the social model of disability, rather than simply a reorganisation of cash limited community care services.

As more diverse user groups access direct payments over the next few years, it is clear that these new interests will need to be represented by support services. Whilst the CILs are increasingly recognised as centres of excellence for user-led support, they require additional resourcing in order to meet new demands. In the context of the social model, this need not be incompatible with a disability rights agenda. However, change does need to be carefully considered to ensure that the rights and interests of disabled people are at the forefront and that support roles are independent and user-led.

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