Devolving direct payments: *A Review of policy development in the UK*

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Abstract
This paper presents some of the initial findings from an ESRC funded study: *Disabled People and Direct Payments: A UK Comparative Study*, which runs from 2004-2005. The study examines the implementation of direct payments across the UK for disabled people and is being carried out by researchers at the Universities of Edinburgh, Glasgow and Leeds. The project employs a multi-method strategy including a base-line statistical analysis, a policy review, key informant interviews, focus groups and targeted case studies to examine the history, policy and implementation of direct payments.

Whilst the Community Care (Direct Payments) Act 1996 permitted local authorities to make payments in lieu of services to disabled people from April 1997, the impact of these changes has been highly variable in different parts of the UK. Overall, this has seen a concentration of users in areas of the south of England, with more sporadic access elsewhere. By outlining the background to policy development in each of the four locations and figures for current take-up, discussion explores some of emergent issues and themes to this pattern. In particular, this will highlight the role of disability activism and local political cultures in facilitating access to direct payments.

Introduction

The enhanced control, flexibility and choices offered by cash payments have been well documented over the past decade (see for example, Zarb and Nadash, 1994; Witcher *et al*, 2000; Clark *et al*, 2004) However, whilst alliances between disability activism and particular political cultures have been important in promoting payment access, it is clear that some areas and groups continue to remain relatively disadvantaged, with limited opportunities for those who might wish to use this mode of service provision.

Hence, seven years on from the implementation of direct payments, policy remains largely marginalised with current figures estimating just over nine and a half thousand users across the UK. In seeking to unravel these figures, we begin with a brief overview of the policy framework, and then move on to examine the mapping of take-up and key issues arising from this stage of the research. We then discuss the broader impact of disability activism and political cultures in accessing direct payments. This identifies some of the key tensions in policy implementation across the UK.

Policy Frameworks

Over the past two decades, the availability of state funded cash payments for personal assistance in the UK has been characterised by inequitable access and a largely confused policy framework. This has seen two main routes for cash payments: the sporadic adoption of indirect payments by some local authorities, mainly in the south of England, latterly formalised through the 1996 Community Care (Direct Payments) Act and the introduction of the Independent Living Fund (ILF).

The ILF originated amid a broader reorganisation of social security support for disabled people and the development of community care policy (see for example, Berthoud, 1998). This was set up in 1988 in co-operation with the Disablement Income Group (DIG) to compensate for the loss of additional domestic payments made to disabled people which were removed during this period of reform. Although criticised by many within the disability movement (Wood, 1991) for replacing benefit entitlements with discretionary awards from a charity, the ILF proved to be highly popular and represented the first large scale opportunity for disabled people in the UK to receive cash for personal assistance. As a result, plans to use the ILF as only a temporary measure, ahead of the implementation of community care were abandoned and a revised (albeit more restrictive) scheme was set up in 1993 (see Kestenbaum, 1995). Since its revision in 1993, the ILF'93 has primarily been used to top-up local authority services for people living in their own homes where the costs of services would otherwise exceed the price of residential care. Given that funding is allocated from central government, it is likely that the ILF has been an attractive option to many local authorities reluctant to embrace indirect or direct payments.

From the mid-1990s, agreements between local authorities and disabled people emerged in a number of areas which allowed the receipt of cash rather than services. However despite these successes and the popularity of the ILF, the Conservative government remained unconvinced over the shift with concerns about cost efficiency, accountability of public funds and fears of exploiting disabled people (Campbell, 1996). After a lengthy campaign and research published by the British Council of

Disabled People highlighting their cost effectiveness, the struggle to gain direct payments on the statute was eventually secured. Undoubtedly, this represented a significant victory for the independent living movement, but similarly for advocates of the free market, policy was also linked in with the promotion of 'local care markets' developed through welfare reform in the early 1990s (Pearson, 2000).

Since implementation of the 1996 Community Care (Direct Payments) Act in April 1997, there have been a number of developments to the original policy framework which, in turn, have differed slightly across the UK (see Pearson, 2004a for more details). This has seen the inclusion of older people and 16 and 17 year olds. Access has also been granted to non-disabled persons, including parents of disabled children and carers. Scottish legislation differs from the rest of the UK in that it does not extend access to carers and from April 2005 payments will be offered to all 'community care' users in the country, covering groups such as asylum seekers, persons fleeing domestic violence and people recovering from drug and alcohol addiction. As discussion later in the paper outlines, this shift raises a number of questions for the disability movement in terms of the control and 'ownership' of policy.

Mapping take-up: Direct payments across the UK

Before moving to look at current direct payment figures, this section provides an overview of some of the key trends in take-up across the UK in the initial period of implementation from 1997-2000.

Initial take-up: 1997-2000

The impact of the early years of direct payments across the UK may be best described as limited. Whilst local authorities with established indirect payment schemes used legislation to formalise and develop existing practice, elsewhere the picture was far less positive and presented acutely different patterns of take-up across the UK.

Already at this stage, progress in England showed a marked contrast with the rest of the UK. In 1998, it was reported that just over half of English local authorities offered payments to 1404 users. Ninety-five per cent of them were defined as having physical and sensory impairments (see Auld, 1999). This extended to 80 per cent coverage across England and Wales in 2000, with 3612 users (Jones, 2000). Again, Jones' survey also highlighted the predominance of users with physical impairments and found that a number of local authorities excluded access to persons with perceived learning difficulties and mental health problems. Similarly, in line with the earlier pattern of indirect payments (see Zarb and Nadash, 1994), it was evident from this early stage that there was a clear regional pattern to take-up, with only very few payments being offered outside the south of England.

The first major study of direct payments in Scotland was carried out by Witcher, Stalker, Roadburg and Jones (2000). This research commissioned by the Scottish Executive, confirmed the limited availability of direct payments, with only 13 out of the 32 local authorities having fully operational or pilot schemes, and a total of 143 users in Scotland. Although figures have since risen (this will be returned to shortly), take-up is still proportionately lower than in England. Findings from Witcher *et al*'s (2000) study also highlighted an imbalance between impairment groups with 125 (87 per cent) of total users with physical and sensory impairments, against 17 (12 per

cent) with perceived learning difficulties and no persons with 'mental health problems'. Payment access for users from black and minority ethnic communities was also found to be disproportionately poor.

In Northern Ireland, initial progress with direct payments was also especially slow. Whilst there were a number of disabled people employing their own staff using money from the ILF, there did not seem to be any significant demand for direct payments from disabled people themselves (NICOD, 1999) in contrast with other parts of the UK (see Acheson, 2001). Some of these issues were picked up in a research project run by the voluntary sector organisation, NICOD. The project was set up with a view to recommend a model of best practice for independent living and personal assistance in the Province. Like other early research discussion (see Zarb and Nadash, 1994; Kestenbaum, 1996), the NICOD findings echoed overwhelming user support for payments. However, it was clear that the disabled people involved in the project had received no information about the availability of direct payments prior to their involvement in the pilot.

Early policy development in Wales also showed minimal impact. Only limited information about direct payments has been documented from this time and much of the literature (see for example Glasby and Littlechild, 2002) tends to merge details with England. However, an evaluation of the Cardiff and Vale Independent Living Scheme and early approaches to direct payments by Stainton and Boyce (2001), highlighted a number of key issues. This revealed an uneven coverage across the country with much of the knowledge base and early activity located in the Cardiff area. Likewise, access to different user groups also showed a similar imbalance towards persons with physical impairments.

Expanding access?: exploring impact of policy change since 2000

As discussion has shown, coverage of direct payments across the UK in the early years of policy implementation met with only limited success. This section moves to explore the current patterns of uptake and the implications of these by looking at data from the ESRC study and broader policy themes. The initial mapping exercise was set up to examine the impact of a range of variables, including the political control of the local authority, the number of people labelled as being 'disabled' or having a 'long-term limiting illness' in the 2001 census and the presence of a support organisation for direct payment users. All direct payment figures are based on publicly available statistics and statistical breakdowns available on 18 February 2004. They include all direct and indirect payments recorded by relevant authorities. The term 'direct payments' has therefore been used generically to cover all cash payments made to individuals to purchase services, whether or not made through a third party. Information was obtained from the Scottish Executive, Direct Payments Scotland, the Department of Health, the Local Government Data Unit Wales, the Department of Health, Social Services and Public Safety in Northern Ireland and the National Centre for Independent Living.

Take-up across the UK

Data from the 2001 census estimates indicate that there are over 10.9 million people defined as having a 'long-term illness' or 'disability' in the UK. As table 1 shows, Wales has the highest percentage of persons in this category, with just over 23 per cent of the population identified in this way. However, when looking at take-up for

direct payments, Wales is recorded as having only marginal policy use. A similar pattern is shown in Northern Ireland and Scotland. Conversely, although England covers a significantly larger population, it has the lowest rate of 'long-term limiting illness' and 'disability' at eighteen percent, but the highest take-up of direct payments in the UK. Whilst it is noted that eligibility to a direct payment would be restricted to a limited number of this population through the community care assessment system, the figures are useful in that they highlight the geographical inequity in policy take-up, with approximately twice as many direct payment users in England relative to population. It is therefore clear that direct payments are not being used to their full potential.

Table 1: Number of direct payment users in each country/province of the UK between 2000/1 and 2003.

Country/province	% LTID	2000/1	2002/3	2003	% on Direct Payments in the UK
England	18	4,900	6,300	9,700	90%
Scotland	20	207	392	571	6%
Wales	23.5	*	185	*	2%
Northern Ireland	22.5	33	49	128	1%

Notes: *(1)LTID refers to the percentage of people reporting a long-term limiting illness or disability in the 2001 Census. (2) Figures for Wales not available for 2000/1 and 2003 due to recording methods of the Welsh executive (3) Percentages in the column '% on direct payments in the UK' do not add to 100 due to rounding.*

In focusing on these differences, the following section attempts to unravel some of these issues by looking at the impact of local authority political control and the presence of support schemes.

Political Control of Authorities and Direct Payment Support Schemes: mapping the UK pattern

As noted, there is considerable variation in the spread of direct payments across local authorities and in the UK overall. In looking at these figures, preliminary analysis for the study identified two key factors which appeared to impact on this pattern: political control and the spread and type of direct payment support schemes. In this section, these themes are highlighted by looking at the distribution of authorities with *no* users and those with the highest recipients.

Based on the data available at February 2004, tables 2 and 3 indicate that there are 18 authorities without any Direct Payment users. Of these authorities, ten are in Scotland, five in Wales and two in Northern Ireland and most are Labour controlled. In England, only the Isles of Scilly fall into this category. The tables indicate that half of the authorities without any users have support schemes in place, while half do not. Support schemes are important in raising awareness and providing assistance to those thinking of, or using direct payments. However, it seems that their existence does not guarantee that relevant authorities will be enabling policy access – this will be returned to later in the paper. First, tables of those authorities without any Direct Payment receipts are given with relevant political and demographic data including population density for each area.

Table 2: Authorities without any Direct Payment users or known Support Schemes in the UK

Country/LA/Trust	*DLA (Percentage)*	*LTID (Percentage)*	*Population*	*Density*	*Major Political Party*
Scotland					
Argyll and Bute		9	91,306	0.5	Lab/LD
East Refrewshire		8	89,311	5.14	Lab
Falkirk		10	145,191	4.88	Lab
Shetland		7	21,988	1.71	LD
South Lanarkshire		7	302,216	5.8	Lab
Northern Ireland					
Causeway Health Social Services	6.2	-	-	-	-
Craigavon and Bainbridge Community Trust	9.2	-	-	-	-
Wales					
Methyr Tydfil		30	55,981	5.1	Lab
England					
Isles of Scilly		13	2,153	1.3	-

Sources: Current NCIL data, 2001 Census data, NISRA and Parliament UK Directory
Notes: (1)LTID=long-term illness and disability,(2) Lab stands for Labour or New Labour, LD stands for Liberal Democrat (3)Density=individuals by hectare to the nearest decimal point(4)Census data for Northern Ireland does not include breakdowns by Trust, but by district and Trust area. Therefore, figures are given for percentage receiving Disability Living Allowance as Trust area is too wide a definition.

Table 2 above, shows those authorities without any Direct Payment users, or any known support schemes in place. Key issues in this table are national spread and major political party affiliation patterns. Indeed, the profile shows that there is one English and one Welsh authority without any Direct Payment users and without a known support scheme in place. In addition, the majority of areas are Labour led. Table 3 shows authorities without Direct Payment users but with known support schemes. Again national spread and majority political emphasis are apparent. This table includes Scottish and Welsh authorities only, with ninety percent being Labour led.

Table 3: All authorities with support schemes but without any Direct Payment users in the UK

Country/LA	*Scheme Type*	*LTID (Percentage)*	*Population*	*Density*	*Major Political Party*
Scotland					
Midlothian	CIL	9	15,521	2.29	Lab/LD
North Ayrshire	LA	11	135,817	1.53	Lab
East Dumbartonshire	CIL	8	108,243	6.20	Lab
Stirling	No info	9	86,212	5.88	Lab
Dundee	Charity	11	145,663	24.35	Lab
Wales					
Gwynedd	CIL	20	116,843	0.5	Lab
Torfaen	Voluntary	25	90,949	7.2	Lab
Conwy	Charity	23	109,596	1.0	LD
Flintshire	Charity	19	148,595	3.4	Lab

Sources: Current NCIL data, 2001 Census data, Direct Payments Scotland data and Parliament UK Directory

Notes: (1)LTID=long-term illness and disability,(2) CIL stands for Centre for Integrated/Independent Living support scheme and represents one led by disabled people. L.A stands for local authority led support scheme.(3) Lab stands for Labour, or New Labour and LD stands for Liberal Democrat.(4) Density=individuals by hectare to the nearest decimal point(5) Stirling's scheme is 'Forth Valley Direct Payments Support scheme', but it is not clear which category this falls into. It is not a user-led scheme because Direct Payments Scotland report the development of a user-led scheme for this area to replace 'Forth Valley Direct Payments'. In addition, all Scottish areas without Direct Payment Direct payment support schemes are reported to be developing user-led schemes.

At the opposite end of the scale, table 4 outlines the top ten authorities with the highest numbers of Direct Payment users. As the figures show, all are found in England – with 70 per cent in the south or London and two in East Anglia. Only one is located in the north. All have support schemes in place and the majority are described as 'user-led'. It is, however, important to acknowledge the historical context of local schemes, whereby Hampshire was one of the first authorities to sanction direct payments in the 1980s and had a strong advocacy base in its CIL. Similar traditions have also been apparent in Norfolk, Essex, Hampshire and Southampton. The predominance of Conservative controlled authorities is another significant factor from this list and may reflect stronger localised notions of individualism or consumer choice. It therefore appears to present a direct contrast to those authorities with no direct payment users and gains greater credence when the percentage rates of 'long-term illness' and 'disability' are examined. Indeed, all the 10 local authorities identified fall below the average percentage for long-term illness/disability recorded in England (Riddell *et al*, *forthcoming*).

Table 4: Top Ten Authorities with highest Clusters of Direct Payment Users

L.A	Area	Number Receiving Direct Payments	Support Scheme Type	LTID (Percentage)	Population	Density	Major Political Party
Oxfordshire	S.East	143	User Led	13	605488	1.9	Con
Croydon	London	150	Voluntary	15	330587	38.2	Lab
West Sussex	S.East	166	User Led	17	753614	3.8	Con
Somerset	S.East	179	Charity	16	199517	5	Con
Surrey	S.East	186	CIL	13	1059015	6.4	Con
Southampton	S.West	187	CIL	17	217445	43.6	Lab
Cheshire	North	254	Disability Organisation	17	673788	3.2	Lab
Norfolk	E.Anglia	258	User Led	19	796728	1.0	Con
Hampshire	S.West	625	CIL	15	1240103	3.4	Con
Essex	E.Anglia	642	User led	16	1310835	3.8	Con

Sources: Current NCIL data, 2001 Census data and Parliament UK Directory
Notes: (1)LTLID=long-term illness and disability,(2)Con stands for Conservative
(3)Density=individuals by hectare to the nearest decimal point.

In summary, it appears that political control of authorities may be a significant factor in accessing direct payments, with many Conservative areas more likely to enthusiastically embrace policy than those in the more traditional Labour heartlands where policy may be perceived as a more privatised mode of welfare provision. Interestingly, in the same way as disability organisation's support schemes for cash payments rest on the enhanced control and independence allowed to disabled people, many local authority's co-operation may simply rely on the potential for a new 'marketised' model of service delivery. Therefore as already documented in the literature (see Pearson, 2000; Spandler, 2004) it may be that the promotion of consumer markets, individual 'choice' and 'cost efficiency' enabled through cash rather than service provision appeals to certain Conservative-led authorities. Yet, for direct payments, it seems that a strong and essentially well funded user-led support scheme (such as a CIL) brought about by early and continuous disability activism is a major factor in increasing take-up of direct payments in relevant areas. Indeed, figures show that user led support schemes are able to increase up-take across the UK by a relative margin of 80% in comparison with other types of direct payment support schemes. By referring to some of the broader research in this area, the next section explores some of these issues in more detail.

Promoting payments: exploring supporting roles and widening access

In looking at the broader development of direct payments in the UK over the past decade, it is clear that the policy framework and access has hinged on a number of competing discourses (Pearson, 2000; 2004a). As noted already, it is evident that the role of disability activism has been central in gaining both national and local change. However, as suggested it is also important to acknowledge the wider impact of social policy both through the introduction of quasi-markets in service provision (see Le Grand and Bartlett, 1993) and the promotion of 'community care' as the main structure of support for disabled people in the UK. Reflecting on the figures presented in this paper and wider themes from the growing body of research, this section looks more closely at how policy has been promoted and highlights some of the areas to be pursued in forthcoming stages of the study. In doing this, discussion focuses on the role of social workers as gatekeepers to direct payment access and support structures as a means of promoting the personal assistance role within the policy framework.

Social work roles in the UK have undoubtedly received something of a mixed press in relation to direct payments. Whilst examples of good practice have been highlighted in different parts of the UK (see Stainton, 2002; Clark *et al*, 2004) whereby direct payments have been actively promoted as service options, social worker's positions as 'gatekeepers' to cash limited 'care' budgets have invoked a series of conflicts. Indeed on the one hand, Sapey (2001) suggests that direct payments are an important means of challenging the 'culture of welfare' across social service departments. However, as a number of commentators have indicated, many practitioners are unaware of the principles of independent living and social justice promoted by the disability movement in campaigning for policy change (see Dawson, 2000; Pearson, 2004a). Although Stainton (2002) argues that structural conflicts of interests in relation to social worker's roles within the community care system are greater threats than individual views and practice, it is clear that attitudinal barriers prevail. Moreover, there is inevitably a concern for many disabled people that the impact of direct payments may be lessened through their positioning in a wider network of cash restricted 'care services'.

Access to policy by different user groups has been shown to be clearly related to the level of policy promotion and the attitudes of key staff (see for example, Clark *et al*, 2004) This is illustrated in table 5 which outlines the main user group coverage in England, Wales and Northern Ireland (data in this format were not available for Scotland), and compares the average and range within authorities in each area. As detailed earlier in the paper, in all parts of the UK, people with physical and sensory impairments are by far the most likely to be receiving a direct payment, and persons labelled as having 'mental health problems' the least likely. There is also evidence from other studies to suggest that black and minority ethnic communities have had limited information and access to policy (see Bignall and Butt, 2000). Indeed, the absence of data highlights the need for planners to systematically identify these inequalities by routinely monitoring access by age, socio-economic class, ethnicity, gender and impairment.

Table 5: Averages and Range for Estimated User Groups by Area

	65+		*Learning Difficulty*		*Mental Health*		*Physical and Sensory Impairment*	
	Average Number of Direct Payments per User Group	**Range for User Group**	**Average Number of Direct Payments per User Group**	**Range for User Group**	**Average Number of Direct Payments per User Group**	**Range for User Group**	**Average Number of Direct Payments per User Group**	**Range for User Group**
Northern Ireland	3.6	**1-10**	13.7*	**2-45**	1**	**-**	6.2	**2-15**
Wales	2.2	**1-6**	2.9	**1-4**	1.3	**1-2**	8.3	**1-43**
England	8.9	**1-100**	7.5	**1-83**	3.2	**1-29**	41.3	**1-425**

Sources: Current NCIL data, DoH data, LGUDW, DHSSPS
Notes (1) Average is skewed by Armagh and Dungannon with 45 learning difficulty users based on current NCIL data (2)**There is just one mental health user in Northern Ireland in the Down Lisburn health Trust(3) All averages are based on the mean average*

Resistance from within social work has also centred on broader ideological concerns over the use of direct payments as a mode of service provision. Indeed, the figures presented within this paper have highlighted a general pattern whereby many traditional Labour controlled local authorities have failed to develop direct payments. Conversely, in Conservative administrations – particularly where there is a strong user-led support organisation – recipients have increased significantly. It is also important to note that there is very wide regional variation, where in certain parts of the south east of England, direct payments have been embraced with relative enthusiasm compared with more reluctance elsewhere. Indeed, there is evidence to suggest that trade union resistance to direct payments has impacted on policy development in some Northern English authorities and in Northern Ireland and Wales (personal communication) and this is an issue that will be explored in more detail as the study progresses. However, this has certainly been a dominant theme in Scotland (see Pearson, 2000; 2004b) where overall the marketisation of social services has been more strongly resisted than many other parts of the UK. Indeed, the public sector union Unison has documented their particular concerns over the impact of policy for workers (see Unison Scotland, 2004).

To recap, the role of user-led direct payment support schemes have undoubtedly proved to be central to the implementation of direct payments, with an 80 per cent increase in users where a support scheme is present in a locality. Likewise this finding has been emphasised from both the disability movement (see Hasler *et al*, 1999; Evans and Hasler, 1996) and policy planners across the UK (see Department of Health 2000; Department of Health, Social Services and Public Safety, 2003; Scottish Executive, 2003). However at this stage of policy development, there remain

questions over the direction and control of these support structures. Whilst to date, CILs and user-controlled support groups have been viewed as the main centres of expertise for direct payment support, there has also been a growth in other organisations. Yet as Barnes *et al* (2001) 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. Instead, they may be run by private or voluntary sector organisations with limited input from direct payment users themselves. Although it is unclear at this stage of the research whether organisational control impacts on user choices or experiences in relation to direct payments, a shift away from a user-led ethos looks set to push policy further away from its independent living roots and towards a more welfarist mode of service provision.

Discussion

This paper has set out some of the initial themes emerging from the ESRC study. Overall seven years after implementation, direct payments remain marginal as a support option for disabled people. Data so far reveals an inequitable access across the UK, as well as reiterating the divisions between impairment groups, age and ethnicity. As stated, closer monitoring of uptake from local authorities and a more detailed examination of social divisions within this study will be required to understand these patterns in more detail. However, the statistical analysis and policy review so far, has highlighted the impact of disability activism and local political cultures in promoting policy access. In particular, the prominence of a Conservative run local authority and user-led support organisations appears to have been a significant partnership in the development of local schemes. Therefore, alliances developed between activists and policy planners have presented a stark contrast between the relatively quick growth of schemes in parts of the south of England, compared with elsewhere in the UK. In contrast, the absence of widespread pressure from the disability movement to encourage implementation in Northern Ireland looks to have been an important factor in the slow uptake of policy. Furthermore, resistance to direct payments from public sector workers in many parts of Scotland has been difficult to overcome when activism has been less prominent.

The issue of support for direct payment users underpins many of the broader debates around direct payments promoted by the disability movement. As discussion has highlighted, the impact of a user-led support structure in a locality is undoubtedly important in promoting uptake. However, it is the direction and ethos of this support which will prove critical to the future of expanding policy use. As direct payments are increasingly promoted by UK administrations, it is likely that the 'market' for user support will become more competitive. Notably, proposals by the Scottish Executive to open up access to all 'community care groups' from April 2005 and the current push to open access to 'carers' in the rest of the UK, may undermine the broader goals of independent living which have been central to campaigning.

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