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The Development of Direct Payments in the UK: Implications for Social Justice

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Direct payments have been heralded by the disability movement as an important means to achieving independent living and hence greater social justice for disabled people through enhanced recognition as well as financial redistribution. Drawing on data from the ESRC funded project Disabled People and Direct Payments: A UK Comparative Perspective, this paper presents an analysis of policy and official statistics on use of direct payments across the UK. It is argued that the potential of direct payments has only partly been realised as a result of very low and uneven uptake within and between different parts of the UK. This is accounted for in part by resistance from some Labour-controlled local authorities, which regard direct payments as a threat to public sector jobs. In addition, access to direct payments has been uneven across impairment groups. However, from a very low base there has been a rapid expansion in the use of direct payments over the past three years. The extent to which direct payments are able to facilitate the ultimate goal of independent living for disabled people requires careful monitoring.

Introduction: social justice and direct payments

As noted by Goodlad and Riddell in this special edition, social justice may be conceptualised in relation to the distribution of both material and social goods, the latter including access to education and social services (Harvey, 1992). Social justice is also concerned with cultural claims, associated with the politics of recognition or identity (Young, 1990). Sometimes, the politics of redistribution and the politics of recognition have been construed as separate, and possibly competing, arenas of struggle. For example, Fraser maintained that the focus on identity politics was detracting from the struggle to achieve economic inequality for marginalised groups (Fraser, 1997). Phillips (1997) has argued that the distribution of material and social goods and social respect are not separate but inter-connected, so that individuals and groups who enjoy high social status are likely to secure access to better welfare services, thus further boosting their economic position and social prestige. Conversely, disadvantaged groups are likely to experience inequalities in accessing services, further exacerbating their cultural and economic marginalisation.

Direct payments is a form of welfare whereby cash payments are made directly to the individual to purchase the services they are assessed as requiring. The development of

direct payments has been a key goal of the disability movement for the past two decades and has been seen as playing a role in the struggle for both redistribution and recognition. In relation to redistribution, it is envisaged that by allowing disabled people the freedom to determine the types of assistance they require, the quality of services available will be improved. In relation to recognition, direct payments are regarded as having the potential to improve the social status of disabled people by transforming their identity from that of passive service recipient to active employer, creating wealth in the increasingly important service sector Barnes (2004). This paper draws on data from the ESRC funded project *Disabled People and Direct Payments: A UK Comparative Perspective*, which is being carried out by researchers at the Universities of Edinburgh, Glasgow and Leeds between 2004 and 2006. The research includes an analysis of policy and official statistics on uptake of direct payments, telephone interviews with local authority representatives throughout the UK and case studies of local authorities with different approaches.

In the paper, we first briefly describe the development of direct payments, before considering their contribution to social justice goals concerned with both redistribution and recognition. We explore the extent to which direct payments are equally available to disabled people in relation to geographical location, political complexion of the local authority and impairment group. Subsequently, we consider the extent to which direct payments appear to be having a positive impact in reducing the poverty experienced by disabled people relative to the rest of the population. Finally, we consider the extent to which direct payments may contribute to social justice goals by enhancing the respect accorded to disabled people by repositioning them as active agents rather than passive recipients of welfare.

The development of direct payments

Disabled people's struggle to cast off the discourse of charity has been well documented by writers such as Oliver (1990). A key part of the struggle centred round the achievement of support services geared towards allowing people to live independently. In the 1960s and 1970s, the Disablement Income Group campaigned for a 'modest disability income', but this solution was rejected by the disability movement on the grounds that it did not alter the fundamentally unequal relationship between the individual and the state and the damaged identity this produced. The Union of the Physically Impaired Against Segregation argued:

> Disabled individuals wishing to claim the disability income would be required to present themselves for assessment by 'social administrators'. They would have to appear 'passive, nervous' and 'deferential' in order to conform to the expert view of disability; in other words, they would have to reinforce all the traditional assumptions associated with disabled people, and thus relinquish any claims to economic and social equality. (UPIAS, 1976, 18, cited in Barnes, 2004)

The idea of a 'modest disability income' was dismissed, therefore, partly because it was likely to have only a limited impact on reducing poverty, but also because it was unlikely to tackle the problem of lack of respect. In the 1970s and 1980s, the Centres for Independent Living (CIL) in the US, notably the Berkeley CIL, had experienced some success in persuading the local state to make payments to individuals to purchase

the support services needed to underpin social inclusion. This philosophy, rooted in a human rights approach, was adopted by emerging CILs in the UK (Barnes, 2004). In 1988, in response to active campaigning, the Independent Living Fund was established, which involved the Department for Social Security (DSS) making direct cash payments to individuals.

Despite the fact that the DSS had demonstrated the feasibility of making cash payments to individuals, local authorities were not permitted to make direct payments and there were concerns about exploitation and fraud. Indirect payment schemes were developed, whereby funds were channelled via a third party such as a voluntary organisation to a disabled person to purchase personal assistance. Following further campaigning and the publication of research demonstrating the cost effectiveness of direct payments (Zarb and Nadash, 1994), the Direct Payments Act 1996 eventually provided the legislative basis to enable schemes to develop (see Department of Health, 2000a, 2000b, 2001, 2002, 2003). The scope of direct payment schemes has extended over time (see Department of Health, 2000a, 2000b, 2001, 2002, 2003), and they have now become mandatory throughout the UK. The Scottish Executive recently announced its intentions to extend direct payments to all community care users, including refugees and asylum seekers, women fleeing domestic violence and people recovering from drug and alcohol addiction. Having resisted direct payments for many years, the governments of the UK and the devolved administrations now strongly promote direct payments as articulating with both the social justice and modernising welfare agendas. As we shall see below, this enthusiasm is not shared by all local authorities, some of whom argue that direct payments undermine other services and threaten public sector jobs. The impact of direct payments, and their implications for social justice, is discussed in the following section.

Direct payments in practice

Take-up across the UK

As a first step in the ESRC project referred to above, we set out to identify patterns in the uptake of direct payments in different parts of the UK and to explore the impact of a range of variables, including the political control of the local authority, the number of people reporting a long-term limiting illness in the 2001 census and the presence of a support organisation for disabled people wishing to make use of direct payments. All direct payments 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' is thus being used generically to cover all cash payments made to individuals to purchase services, whether these are made through a third party or not. Information was obtained from the Scottish Executive, Direct Payments Scotland, the Department of Health, the Local Government Data Unit Wales, the Information Unit at the Department of Health, Social Services and Public Safety Northern Ireland and the National Centre for Independent Living.

Table 1 shows that England has about twice the number of DP users relative to its population compared with Scotland, Northern Ireland and Wales, despite having the lowest proportion of people with long-term illness or disability. Nonetheless, there have been significant increases in use throughout the UK.

Table 1 Direct payment users in each country/province of the UK between 2000/1 and 2003: number and rate per thousand people with LTID

Country/ province	Population	% LTID	2000/1: number & rate per thousand people with LTID	2002/3: number & rate per thousand people with LTID	2003: number & rate per thousand people with LTID
England	50 million	18	4,900 (0.54)	6,300 (0.7)	9,700 (1.0)
Scotland	5 million	20	207 (0.20)	392 (0.4)	571 (0.57)
Wales	3 million	23	*	185 (0.26)	*
Northern Ireland	1.5 million	23	33 (0.09)	49 (0.14)	128 (0.37)

Notes:

- Figures for Wales not available for 2000/01 and 2003.
- LTID refers to the percentage of people reporting a long-term limiting illness or disability in the 2001 Census. 10.9 million people in the UK reported LTID with significant regional variations (London & South East: 15 per cent; Northeast England: 23 per cent).

Take-up by local authority

The large majority of authorities in the UK (89 per cent) reported direct payment users in their locality. The mean number of direct payment users per authority was 44. However, there is considerable variation both by authority and by devolved area. The highest number of direct payment users in England (642) are recorded as being in Essex; the highest number in Scotland (120) are in Fife; in Wales, Cardiff (47); and in Northern Ireland, Armargh and Dungannon (47). Initially we identified those authorities that have 0–1 Direct Payment users and, secondly, the ten UK authorities with the highest numbers of Direct Payment users.

Based on currently available data for the UK there are 18 authorities without any direct payment users. Of the 18 authorities with no reported direct payments users, ten are in Scotland, five in Wales and two in Northern Ireland. For England only the Isles of Scilly does not have any reported Direct Payment users. Tables 2 and 3 show relevant authority areas in detail with demographic and political data for each. Most of these are in Scotland or Wales and are Labour-controlled; about half have a support scheme in place, while half do not. Support schemes are important in raising awareness and providing assistance to those thinking of, or using direct payments, and they are generally given a grant by the authority to undertake this work. However, it seems that the existence of a support group does not necessarily mean that authorities in the area will be providing direct payments. First, tables of those authorities without any direct payment receipts are given with relevant political and demographic data including population density for each area.

At the opposite end of the scale, the top ten authorities with the highest numbers of direct payment users were identified throughout the UK. In contrast to authorities without any direct payment users (or with just one direct payment user), all of the top ten authorities are in England and all have support schemes in place. Table 3 gives more details for each of these authorities.

Table 2 All authorities with support schemes but without any direct payment users in England, Scotland and Wales

Part of UK/LA	Scheme type	LTID (percentage)	Population	Density	Major political party, March 2004
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	Voluntary	11	145,663	24.35	Lab
Argyll & Bute	None	9	91,306	0.5	Lab/LD
East Renfrewshire	None	8	89,311	5.14	Lab
Falkirk	None	10	145,191	4.88	Lab
Shetland	None	7	21,988	1.71	LD
South Lanarkshire		7	302,216	5.8	Lab
Wales					
Gwynedd	CIL	20	116,843	0.5	Lab
Torfaen	Voluntary	25	90,949	7.2	Lab
Conwy	Voluntary	23	109,596	1.0	LD
Flintshire	Voluntary	19	148,595	3.4	Lab
Merthyr Tydfil	None	30	55,981	5.1	Lab
Northern Ireland					
Causeway Health & Social Services	None	–	–	–	–
Craigavon & Bainbridge Community Trust	None	–	–	–	–
England					
Isles of Scilly	None	13	2,153	1.3	–

Sources: Current NCIL data, 2001 Census data, Direct Payments Scotland data and Parliament UK Directory 2004.
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 Support schemes are reported to be developing user-led schemes.

There are several obvious commonalities between the top ten authorities with the highest clusters of direct payment receipts. As already mentioned all the local authorities have support schemes and 70 per cent of these could be described as user-led (that is, support schemes such as CILs run by disabled people). However, history is also important. Hampshire was one of the first authorities to sanction direct payments in the 1980s and had a strong advocacy base in its CIL. Hampshire is also one of the 70 per cent of the 'top ten' authorities that are Conservative controlled (although political control of local authorities is quite volatile). This might reflect stronger localised notions of individualism, stake holder participation and consumer choice.

Table 3 Top ten authorities with highest clusters of direct payment users

LA	Area	Number receiving direct payments	Support scheme type	LTID (percentage)	Population	Density	Major political party
Oxfordshire	S.East	143	User-led	13	605,488	1.9	Con
Croydon	London	150	Voluntary	15	330,587	38.2	Lab
West Sussex	S.East	166	User-led	17	753,614	3.8	Con
Somerset	S.East	179	Voluntary	16	199,517	5	Con
Surrey	S.East	186	CIL	13	1,059,015	6.4	Con
Southampton	S.West	187	CIL	17	217,445	43.6	Lab
Cheshire	North	254	Disability organisation	17	673,788	3.2	Lab
Norfolk	E.Anglia	258	User Led	19	796,728	1.0	Con
Hampshire	S.West	625	CIL	15	1,240,103	3.4	Con
Essex	E.Anglia	642	User led	16	1,310,835	3.8	Con

Sources: Current NCIL data, 2001 Census data and Parliament UK Directory 2004.
Notes: (1) LTLID = long-term illness and disability. (2) Con stands for Conservative. (3) Density = individuals by hectare to the nearest decimal point.

Access by different user groups

Table 4 shows access to direct payments by different user groups 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 part of the UK. In all three areas, people with physical and sensory impairments are by far the most likely to be receiving a direct payment, and people with mental health problems the least likely. However, this does not reflect the distribution of such impairments in the working age population, as indicated by Table 5.

To summarise, early findings from the research indicate that throughout the UK, uptake of direct payments is quite low. Whereas there has been a marked increase in their use over the last three years, it is as yet unclear whether they will remain a marginal or become a mainstream option. England has made greater use of direct payments than Scotland, Wales and Northern Ireland. However, within England there is very wide regional variation. The North East, like its neighbours to the north, has treated the new form of welfare provision with suspicion, whereas in certain parts of the South East, direct payments have been embraced with relative enthusiasm. In general, Labour controlled authorities have failed to develop direct payments, whereas in Conservative controlled local authorities, particularly where there is a strong user-led support organisation, the number of direct payment recipients has increased markedly. There are clearly inequalities in relation to access by different user groups, with local authorities much less likely to sanction payments to people with learning disabilities and mental health problems. There is also some evidence to suggest that members of minority ethnic communities have little knowledge of direct payments and uptake is very low (Bignall and Butt, 2000; Vernon, 2002). This raises important issues of equity. In the following sections, we review some of the questions we intend to explore further in the later phases of the study, which include telephone interviews with authority representatives and case studies of local authorities throughout the UK.

Table 4 Averages and range for different user groups by authority in specific countries

	65+		Learning disability		Mental health		Physical and sensory impairment	
	Average number of direct payments in authorities	Range for user group	Average number of direct payments in authorities	Range for user group	Average number of direct payments in authorities	Range for user group	Average number of direct payments in authorities	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 disability 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.

Table 5 The reported conditions of Incapacity Benefits claimants, May 2002

Diagnosis group	Percentage of total IB claimants
Mental disorder	35
Musculo-skeletal	22
Circulation & respiratory system	11
Others	16
Nervous system	10
Injury, poisoning	6

Source: Pathways to Work: Helping People into Employment DWP, 2002.
Note: The 'others' category is made up of the other 13 International Classification of Diseases diagnosis groups including (by order of size): diseases of the digestive system; endocrine, nutritional & metabolic diseases; neoplasms; certain infectious and parasitic diseases; and diseases of the genito-urinary system.

Table 6 Quintile distribution of household income (after housing costs) for working age adults by disability, 2001/2 (percentages)

Family	Bottom quintile	Second quintile	Third quintile	Fourth quintile	Top quintile
1 or more disabled adults	28	21	19	17	15
No disabled adults	15	14	19	24	28

Source: Households Below Average Income, 1994/5–2001/2, DWP, 2003, table 5.1.

Do direct payments promote social justice?

As argued above, direct payments were promoted on the grounds that they could go some way to redressing the economic, cultural and social inequality experienced by disabled people. To what extent have they fulfilled this potential in the seven years since the implementation of the legislation? In the following paragraphs, we first consider the contribution of direct payments to both redistribution and recognition aspects of social justice.

Direct payments and redistribution

First, as demonstrated clearly above, direct payments are only being made available to a tiny minority of disabled people, so their potential has not yet been realised. However, it is clear that, compared with the non-disabled population, disabled people have a much higher risk of poverty (see Tables 6 and 7 below). Table 6 shows that households with a disabled person are much more likely to be in the bottom fifth in relation to household income in comparison with households which do not include a disabled person.

Table 7 shows that households which include a disabled adult are twice as likely to be classified as poor as those which do not include a disabled adult. Poverty is defined as 60 per cent below the median, equivalised for differences in the composition of the household. This is the current definition favoured by the UK Government.

Table 7 Risk of poverty for working age adults by disability, 2001/2 (percentages)

Family	Proportion poor
One or more disabled adult	30
No disabled adult	16

Source: Households Below Average Income, 1994/5–2001/2, DWP, 2003, table 5.7.

The greater risk of poverty is associated with exclusion from employment. DWP figures (2003) indicate that 31 per cent of households including one disabled adult are workless, compared with only 9.6 per cent of households with no disabled adult. One of the strengths of direct payments is their flexibility and ability to be used to support a range of activities including employment. The expanded use of direct payments might therefore contribute to the Government's goal of raising rates of economic activity and tackling poverty, including child poverty. Much would depend on whether local authorities encourage flexibility in their use, and make sufficiently large payments to provide the support needed by individuals with more significant impairments to sustain employment. Earlier research (Pearson, 2000) indicated that some local authorities used direct payments to support personal care only. The scope and size of direct payments will be investigated more fully in subsequent phases of the current ESRC research project.

Amongst the small number of disabled people who are receiving direct payments, there is evidence of inequality with regard to their use by nature of impairment, local authority and part of the UK (see above). This indicates that the potential benefits of direct payments are being unequally distributed, and these inequalities might intensify if direct payments are more widely used in the future.

Direct payments and recognition

Earlier research has demonstrated the potential of direct payments to enhance the extent to which disabled people are able to exercise control over important aspects of their lives (see Barnes, 2004, for a review). As noted above, the restricted use of direct payments to date in the UK, particularly in the North East of England, Scotland, Wales and Northern Ireland, means that their contribution to improving the social status of disabled people has been limited, but could be further developed in the future. However, there is a danger that differences in recognition accorded to specific groups of disabled people may be exacerbated unless local authorities make great efforts to equalise take up by different groups. People with mental health problems, for example, have the lowest rate of employment of any impairment group (21 per cent). Relative to their participation in employment, they are more likely to bring cases to tribunal under the Disability Discrimination Act, indicating a greater risk of discrimination. In addition, they make up a third of all new Incapacity Benefits claimants. The data presented above show that people with mental health problems are much less likely to be in receipt of direct payments. Research has also documented the attribution of a spoiled social identity to people with learning disabilities (Riddell *et al.*, 2001), who are also less likely to be in receipt of direct payments. In addition, disabled people from minority ethnic groups

are under-represented as direct payment users (Witcher *et al*., 2000). This underlines the potential of direct payments to be used by local authorities to reinforce, rather than challenge, existing inequalities in the social recognition accorded to particular groups of disabled people. Close monitoring of local authority practices over time is necessary to identify inequalities in uptake of direct payments by social class, gender, ethnicity and impairment. The research reported here is intended to contribute to this task, although it is already evident that improvements are needed in the routine data gathering undertaken by local authorities.

Conclusion

The legislation to enable local authorities to make direct payments to disabled people was the result of a long struggle by disabled people. As argued in this paper, direct payments have the potential to make a major contribution to social justice for disabled people by enabling the principles of independent living to be put into practice, in a way which may result in a reduction in poverty and should mean an increase in respect. The fact that uptake of direct payments has been slow, despite the growing enthusiasm of the government, means that their potential to contribute to the creation of a more just society has not yet been realised. If direct payments become a mainstream option, there is also the danger that the policy may become domesticated and may lose its potency for meaningful social change. For example, some local authorities are suggesting that disabled people might use their payments to purchase local authority services. There is also a relaxation in the rules governing the employment of close relatives. If these services offer choice and autonomy, then it may not matter whether the provider is in the public, private or voluntary sector. However, there is the possibility that former relationships based on inequality and dependency may re-emerge. On-going monitoring of local authorities' use and interpretation of direct payments policy is required, and we hope that the research project described above will contribute to the process.

Finally, there is an emerging opposition to direct payments from Labour controlled local authorities and public sector workers unions (Unison, Scotland, 2004). It is argued that direct payments exemplify an individualised and privatised form of welfare which threatens the pay and conditions of low-paid workers and the principles of universal public services. Public sector trades unions also deploy social justice arguments to oppose the development of services which they believe threaten the power of the local authorities. Further discussion of the principles of social justice, which underpin direct payments, and their relationship to alternative conceptions of social justice, will need to take place.

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