

# Disabled People and Direct Payments: A UK Comparative Study

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Sheila Riddell, Mark Priestley, Charlotte Pearson, Geof Mercer, Colin Barnes, Debbie Jolly, Victoria Williams

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This report presents findings from a ‘four-country’ study exploring a relatively new and radical form of welfare provision, direct payments. The purpose of the research was to support future policy development by explaining variation in the implementation of national direct payments policies in different localities across the UK, and particularly within the context of devolution in England, Scotland, Wales and Northern Ireland. Empirically, the research involved a multi-method and multi-stakeholder analysis, focusing on the changing practices and cultures of purchasing authorities. The findings explain implementation as a multi-factored phenomenon, concluding that local variation is not attributable solely to ‘local factors’, and that varied techniques of devolved governance impact on equity and social justice for disabled people. The research has considerable policy implications, for national and local government and for those purchasing and supporting direct payments, and has generated extensive knowledge transfer and dissemination outputs.

## **Background**

Direct payments are funds paid by local authorities to disabled people and other community care service users to purchase their own support (e.g. by employing their own ‘personal assistants’). The origins of direct payments lie in the social claims and activism of the movement for independent living, for greater choice, flexibility and control in disabled people’s lives (Priestley 1999) but have now become part of the mainstream of welfare policy in the UK. Although government policy strongly advocates their expansion, questions continue to be raised about whether they are an appropriate form of provision for all, and the extent to which some may find them too difficult to manage without adequate support (Ungerson, 1997; 2002). Within purchasing authorities direct payments have been viewed variously as an important means of empowering consumers as ‘co-producers’ of welfare (Glasby and Littlechild, 2006) or as a form of ‘creeping privatisation’ (Pearson, 2006). Additional concerns have been raised about the supply, pay and working conditions of personal assistants employed on direct payments (Leece, 2006; Ungerson 2006) and about the sustainability of the community-based support services that direct payments users require in order to effectively manage direct payments (Barnes and Mercer 2006).

The NHS & Community Care Act 1990 put in place new arrangements for the management and delivery of social care. Following the 1989 White Paper *Caring for People: Community Care in the Next Decade and Beyond* the new regime sought to develop a strong independent sector alongside high quality public services. In England and Wales, but not in Scotland, it was stipulated that 85% of new resources (money transferred from the social security budget) should be spent on private and voluntary sector care providers. The development of a ‘mixed economy’ of welfare, involving an array of services delivered by public, private and voluntary sector providers, was further promoted by the 1999 White Paper *Modernising Government*, along with tighter regulation through service standards and stricter audit and inspection regimes, in part to safeguard quality for socially disadvantaged service users. It is therefore important to evaluate the implementation of direct payments policies in the context of both the marketisation and the modernisation of social care.

Following the Conservative Government's decision to introduce legislation enabling local authorities to make direct payments to meet assessed community care needs (Pearson, 2000), there has been gradual extension of direct payments to different user groups. In England, the Health and Social Care Act 2001 required local authorities to offer direct payments to all those eligible for community care services who consented to and were able to manage payments. A year later, the Community Care and Health (Scotland) Act 2002 also made it mandatory for all Scottish local authorities to offer direct payments to eligible client groups and this was implemented throughout the UK during 2003 and 2004. Subsequent policy documents and ministerial statements (e.g. Department of Health, 2005; Department of Health, 2006) and the 2006 White Paper *Our Health, Our Care, Our Say* articulate a strong commitment to direct payments in England and Wales, and the extension of the principle to 'individualised budgets' for disabled people (merging funds from different sources including local authority social services, housing adaptations and equipment and individual living funds). In Scotland and Northern Ireland, whilst there is a commitment to the delivery of more personalised and flexible services, direct payments have been viewed as only one of a number of means of achieving this goal (Scottish Executive, 2006).

### **Research themes and objectives**

The research examines the implementation of direct payments policies in the UK during the ten years since their introduction in 1997. It is concerned with explaining impact and variation at the level of locality, within the context of devolved governance in the four main jurisdictions, or 'countries', of the United Kingdom (acknowledging the definitional and political disparities that exist between institutions of government in England, Scotland, Wales and Northern Ireland). The following research questions were considered:

- What are the key differences in direct payment policies, implementation strategies and practices in England, Wales, Scotland and Northern Ireland, and within each 'country' what variations are apparent at a local level?
- To what extent have direct payment policies had an impact on forms of welfare production and consumption?
- To what extent have purchasing authorities changed their cultures and practices to facilitate new modes of welfare delivery?

The key analytical themes highlighted in this report are primarily concerned with the supply of and demand for direct payments, in terms of: (a) the impact on local practices, cultures, politics and economies of welfare production; (b) the influence of national and devolved techniques of governance on local implementation; (c) the significance and sustainability of community-based claims and support for direct payments.

### **Methods**

The research adopted a progressive focussing strategy, beginning with a 'broad brush' approach to the analysis of policy and official statistics and focusing down, from key informants, through postal questionnaires, telephone surveys and case study work, to

the experiences of specific actors in local settings. The analysis is therefore multi-tiered and considers the role of national government, devolved government, local government, social movements, support organisations, purchasers, providers, managers, frontline staff, and consumers. Details of the specific research tasks undertaken are described below:

### ***Policy and literature review***

In addition to research literature, a systematic review of the development of relevant legislation and official policy documents, produced by the UK government and the devolved administrations, was undertaken. A summary and analysis was published as a working paper on the project website (WP1) and developed in a subsequent journal paper (Pearson et al. 2005).

### ***Initial analysis of official statistics***

A quantitative review was conducted of official statistics gathered in different parts of the UK to identify patterns and irregularities in the uptake of direct payments during the discretionary phase of policy implementation (1997-2003). The analysis examined associations with a range of variables, including: the political control of the local authority; the number of people reporting a long-term limiting illness or disability in the 2001 Census; and the presence of a support organisation for disabled people wishing to make use of direct payments. This work was published in two working papers on the project website (WP2 and WP3) and developed in a subsequent journal paper (Riddell et al. 2005).

### ***Key informant interviews (21 interviews)***

To sensitise the researchers to the key issues, and to frame themes and questions for the later stages of the research, 21 interviews were conducted in mid 2004 with key informants involved in the development of direct payments policies and their implementation (including disability activists, support organisations, policy makers at UK level, in the devolved administrations and in local authorities). A summary analysis was published as a working paper on the project website (WP4), along with the interview topic guide, and discussed with the project advisory group.

### ***Telephone survey (102 interviews)***

A telephone survey was conducted with individual officers responsible for direct payments in purchasing authorities throughout the UK between November 2004 and April 2005. The target was to access all responsible bodies in Scotland (32), Wales (22) and Northern Ireland (12), and a sample of local authorities in England (50). The English sample was randomly selected but stratified to include different authority types. Overall, the response rate was 88% and tape-recorded, semi-structured interviews were conducted with 102 informants in 30 local authorities in Scotland, 18 in Wales, 46 in England and in 8 Health and Social Service Trusts in Northern Ireland (in three of the four Board areas). Thematic analysis was conducted using NUD\*IST/Nvivo, published as a working paper on the project website (WP5), and developed as a subsequent journal paper (Priestley et al. 2006).

### ***Postal questionnaire survey (all purchasing authorities and support organisations)***

Although this was not part of the original research design, the ESRC team collaborated with two other research groups to administer a questionnaire survey to all local authorities in England, Wales and Scotland and to Health and Social Service Trusts in Northern Ireland. The analysis and findings from this task are included in a joint report (Davey et al, 2006) and are summarised briefly in Appendix 2.

### ***Local case studies (8 local authorities and trusts)***

Case studies were conducted with eight local authorities (two each in England, Wales and Scotland) and with two Health and Social Service Trusts in Northern Ireland. In addition to gathering official policy documents and statistics, focus groups and individual interviews were conducted with users, non-users, local authority managers, politicians, union representatives, finance officers, social work staff and support organisation workers. The table below summarises the research conducted in each location.

**Table 1: Focus groups and individual interviews conducted in each case study location**

<b>Case study</b>	<b>Focus groups</b>	<b>Interviews</b>
Scottish LA1	2	8
Scottish LA2	3	8
NI H & SS Trust 1	2	3
NI H & SS Trust 2	3	11
English LA 1	2	17
English LA 2	3	3
Welsh LA 1	3	3
Welsh LA 2	4	5

### **Ethical governance**

The research was conducted in periodic consultation with an independent project advisory group, including representatives from the independent living movement, government, social services and academics. Prior to the commencement of fieldwork, the research was approved by ethical committees in the three universities involved (Edinburgh, Glasgow and Leeds). The ethical guidelines of the Social Policy Association were adhered to (latterly accommodating the introduction of the ESRC Ethical Framework). Formal approval and endorsement for the fieldwork involving local authorities was gained from the Association of Directors of Social Services and, for the postal questionnaire survey, from the Department of Health.

## Results

### **Policy and research review (findings from Working Paper 1)**

- It is important to place the implementation of the Community Care (Direct Payments) Act 1996 in both national and historical context. The marketisation of welfare and the social claims of the independent living movement are particularly significant.
- The knowledge gained from informally negotiated and ‘indirect’ payments schemes developed prior to legislation, together with experiences from the Independent Living Fund, were important in framing expectations for the Act’s implementation.
- Lessons from user-led pilot schemes in the 1980s and early 1990s pre-figure many of the tensions and concerns that have arisen since 1997 (such as tensions between the purchasers, providers and users of direct payments support services).
- The legitimisation of direct payments fostered growth in the number of organisations offering support to direct payments users.
- The introduction of the social care modernization agenda, and extension of eligibility to new user groups, heralded a broadening of direct payments policy discourse (beyond its historical focus on independent living solutions for disabled adults).
- With few exceptions, previous government, academic and practice-based research has been carried out in England (and to a lesser extent Scotland) and there has been a notable absence of any UK-wide national research on direct payments.
- Understanding the micro-politics of implementation is as important as understanding the macro-policy context.

### **Initial analysis of official statistics to 2003-4 (findings from Working Papers 2 and 3)**

- There were considerable discrepancies in the collection and reporting of official statistics on direct payments between England, Scotland, Wales and Northern Ireland (e.g. in terms of age or impairment groups). No official data were available on the provision of indirect payments nor, importantly, on the size of individual direct payments packages or on gender.
- By the time implementation became mandatory, in 2003-4, the large majority of purchasing authorities in the UK (88.7%) were already reporting disabled people using direct payments.
- The mean average number of direct payments per authority was then 44.4 but there was considerable variation, both between localities and between countries (the median average was in fact only half the mean at 22).
- At this time, the highest number of reported DP users in England was in Essex (642); the highest in Scotland was in Fife (120); in Wales, Cardiff (47); and in Northern Ireland, Armagh and Dungannon (47).
- However, there were still 19 authorities with no reported direct payments users. Eleven of these were in Scotland, five in Wales and two in Northern Ireland, plus the Isles of Scilly. Three authorities reported only one user (two in Wales and one

in Scotland). All of the English mainland authorities were reporting more than one direct payments user.

- Of the 59 authorities reporting more direct payments than the mean average only five were outside England (three in Scotland, one in Wales and one in Northern Ireland). In all of these localities there was a local support organisation, and there was a positive association between the take-up of direct payments and the presence of a local support organisation described as ‘user-led’ in the NCIL database.
- While rapid increases in numbers were apparent between 2000 and 2003 (when implementation became mandatory for most of the UK) these were uneven between different countries and different user groups.
- The pattern of take-up across the UK during the discretionary phase of policy implementation was at odds with the demographic distribution of people reporting ‘long term limiting illness or disability’ in the 2001 Census and this raised further questions about equity and social justice between regions.
- Seven of the ‘top ten’ authorities, such as Hampshire (all in England) were Conservative controlled, and this may reflect local political histories of welfare individualism, stake holder participation and consumer choice.
- By 2003, England had established twice the rate of take-up per 100,000 adult population compared with other parts of the UK. Whilst there have been rapid increases in all parts of the UK since then, this differential was still evident in 2005.

**Table 2: 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	% Long Term Illness / Disability	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 (0.70)	9,700 (1.00)
Scotland	5 million	20	207 (0.20)	392 (0.40)	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 unavailable for 2000/1 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 %; Northeast England 23 %)*

#### **Key informant interviews (findings from Working Paper 4)**

- Explaining the historically uneven geographical take-up of direct payments in the UK involves many interrelated factors.
- These included: the presence of a strong disability advocacy base; adequate funding for policy development; the political culture of national, regional and local government; local markets for the supply of social care; the role of local champions within purchasing authorities; and the existence of appropriate infrastructure (specifically, but not exclusively, user-led direct payments support schemes).

- All of these factors, and others, can usefully be considered within the overarching concept of a local or regional opportunity structure for policy implementation.
- There have been difficulties in monitoring and ensuring equity between different user groups. Although this was improving, attention must be paid to patterns of implementation and initiatives for advancing take-up by specific groups (including the implications for other groups).
- While monitoring the level of take-up is useful there were concerns at the absence of meaningful quality monitoring data.
- Implementation for under-represented user groups appeared to be improving, and there was a keen awareness in support organizations of where the deficiencies lay.
- There were concerns that marketisation and contracting would impact negatively on the quality and scope of support typically valued within the independent living philosophy.
- There are complex relationships of interdependency between central and devolved government, purchasing authorities, professionals, disabled people's organizations and support groups. The links between them, and the impact on take-up, quality and outcomes require close attention.
- Communications between purchasing authorities and support organizations are not always positive or beneficial, particularly where there is pressure to increase take-up amongst new user groups without adequate resources (this was particularly noted in areas outside England).
- There was some support for a more radical policy future, including some advocacy for replacing local authority responsibilities with a more nationally coordinated and funded provision of direct payments.

#### **Telephone interviews (findings from Working Paper 5)**

- Direct payments were widely welcomed for the positive outcomes that could be achieved by disabled people and for the new creative options they provided to care managers and purchasers.
- All of the interviewees said that direct payments gave users greater choice, control and flexibility, and there were many innovative examples of how they could be used to promote independent living. However, there were substantial differences in the degree of flexibility and choice available to users in different localities.
- The bulk of resources were devoted to personal care, with the majority focusing direct payments on support for personal care but a significant minority adopting a more open approach to meeting any assessed need.
- 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.
- Responsibility for the implementation of direct payments within purchasing authorities varied greatly, with evidence of an increase in the number of dedicated direct payments officers in all parts of the UK. However, English authorities were far more likely to have designated officers compared with Scotland, Wales and Northern Ireland. The availability of development funding from central government had a significant impact on this.



- Sixty-five percent (28) of those in the English sample were in designated full-time direct payment posts, compared to 23% (7) in Scotland, just one in Wales and none in Northern Ireland.
- Policy guidance from UK and devolved governments was broadly welcomed but street level bureaucracy and the local interpretation of national guidelines was a significant factor in successful implementation. Specific examples were given of needs for clarification from central government (e.g. in relation to capacity and consent or disabled children and young people). There was little indication or evidence of policy discussions having been promoted on any scale in Northern Ireland.
- Where there was resistance or scepticism to the principle of direct payments (by local politicians, managers or specific staff groups) such claims of policy ambiguity were compounded.
- 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). Fair Access to Care criteria were also noted by several interviewees in England and Wales as a restriction on access to direct payments.
- Comprehensive training for social work and finance staff was much more likely to be available in some authorities than others. The presence of a designated officer or champion was associated with a marked increase in knowledge about direct payments throughout the local authority. More effective training, publicity and monitoring strategies were also more likely to result.
- There were numerous examples of innovative and effective interventions in training and information provision for staff and potential users, and evidence that these resulted in increased take-up. Such examples included individual authorities and collaborative initiatives between groups of neighbouring authorities.
- The imposition of mandatory duties to offer direct payments across the UK had a marked effect on local policy development and take-up. Many authorities that were 'slow starters' only began to develop local policy at this point. In England, performance targets, often resisted in other parts of the UK, appeared to have a positive impact.
- The extension of eligibility to new user groups was welcomed throughout the UK. In Scotland, an even wider extension had been proposed to groups (such as women fleeing domestic violence, those recovering from alcohol and drug addiction and refugee and asylum seekers). However, on further consideration the Scottish government decided that this was potentially too controversial.
- 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 users and improved outreach created a positive impact on the development of best practice more generally.
- There was evidence of difficulty in recruiting personal assistants in several areas (including half of Welsh authorities). 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 the majority of areas, the employment of relatives continued to be viewed with some caution whether they lived in the same household or not. 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).
- In Scotland and Northern Ireland, despite some unease over the principle of direct payments, the impact on existing services and future commissioning was minimal. Direct payments remained a ‘minority service’ and the number of users was rarely high enough to prompt any restructuring of existing services.
- Concerns appeared more tangible in England and Wales, with around 35% reporting management unease about the financial impact on block contracts and the potential decommissioning of local services. In England, where take-up has been highest, there was evidence of some resource transfer from services for people with physical impairments and learning difficulties (and potential impact on children’s services and respite care).
- 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).
- Authorities with the greatest numbers of direct payments users had generally developed a productive synergy with local disability groups over many years.
- At the time of interviews, only one quarter of support organisations were seen by purchasing authorities as in some way user-led in England, with a higher proportion in Scotland and a lower proportion in Wales and Northern Ireland. Such organisations varied from those with a clear disability campaigning remit, to those focused on a specific operational task.
- User-led organisations took an initial policy lead in parts of England and the major Scottish cities but were largely absent elsewhere. However, as implementation has moved forward some of these organisations have 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. There is now some concern about the sustainability of links between direct payments and disability activism.

### **Local case studies (pre-publication findings)**

See Table A1 in Appendix 3

## Conclusions

Past research has identified considerable variation in the take-up of direct payments within and between different parts of the UK. However, such studies have tended to explain this variation only at the level of individual purchasing authorities or within single countries/regions. We conclude that it is impossible to understand the dynamics of uneven implementation without considering the UK as a whole. The picture is complex but three themes are particularly important.

### *The politics of devolution*

Whilst ministers throughout the UK have broadly endorsed direct payments, expressions of support have been much stronger in England than elsewhere (e.g. that direct payments should be the default option in social care purchasing). Endorsement has been bolstered by the Prime Minister's Strategy Unit, by targets and performance indicators for year on year increases, and by the 2006 White Paper. In Scotland, by contrast, official documents continue to present direct payments as one of a number of means to deliver improved and more person-centred social services. No member of the Scottish Parliament has spoken out strongly in favour of direct payments, and no national targets have been set for local authorities. As in parts of Wales, some parts of Northern England and in Northern Ireland, there is also evidence of a greater suspicion about direct payments, either from local politicians or from public sector trades unions. For example, the traditional domination of the Labour Party in Scotland and Wales is reflected in defence of collective welfare and the protection of public sector jobs against 'creeping privatisation'. These differences, coupled with some suspicion about the Westminster modernisation agenda, appear to be resulting in some divergence of policy under devolution.

Examining policy implementation through the lens of devolution allows us to reframe the direct payments implementation debate and to raise new questions about the impact of devolved governance on equity and social justice for disabled people in different parts of the UK. If the ambitions of the 2006 White Paper, for rapid growth and expansion of the direct payments principle (e.g. by extension to individualised budgets) are to be realized, then important lessons must be learned about the capacity and commitment of different devolved governments, purchasing authorities and support organizations to deliver equity of outcomes for disabled people in England, Scotland, Wales and Northern Ireland.

### *Local cultures of welfare*

Although devolution has created different opportunity structures for the implementation of direct payments policies in different regions of the UK, local economies of welfare and the micro-politics of purchasing authorities remain critical factors. The existing pattern of direct service provision, the extent of block purchasing agreements, the demographics and geography of locality, and the political orientation of local councils all influence local planning and responses. The extent to which direct payments are, or are not, 'championed' by key politicians and senior managers, the

degree of knowledge about or resistance to direct payments amongst key staff groups, and the relative ease or complexity of local purchasing mechanisms also impact on implementation at the front line.

*The influence of the disability movement*

The social claims of disabled people, for access to independent living outcomes and for direct payments as a route to this end, were highly significant in policy development both locally and nationally. Where there had been an absence of strong advocacy for direct payments, or peer-to-peer knowledge sharing, there was little evidence of local or regional policy development, particularly during the discretionary phase of implementation. Policy developments were strongest where there were shared goals and direct relationships between members of the disability community and local champions within purchasing authorities. Since the move to mandatory implementation and the expansion of direct payments this picture has changed somewhat. Some user-led organisations have been drawn away from advocacy work towards more operational service provision, and many have struggled to survive in this role. New providers from the voluntary sector, and in-house support schemes within purchasing authorities, have emerged and there is now some concern about the sustainability of links between the independent living movement and direct payments users, particularly in England.

## **Outputs and activities (see Appendix 1 for detailed list)**

Dissemination activity has so far been very considerable, as the following examples demonstrate:

A public web page was created on the Centre for Disability Studies website at the outset of the research (the CDS site receives approximately 1,000 visitors per month, 48% from outside the UK). This currently includes a research summary, examples of the research tools used, five working papers, and links to published outputs. The address is: [www.leeds.ac.uk/disability-studies/projects/ukdirectpayments.htm](http://www.leeds.ac.uk/disability-studies/projects/ukdirectpayments.htm)

In addition to this online presence, the research findings have been extensively disseminated through the following means: a published book with specific reference to Scotland; four published articles in international refereed journals; two book chapters; and two collaborative published research reports. Five dissemination events have been held (in Scotland, England and Wales) in collaboration with policy, community and academic partners, and involving more than 300 participants in total (including politicians, civil servants, policy advisors, local government staff, voluntary organisations, researchers, postgraduate students, disabled people's organisations, and consumers of disability services and direct payments). Members of the research team have so far made 20 presentations to seminars, briefings, national and international conferences (the majority of them invited presentations). **A detailed list of outputs is included in Appendix 1.**

The significance of the research and its impact is evidenced by the large number of requests to speak to policy and user organisations, presentations at ESRC-funded seminars and involvement with policy development at a national level (e.g. invitations to present evidence to the Department of Health and the Scottish Parliament Health Committee). An invited workshop was included in the 2005 'Community Care Live' event. The Disability Rights Commission drew on aspects of the findings in developing clauses for the Independent Living Bill 2006. The Scottish Parliament commissioned a more detailed report summarising evidence from Scotland to inform its policy in this area, and the British Council funded a visiting international fellow to examine the research and make comparisons under its British-Polish Young Scientists Scheme,

### **Future Research Priorities**

The research findings and conclusions raise a number of themes and priorities for further research in the following areas:

- The development of direct and indirect payment principles through individualised budgets and personalised care (as proposed in the 2006 White Paper) continues the shift towards new modes of welfare consumption in the mixed economy. It will be important to understand how these new changes impact on different

groups of disabled people in different parts of the UK and the extent to which regional policy implementation appears to be harmonizing or diverging.

- There are issues in the management of direct payments, including the management of personal assistants, the financial process, and the quality of support. Local case studies and the sharing of good practice in this area might provide a useful contribution to further policy development.
- Expanded direct payments usage is unsustainable without well-resourced and knowledgeable support services to direct payments users. It will be important to monitor the impact on local user-led organisations of disabled people as direct payments and individualised budgets extend to other user groups.
- There have been developments in the provision of direct payments and related mechanisms in many other countries both within and outside the EU. Cross-national research involving user-led organisations and policy makers would be particularly valuable here.

## **Appendix 1: detailed list of outputs and activities**

### **Published outputs**

#### *Book*

Pearson, C., Riddell, S. and Williams, V. (2006 forthcoming) *Direct Payments and the Personalisation of Care* Edinburgh: Dunedin Academic Press.

#### *Journal and periodical papers*

Barnes, C. (2005) Independent Living, Politics and Policy in the United Kingdom: A Social Model Account, *Review of Disability Studies*, 1(4): 5-13

Barnes, C. (2004) 'Direct Payments and their Future'. In *Independently: National Centre for Independent Living Newsletter*, November/December, pp. 2/3

Pearson, C., Barnes, C., Jolly, D., Mercer, G., Priestley, M. and Riddell, S. (2005) Personal Assistance Policy in the UK: What's the problem with direct payments?, *Disability Studies Quarterly*, 25(1), [http://www.dsqsds.org/login.asp?referer=/\\_articles\\_html/2005/winter/pearson.asp](http://www.dsqsds.org/login.asp?referer=/_articles_html/2005/winter/pearson.asp)

Priestley, M., Jolly, D., Pearson, C., Riddell, S., Barnes, C. and Mercer, G. (2006) Direct payments and disabled people in the UK: supply, demand and devolution, *British Journal of Social Work*, available in advance access online at: <http://dx.doi.org/10.1093/bjsw/bcl063>

Riddell, S., Pearson, C., Jolly, D., Barnes, C., Priestley, M. and Mercer, G. (2005) The development of direct payments in the UK: implications for social justice, *Social Policy and Society*, 4(1): 75-85

#### *Book chapters*

Pearson, C. (2004) 'The implementation of direct payments: issues for user-led organizations in Scotland', in Barnes, C. and Mercer, G. (2004) *Disability Policy and Practice: Applying the Social Model*, Leeds: The Disability Press.

Pearson, C. (2006) 'Direct Payments in Scotland', in Leece, J., and Bornat, J. (eds) *Developments in direct payments: Comparative perspectives from the UK and beyond*, Bristol: Policy Press.

#### *Working papers published online*

Jolly, D., & Priestley, M. (2004). Working Paper on Direct Payment Patterns in the UK: Preliminary Analysis of Quantitative Mapping and Potential Research Issues. Centre for Disability Studies. <http://www.leeds.ac.uk/disability-studies/projects/UKdirectpayments/Initial%20Quant%20Analysis.pdf>

Pearson, C. (2004) Direct Payments: Policy development across the UK (second draft), <http://www.leeds.ac.uk/disability->

[studies/projects/UKdirectpayments/draft%20policy%20development%20paper.pdf](http://www.leeds.ac.uk/disability-studies/projects/UKdirectpayments/draft%20policy%20development%20paper.pdf)

Priestley, M. (2004) Overall numbers of reported direct payments users in the UK – rank order and sampling issues. Centre for Disability Studies.

<http://www.leeds.ac.uk/disability-studies/projects/UKdirectpayments/basic%20rank%20order%20DP%20users.pdf>

Priestley, M., Jolly, D. & Pearson, C. (2005) Implementing direct payments for disabled people in the UK: initial findings from interviews with purchasing authorities. Centre for Disability Studies. <http://www.leeds.ac.uk/disability-studies/projects/UKdirectpayments/DP%20interview%20summary.pdf>

Priestley, M., Pearson, C., Riddell, S., & Jolly, D. (2004). Disabled People and Direct Payments in the UK: preliminary analysis of key informant interviews. Centre for Disability Studies. <http://www.leeds.ac.uk/disability-studies/projects/UKdirectpayments/Key%20Informant%20Summary.pdf>

Riddell, S., Pearson, C. and Williams, V. (2006) Disabled People and Direct Payments: A UK Comparative Study Edinburgh: Centre for Research in Education Inclusion and Diversity. [www.creid.ed.ac.uk](http://www.creid.ed.ac.uk)

#### *Published research reports*

Davey, V., Fernández, JL, Knapp, M., Vick, N., Jolly, D., Swift, P., Tobin, R., Kendall, J., Ferrie, J. Pearson, C., Mercer, G. and Priestley, M. (2006) *Direct Payments Survey: A National Survey of Direct Payments Policy and Practice*, Personal Social Services Research Unit/London School of Economics and Political Science

Riddell, S., Ahlgren, L., Pearson, C., Williams, V., Watson, N. and MacFarlane, H. (2006) *The Implementation of Direct Payments for People who use Care Services* Edinburgh: Scottish Parliament

#### **Knowledge transfer and dissemination activities**

*Disabled People and Direct Payments: national dissemination event*, 13 March 2006, Moray House School of Education, Edinburgh University (conference sponsored by the Scottish Executive Department of Health)

*Direct Payments: the national picture*, 22 March 2006, Weetwood Hall Hotel, Leeds (conference hosted by the Centre for Disability Studies in collaboration with the British Council of Disabled People and the Disability Rights Commission).

*Direct Payments: Developments in Research, Policy and Practice*, 28 March, London School of Economics (seminar hosted by LSE as a collaboration of the Direct Payments Survey Group)

*Direct Payments in Wales*, June 2006, Caerphilly (practice development seminar in collaboration with five Welsh local authorities)



*Presentation of report 'The Implementation of Direct Payments for People who use Care Services' to the Scottish Parliament Health Committee May 16<sup>th</sup> 2006*  
[www.scottish.parliament.uk/business/committees/health/papers-06/hep06-12.pdf](http://www.scottish.parliament.uk/business/committees/health/papers-06/hep06-12.pdf)

**Presentations (at seminars, conferences, briefings and workshops)**

- Barnes, C. (2004) 'Independent Living, Politics and Implications', Invited presentation at the *Social Care Institute for Excellence (SCIE)* National Conference on Independent Living, Kensington Tara Hotel, London, (22<sup>nd</sup> November).
- Barnes, C. (2005) 'Disability Activism and the Price of Success: A British Experience', Invited lecture at the Institute of Advanced Studies, University of Western Australia, Perth, Western Australia (31<sup>st</sup> August).
- Barnes, C. (2006) 'Disability, Independent Living and Direct Payments'. Invited Key Note Address at the Direct Payments Conference, sponsored by Buckinghamshire County Council, Civic Centre, Aylesbury (19<sup>th</sup> January).
- Jolly, D. & Priestley, M. (2005) *Capacity, Risk and Direct Payments*, invited workshop for local authority care assessors, 20 September 2005, Caerphilly
- Jolly, D. (2005) *Direct Payment Research at the Centre for Disability Studies*, invited presentation to the Hackney Direct Payment Launch, 19 July 2005, Hotel Saint Gregory Shoreditch, London
- Jolly, D. (2005) *The Implementation of Direct Payments across the UK*, invited practitioner workshop presented at 'Community Care Live', 19 May 2005, Business Design Centre, London
- Jolly, D. (2006) *Findings from the ESRC Research Project*, invited presentation to Department of Health briefing seminar, London, 12 September 2006
- Jolly, D. and Priestley, M. (2006) *A Postcode Lottery? Explaining the uneven implementation of direct payments*, paper presented to the 'Independent Living and Direct Payments: the national picture' seminar, 22 March, University of Leeds
- Jolly, D. and Priestley, M. (2006) *Diversity and Support for Direct Payments*, invited paper to the 'Direct Payments: Developments in Research, Policy and Practice' seminar, 28 March, London School of Economics
- Pearson, C. & Jolly, D. (2004) *Devolving direct payments: A Review of policy development in the UK*, paper presented to the Disability Studies Association Conference, 26-28 July 2004, University of Lancaster.
- Pearson, C. & Jolly, D. (2005) *Exploring patterns of personal assistance in the UK: the implementation of direct payments*, paper presented to the 8<sup>th</sup> conference of the Nordic Network on Disability Research, 14-16 April 2005, Oslo, Norway.
- Pearson, C. (2004) *Promoting direct payments in Scotland: Exploring issues for users*, invited workshop for 'Community Care Live Scotland', 26 October 2004.
- Pearson, C. (2004) *Promoting personal assistance in the UK: What's the problem with Direct Payments?*, paper presented to the Canadian Disability Studies Association Conference, 'Confluence and Coalition in Community: Creating Dialogue within

- Disability Studies', 29-30 May 2004, Congress of the Social Sciences Federation of Canada, Winnipeg, Manitoba.
- Pearson, C. (2005) *Exploring the ethics of care through the implementation of direct payments*, invited paper to the ESRC seminar series on 'Ethics of Care', University of Reading, 16-17 March 2005.
- Priestley, M. & Jolly, D. (2006) invited briefing to the Department of Health, 24 March, Wellington House, London
- Riddell, S. (2004) *Direct payments for disabled people and user empowerment: tensions in policy and practice*, paper presented to the ESRC funded seminar series 'Non-Familial Intimate Relationships Across the Life-Course', 13 September 2004, University of Edinburgh.
- Riddell, S. (2004) *Disabled People's Experiences of Direct Payments: Lessons for Education*, paper presented to the ESRC seminar 'Private Sector Involvement in Public Sector Education, 14 May 2004, Institute of Education, London
- Riddell, S. (2005) *Direct payments for disabled people and caring relationships: tensions in policy and practice*, paper presented to the ESRC funded seminar series 'Care': Research, Policy and Practice, 13 December 2005, University of Strathclyde, Glasgow
- Riddell, S. (2006) Direct Payment for Disabled People: The Way Forward or Policy Cul de Sac? Seminar at the Social Policy Research Unit, University of York, 6<sup>th</sup> May 2006
- Riddell, S. (2006) *Direct Payments in Scotland*, presentation to the Scottish Parliament Health Committee, 16 May 2006, Edinburgh

## **Appendix 2: Summary of findings from the Direct Payments Survey Group report (Reported fully in Davey et al, 2006)**

In an innovative departure from the initial project plan, the team initiated collaboration with the Department of Health and two other research teams (PPSRU/London School of Economics and the Health and Social Care Advisory Service/Mental Health Foundation/University of Birmingham) to extend the scope of data collection and to avoid duplication of research efforts. A joint questionnaire was sent from this 'Direct Payments Survey Group' to all local authorities in England, Wales and Scotland and all Health and Social Service Trusts in Northern Ireland in 2005. The questionnaire sought detailed information about: the characteristics of direct payments users; the rates paid for different types of personal assistance; the role of support organisations; and the factors facilitating or hindering local uptake of direct payments. Response rates varied greatly across the UK. Following a reminder letter from the Department of Health, 75% of English local authorities returned the questionnaire but the response rate for Scotland, Wales and Northern Ireland was much lower (less than 30%).

To improve the response rate for Scotland, with support from the Scottish Parliament, a shortened version of the questionnaire was administered to local authorities in early 2006. This time, a 66% response rate was achieved. Responses for the national survey were analysed in SPSS and a detailed report published jointly by the three research teams (see Davey et al. 2006). Here, we include only the most relevant findings for England and for Scotland (using data from the shortened questionnaire).

A second joint questionnaire was sent, by the Direct Payments Survey Group, to all organisations throughout the UK that support direct payment users.

- By 2005 the five regions providing the most direct payments to people with physical or sensory impairment continued to be those historically associated with early forms of indirect payments.
- Despite the extension of eligibility, there remain more recipients with physical or sensory impairments than for all other groups, but there is considerable variance between localities. The regional pattern of take-up for older people mirrors that of adults with physical or sensory impairment, albeit on a smaller scale.
- The promotion of direct payments to people with learning difficulties may have slowed down, amidst campaigns to promote access for other groups. The provision of direct payments to people with learning disabilities was strongest in the North West of England, which also had high provision to carers of disabled children.
- There were fewer direct payments to people with mental health problems than to any other group. Examples of innovative practice were often in regions with neither long-standing connections to the independent living movement nor above-average take-up of direct payments (the same was true for carers, although in different regions).

- Expenditure growth between 2003/04 and 2004/05 was noticeable for all user groups and for most regions, yet modest given the policy emphasis on making direct payments available to more people. English authorities that provided data, spent 15.5% of the their community care budget for people with physical impairments on direct payments, considerably more than the equivalent proportions for older people (0.8%), people with learning difficulties (1.1%) or mental health service users (0.4%).
- On average, expenditure on direct payments to people with learning difficulties was lower than the average expenditure on provided services for this group. This was reversed for people with physical impairments.
- The intensity or size of direct payments packages has been studied less often than the take-up rate but is essential in understanding policy implementation. There is enormous variation between and within user groups and regions.
- Almost a third of direct payment recipients with physical impairments in England received funding equivalent to more than 31 hours of support per week, and three-quarters received intensive care packages (according to the Department of Health definition of over 10 hours per week). Although based on smaller numbers, the average intensity of packages for this group appears even greater outside England.
- A majority of direct payment packages for people with learning difficulties provide high levels of inputs (e.g. in England, 68% and 24% of packages provided over 10 and 31 hours per week of care, respectively).
- Average intensity of direct payments to mental health service users was significantly lower than for the other groups (less than half had more than 10 hours per week).
- Approximately three-quarters of local authorities in England and Scotland had made one-off direct payments in the preceding year (e.g. to purchase respite care, equipment or for the setup costs of an ongoing payment). More local authorities had made one-off payments to people with a physical impairment than to any other group but a larger volume of one-off payments were made to groups for whom direct payments provision was otherwise low (carers and mental health service users).
- Although payment rates were consistent across different user groups, there was considerable variation across the UK. Rates paid by local authorities in Northern Ireland and Wales were markedly lower than in England and Scotland.
- There were further variations within England. A North/South divide was apparent, but regional disparities are complex. Above average rates were paid in London and the South East (as might be expected) but local authorities in the South West paid the highest average rate.
- Average weekly rates for people with learning difficulties, people with physical impairments and disabled children were all considerably lower than the average cost of residential care (but vice versa for older people and mental health service users).
- The majority of local authorities include tax and national insurance costs in their hourly rate. After deductions, a direct payment user with physical impairments can afford to pay on average £6.08 per hour. The majority of local authorities offer

some flexibility in their rates, usually responsive to need, but occasionally according to location (e.g. in rural areas).

- Few authorities include start-up costs or contingencies in the hourly rates – they are more likely to provide ad hoc or periodic payments on top of hourly rates.
- Authorities drew on a range of sources to fund support services (only a very small number charged users for this). The results did not suggest a clear relationship between local expenditure on support services and uptake of direct payments, but did indicate a fall in levels of funding for support services from 2003-4 to 2004-5.
- Around two-thirds of local authorities in England stated that they could facilitate access to an alternative support provider on request but there was less inclination to fund such alternatives (presumably due to existing contracting obligations).
- Local authorities identified a range of factors aiding or hindering the implementation of direct payments policies. Most concerned organizational infrastructure (an effective support scheme, staff training and support, local authority leadership, and the provision of accessible information to potential recipients), but positive staff attitudes, demand for direct payments from service users and carers, and national legislation, policy and guidance were also cited.
- Three factors were cited as important in hindering progress: concern about managing direct payments amongst service users and carers; staff resistance to direct payments; and difficulties regarding the supply of personal assistants (there were regional differences in whether this was viewed as an asset or a barrier to implementation).
- Apart from Wales, there was a degree of consistency across the UK in the most frequently cited factors that aid implementation, although authorities in Scotland and Northern Ireland suggested additional factors as critical. There was greater variation between countries in the factors identified as hindering implementation.
- The survey extension research carried out with Scottish authorities in early 2006 produced more comparable data for England and Scotland (but not for Wales and Northern Ireland). This suggested that Scottish authorities were more likely to place emphasis on the importance of local staff attitudes and less likely to see national guidance and legislation as important than English authorities, as shown below (perhaps reflecting a stronger culture of local government autonomy in Scotland).

**Table A2.1: Aiding factors identified as important (England and Scotland)**

<b>Factor</b>	<b>% English Local Authorities (N = 109)</b>	<b>% Scottish Local Authorities (N = 23)</b>
Effective support scheme	89%	87%
Training and support for front line staff	86%	87%
Leadership within the local authority	81%	82%
Positive attitude of staff	80%	91%
National legislation, policy and guidance	82%	68%
Accessible information for service users and carers	78%	87%
Demand from service users and carers	78%	96%

**Table A2.2: Hindering factors identified as important (England and Scotland)**

<b>Factor</b>	<b>% English Local Authorities (N = 109)</b>	<b>% Scottish Local Authorities (N = 23)</b>
Users' and Carers' concerns about managing direct payments	68%	66%
Staff resistance to direct payments	65%	21.7%
Lack of people to work as personal assistants	63%	63%