

Independent Living or Something Else?

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**Independent Living and Direct Payments: The
National Picture Conference**

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Key points and plain English version. For more detailed information and papers please see the project web page:

<http://www.leeds.ac.uk/disabilitystudies/projects/ukdirectpayments.htm>

In this presentation we are going to explain how and why direct payments came about and how they have been used in different parts of the UK. We will look at why it is much easier to get a direct payment in many parts of England than in Scotland, Northern Ireland or Wales.

There are a number of reasons why direct payments are easier to get hold of in certain parts of the country. These include:

- **Political control:** Local authorities run by the Conservative Party have been much more supportive of direct payments than more traditional Labour Party ones because they like the idea of people choosing who they want to work for them. The highest number of users tend to be in these areas.
- **Disability activism and the role of support organisations:** Groups of disabled people have been very important in getting direct payment

schemes up and running. Organisations run by disabled people like *Centres for Independent Living (CIL)* have developed in many areas and these have helped get more people support with their direct payments. However in areas without disabled people working together, progress has been much slower and far fewer people have heard about direct payments. Other organisations not run by disabled people are also appearing in some areas to provide support for users. This is obviously a concern for CILs and other similar groups.

- **The role of social workers:** Social workers and other staff working for local authorities are very important in telling people about direct payments. However, in some areas staff have not always been keen on doing this and this has prevented many disabled people from hearing about them.

From 2003 in England and Scotland (and health and social service trusts in Northern Ireland) and from 2004 in Wales, local authorities had to offer direct payments to any one who asked for them. Before this time, they had the choice whether to develop schemes or not. Therefore in many parts of the UK, this saw many local authorities having to consider direct payments as a service option for the first time.

Whilst direct payments came about largely as a result of campaigning by the disability movement, they are not always used to allow disabled people to live independently. For example, payments may only cover limited tasks in a person's home, rather than allowing them to do other things like going out or getting to work. Again, the amount of direct payment received and what you spend it on varies according to where you live. We will explore some of the issues surrounding these decisions.

***For more information about these research findings,
please visit the website.***

Independent Living or Something Else?

*Understanding national & regional policy
developments in direct payments*

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Developing direct payments

- Long-standing campaign by disabled people
- Initial resistance by Conservative government
- Developing a 'mixed economy of care'
- Community Care (Direct Payments) Act – enabling legislation
- Policy change from devolved administrations – the shift to mandatory implementation & widening user access

Policy differences across the UK

- Policy development led by England & Department of Health

‘The assumption should not only will care be delivered by a direct payment; the assumption should be that the person can manage a direct payment & the only times when care should be delivered, in my view, other than by a direct payment, is when the individual themselves has made a personal & positive choice to receive the care directly & not via a direct payment.

Stephen Ladyman speaking in 2003

- Similar enthusiasm yet to emerge from ministers elsewhere in the UK
- Widening access to new user groups
- Re-inventing policy?: The importance of making payments mandatory

Exploring take-up across the UK

Country/province	Population	% LTID	2000/01: number & rate per thousand people with LTID	2002/03: 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)

- Early take-up showing a 'north-south' – significant regional differences
- Approx twice as many users in England relative to population
- Key factors impacting on take-up:
 - political control
 - Disability activism & the development of support organisations
 - The role of practitioners in promoting policy

Political control

- Conservative authorities more likely to develop DPs than traditional Labour heartlands
- Direct payments & the marketisation of social care
- Highest numbers of users tend to be in Conservative authorities

Disability activism

- Central to partnerships with LAs in developing direct payments – early schemes in Hampshire, Derbyshire, Essex & Edinburgh
- But not enough without LA support
- Areas of limited activism = low take-up:
 - Northern Ireland: lack of ‘ownership’ of policy
 - Wales: Only 1 LA reported working in partnership with a group of disabled people

Independent Living

- Take-up encouraged by up to 80% through presence of a support organisation – user-led role as central
- Geographically dispersed populations – difficult to establish user-led support organisations or for them to take on work involved
- Challenges to the user-led approach – a developing ‘support market’ – threats to CILs & other smaller groups particularly in England

The role of practitioners

- Gatekeepers to direct payments
- Assessment decisions – independent living or something else?
- Developing designated posts – mainstreaming direct payments as a service option

Training & publicity

- Training & publicity roles as critical but highly variable across the UK
- Where designated staff were in place, more comprehensive training
- In other areas restricted to one-off events & adhoc information drives
- Information leaflets & frontline staff most common sources of information for potential users
- Some examples of outreach work

Concerns about over-publicising direct payments

- Impact on budgets – revealing ‘hidden demand’
- Concern over jobs – ‘backdoor privatisation’
- Trade union resistance – pay & conditions for personal assistants + the role of disabled people as employer
- Loosing control
- ‘Willing & able’

Extending direct payments to 'new' user groups

- Significant changes to user access since 1997
 - Removal of upper age limit
 - Extension to parents/guardians of disabled children
 - Extension to 16 & 17 year olds
 - Extension to 'carers' (*not Scotland*)

- Access still poor for key groups: persons with mental health problems, persons from black & minority ethnic groups – across the UK
- Persons with learning difficulties – Northern Ireland
- Importance of development funding from DofH in England for outreach work with older people, children, young disabled people, people with learning difficulties, users of mental health services & persons from black & minority ethnic communities
- No additional targeted monies made available elsewhere in the UK

Payment re-launch: *Changing directions from 2006*

- Shift to mandatory implementation – forced many local authorities/health trusts to consider DPs as a service option for the 1st time
- Limited knowledge of role of disability activism in campaign for DPs – Scotland
- Lack activism & historical ‘ownership’ of policy in Northern Ireland prior to 2003

Are direct payments promoting independent living?

- Examples of payments used to buy in agency services, as a short-term measures to fill-in service gaps & as an alternative budget option.
- Negating personal assistance role
- Block versus spot purchasing
- Concern that direct payments are unveiling 'hidden demand'

Limiting the boundaries of 'independent living'

- Poor publicity – concerns over widened access
- Relaxation of employment of relatives
- Redefining 'independent living' – lodged within service modes which pre-date DPs & have limited input from disabled people themselves
- DPs and support organisations – implications for CILs & user-led approaches

Moving on from direct payments?

- Shifts towards individualised budgets & personalised care
- Taking forward policy agendas to support independent living? *E.g. Improving the Life Chances of Disabled People*

Conclusions

- Take-up of direct payments across the UK is highly varied & reflects a number of factors:
 - Political control – level of support from devolved & local governments
 - The role of disability activism – supporting roles, future threats
 - The role of practitioners – the importance of ‘local champions’ of policy *versus* structural resistance

- Independent living or marketised social care?
- **Future payment patterns?**
 - Devolved responses to facilitating independent living