

'Direct Payments' for Personal Assistants for Disabled People: a key to independent living?

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Introduction

This presentation will discuss the thinking behind the development of 'direct payment' type Schemes for personal assistants (PAs) for disabled people in the UK, and their relationship to the concept of independent living from the perspective of the disabled people's movement.

Attention will then centre on the British Government's policy on direct payments since the 1980s, followed by an examination of the current situation in terms of the distribution, accessibility and support for such schemes at the local level.

It will be suggested that direct payment type schemes are a key element in the quest for meaningful independent living and that further amendments to present policies are needed if this is to become a reality for disabled people, their families and society as a whole.

Independent Living

The phrase ‘independent living’ first entered the English language in the 1970s following its adoption by disability activists in the USA. What became known as the American ‘Independent Living Movement’ (ILM) emerged partly from within the campus culture of American universities and partly

from repeated efforts by American disability activists to influence US disability legislation? During the 1960s, some American universities had introduced various self-help programmes to enable students with 'severe' physical impairments to attend mainstream courses. However, these schemes were rarely available outside university campuses. This unacceptable situation prompted some disabled students to develop their own services under the banner of 'Centres for Independent Living' (CILs).

Unlike other services *for* disabled people controlled by mainly non-disabled professionals, CILs were self-help organisations exclusively run and controlled by disabled people themselves.

Traditional professionally dominated provision focused almost exclusively on medical treatments and therapies within institutional settings that effectively removed disabled people from everyday life. In contrast, CILs provided a new and innovative range of services and support designed to empower people with impairments to adopt a lifestyle of their own choosing within, rather than apart from, the local community.

Subsequently the phrase 'independent living' has had a considerable impact on disability policy throughout the world. Disabled people and representative organisations are increasingly involved in the development of disability policy at both the national and international level. In addition,

there are now CILs or similar user controlled organisations providing services and support for disabled people and their families throughout Britain and many countries across the globe.

Part of the reason for this apparent and unprecedented success is the almost universal appeal of the concept of 'independent living' within western culture. It is apolitical in the sense that it appeals directly to advocates of the politics of the right and of the left, and it is political in that the environmental and cultural changes needed to facilitate meaningful 'independent living' for disabled people will benefit everyone regardless of impairment or status.

Despite terminological differences, there is general agreement amongst disabled activists and their allies that the philosophy of 'independent living' is founded on four basic assumptions. These include:

- 1) that all human life, regardless of the nature, complexity and/or severity of impairment is of equal worth;
- 2) that anyone whatever the nature, complexity and/or severity of their impairment has the capacity to make choices and should be enabled to make those choices;
- 3) that people who are disabled by societal responses to any form of accredited impairment – physical, sensory or cognitive –

have the right to exercise control over their lives; and

4) that people with perceived impairments and labelled 'disabled' have the right to participate fully in all areas, economic, political and cultural, of mainstream community living on a par with non-disabled peers.

Independent Living Services

During the 1970s disabled activists in the UK developed a range of user led services to enable people with impairments achieve an independent lifestyle.

Early examples include:

- peer counselling services and user led 'care attendant' or personal assistant schemes pioneered by the Spinal Injuries Association (SIA);
- integrated housing schemes and telephone Disability Information and Advice Line (DIAL) services by disabled activists in Derbyshire; and,
- what are now generally referred to as, direct payment schemes by a group of disabled residents living in the Le Court Residential Cheshire Home at Liss in Hampshire.

In 1979, the Le Court residents initiated and developed a 'Consumer Directed Housing and Care' programme later known as 'Project 81'. After three years of intensive discussions with their County Council and support from key managers, an innovative arrangement of 'indirect payments' was agreed.

It allowed local authority funding of an individual's institutional 'care', subject to an assessment, with individual cash payments in lieu of the institutional services received. The money was paid into a trust fund (with a local authority or voluntary organisation) on behalf of the user and was used for personal assistance to enable the disabled person to live in the community.

The 'Project 81' group was also responsible for setting up the Hampshire Centre for Independent Living (HCIL) in 1985. It was a user-led organisation committed to the principle that services should be available to disabled people, regardless of their impairment, social and cultural background. User-control was regarded as crucial to developing disabled people's individual and collective expertise in promoting independent living.

The growth of local action in the late 1970s also led to the formation of the Derbyshire Coalition of Disabled People (DCODP) in 1981. Four years later the Derbyshire Centre for Integrated Living (DCIL) was established and identified 'seven needs for independent living':

- Information (know what options exist)
- Peer counselling and support (for encouragement and guidance by other disabled people)
- Housing (appropriate place to live)
- Technical aids and equipment (to generate more self-reliance)
- Personal assistance (controlled by the disabled person/employer)
- Transport (mobility options)
- Access (to the built environment)

These 'seven needs' provided an 'operational framework' for DCIL. This stage-like scheme drew on the collective experience of the disabled people's movement and their struggles to achieve an independent lifestyle in the community outside the confines of a residential institution or dependence on family and friends.

Once meaningful progress was made towards satisfying these support needs, other 'secondary' needs arose in order to enable the disabled person to participate fully in wider society. Hence, in 1989, HCIL added four more areas:

- employment,
- education and training,
- income and benefits,
- advocacy.

Direct payments

However, for many disabled people the key to an independent lifestyle revolves around 'direct payments'. This is a generic term that refers to a range of options that give people who use 'community care' type services cash to buy the support they need. This support may include:

- **Personal services:** may include help with getting up, using the toilet, bathing, dressing eating etc.,
- **Domestic services:** cleaning, washing, shopping and looking after children and so on,
- **Social services:** helping with work, visiting friends, going to the cinema, going to the pub and other leisure activities.

Direct payments can also be used to buy technical aids and equipment.

In short, unlike other traditional professionally led support, direct payment type schemes provide the

disabled person with optimum control over the support needed to live independently within the community.

By giving the disabled person greater choice and control, direct payment type schemes:

- enhance the disabled person's self esteem and self confidence
- allows and encourages the development of more innovative, flexible and personalized support systems and services
- alleviates the pressure on family members and other 'informal carers' who are often held responsible for supporting disabled individuals in the community
- provides the disabled individual with more opportunities to participate fully in the economic and social life of the community.

In sum, when properly implemented the development of direct payment type services improve significantly the quality of life of the disabled individual, their families and the community as a whole.

Moreover, from the outset it was recognized that for disabled people to use direct payments effectively they need appropriate support services. This may

include help with advertising, recruitment, wages, management skills, employment law etc.

This is extremely important as many disabled people have never been employed themselves, and so the idea of employing a personal assistant is often especially daunting. Such services were pioneered by CILs and other local organisations run and controlled by disabled people throughout Britain during the 1980s and 90s.

By 2000 there were over 80 organisations controlled and run by disabled people providing a range of independent living services in the UK; over half providing various direct payment support services.

Disabled people's campaign for the legalisation of direct payments gathered momentum throughout the 1980s, supported by research commissioned by the British Council of Disabled People (BCODP) and Help the Aged, and the establishment of the Direct Payments Technical Advisory Group.

This was necessary because although some forward thinking local authorities had begun to provide direct payments in the 1980s and early 90s, they were technically illegal under the 1948 National Assistance Act.

The campaign led to the setting up of the Independent Living Fund (ILF) in 1987/8. Established to enable what was envisaged by

government, to be a small number of disabled people to apply for direct payments over a five-year period, the ILF proved extremely popular. The number of applications and the funds awarded went far beyond government expectations.

Consequently, in 1992 the Government curtailed the activities of the ILF. Thereafter, applications for ILF funding had to be sanctioned by local authorities. Cash payments by local authorities for disability related services did not become legal until the passing of the 1996 Community Care (Direct Payments) Act.

But most local authorities continued to be reluctant to offer Direct payments to service users, favouring instead traditional professionally led services. Hence, the numbers of people offered this option remained extremely small.

In the first five years after the 1996 Act, there were still some places where no-one at all was using direct payments. In other areas, the numbers were growing very quickly.

The places where direct payments were most successful were those that had support services led by disabled people.

However, the last decade has witnessed something of a sea change in government attitudes toward independent Living and Direct Payments. Subsequent legislative amendments such as the

2000 Carers and Disabled Children Act, 2002 Community Care and Health (Scotland) Act, extended this provision to other service user groups such as parents of disabled children, disabled young people under eighteen, and those over retirement age.

In addition, in April 2003, it became mandatory for local authorities to offer direct payments to all applicants for disability related services.

However, recent government estimates suggest that although approximately 1.46 million people received community based support during the year 2003/4 in England alone, 4 percent more than in the previous year, only 17,300 adults aged 18 and over were in receipt of direct payments. And there are proportionately fewer service users accessing direct payments in Northern Ireland, Wales and Scotland

The current situation

Recent research on direct payments indicates that:

- ***Most UK local authorities now have staff members specifically responsible for direct payments.***

Most English local authorities employ a full-staff member who is responsible for taking direct payments forward in their locale. In other parts of the UK, this is often someone responsible for other services too, or an individual employed on a part

time basis. This has meant that English authorities have had more time and resources to develop direct payments.

- ***Some authorities set targets for direct payments and this has increased the numbers of people using them.***

After 2003-2004, local authorities were required to offer direct payments to disabled people when they carried out a general 'community care' assessment of need. The Government also gave targets to the English local authorities for the number of people who should be using direct payments.

These changes made a big difference and many authorities started to develop direct payments properly for the first time. However, some local authorities, particularly in Scotland and Wales, were strongly against the idea of being set targets by the Government.

- ***Government guidance on the implementation of direct payments is open to interpretation and is interpreted differently by different people in local authorities.***

Many local authority staff maintain it is difficult to understand exactly what people may use direct payments for. Others claim that it is difficult to provide direct payments and keep their 'duty of care' to disabled people.

The question of disabled people's competence to manage direct payments is often raised as a barrier to implementation.

This has particular implications for disabled people labelled with 'learning difficulties' and/or mental health systems users and survivors.

In some authorities, staff are unsure how direct payments will work with children and young people. In Northern Ireland, most of the local Trusts had very little knowledge about how direct payments policies work.

Some authorities contend that they are unable to sanction personal assistants in the same way that they do with their own staff.

- ***In some areas there is a shortage of people willing to work as personal assistants***

There is a shortage of personal assistants in some areas but not others. For example, half of the Welsh authorities had some problems in recruiting staff for all of the disabled people who wanted them.

It can be hard to recruit personal assistants in some areas that are rural or have an ageing population. It can be difficult to recruit people when there are new local jobs available from large employers like supermarkets or call centres.

It can be difficult to find personal assistants to work for disabled people when the number of hours is very small or they need short visits in the evening.

Many disabled people employ people they know, but some local authorities are cautious about people employing relatives and friends.

- ***Local authorities have different rules about how disabled people can spend their direct payments.***

Some authorities will allow disabled people to use direct payments to pay for holiday accommodation, leisure activities, trips abroad and mobile phones.

Others will only allow disabled people to use direct payments for practical help with their 'personal care'.

The outcomes for disabled people are different in different places and this often depends on the decisions of local authority staff.

- ***The law allows local authorities to means test 'community care' services, hence, direct payments users are often charged for running their own support system.***

Charging policies are not consistent across the UK. It is therefore a postcode lottery whether a disabled person will be charged for choosing the direct payment option.

This acts as a major disincentive for some sections of the disabled population, notably older people, when applying for cash for personal assistant services.

- ***Although the Government has endorsed the wider use of direct payments, they have not provided additional funding to put policy into practice.***

A concern amongst many local authorities is that if more people take direct payments there will be less money for other services like day centres or respite 'care' facilities.

Large sums of money are often invested in block contracts for existing services; consequently, they maintain they are unable to re-direct funding into the development of direct payments type options.

- ***Despite Government commitments to ensure that each local authority has a CIL type organisation by the year 2010, local support organisations are closing at an alarming rate.***

Decades of under funding and limited resources has meant that both local and national organisations run and controlled by disabled people are severely disadvantaged in the increasingly competitive market for local and national contracts for independent living and direct payment services.

Since direct payments became mandatory, many local authorities have developed their own support services. In addition, competition for local contracts to provide direct payments support services has intensified considerably. Local groups now have to compete with well-resourced national organisations and large charities.

The emphasis on compulsory competitive tendering and 'best value' by central government has resulted in many local authorities awarding direct payment support service contracts to national organisations and charities - the majority of which are not run and controlled by disabled people.

In 2005, less than a quarter of the English authorities could claim to have a user-led direct payment support scheme.

There is therefore the very real danger that without firm Government action, the link between the disabled people's movement: organisations controlled and run by disabled people, independent living and direct payments will be lost.

Independent living in an inclusive society

To facilitate greater user involvement in the development and delivery of services, people have to feel empowered. But empowerment cannot be imposed from above, it must be organic in that people must want to empower themselves.

With limited resources, severe under-investment and varying degrees of opposition from traditional service providers, the disabled people's movement and its member organisations have, by example, had a major impact on the way social services and support are delivered.

In so doing they have empowered thousands of disabled people across the UK. If this process is to continue it is essential that appropriate funding be made available to local organisations led, managed and controlled by disabled people, particularly in the process of delivery and infrastructure of direct payments, and freed of local authority regulation and control.

Sufficient resources must be made available to ensure that these organisations are able to develop initiatives that are sensitive and responsive to impairment, ethnic and cultural diversity within the disabled population at the local level.

Much of the rhetoric surrounding independent living revolves around enhancing individual 'choice' in provision. However, the main self-determination issue for disabled people is not simply about service delivery mechanisms, but about whether levels of resources are sufficient to deliver the required services.

All too often funding at the local level is insufficient to enable people to access the services needed to

live independently. This has to be resolved if meaningful independent living is to become a reality.

Furthermore, the concept of independent living encompasses the full range of human experience and rights. To attain a meaningful independent lifestyle disabled people need equal access to mainstream schools, jobs, transport, houses, public buildings, leisure etc. - all the things that non-disabled people take for granted.

Given the limited ambition of recent Government initiatives in this regard, little significant progress will be made without further changes. It must be recognised that these will have significant resource implications, as effective barrier removal cannot be achieved 'on the cheap'. These short-term costs must be offset against the long term gains of a barrier free environment in which socially created and imposed dependence is considerably reduced if not eliminated altogether.

Resources

For further information about the research upon which this presentation is based see:

The outputs from the ***Implementation of UK Direct Payments*** research project

<http://www.leeds.ac.uk/disability-studies/projects/ukdirectpayments.htm>

Barnes, C. and Mercer, G. 2006: ***Independent Futures: Creating User Led Disability Services in a Disabling Society***, Bristol: The Policy Press.

Barnes, C., Mercer, G. and Morgan, H. 2000: ***Creating Independent Futures: An Evaluation of Services Led by Disabled People. Stage One Report***. Leeds: The Disability Press (Also available on: www.leeds.ac.uk/disability-studies/archiveuk/index).

Barnes, C., Mercer, G. and Morgan, H. 2002: ***Creating Independent Futures: Conference Report***. Leeds: The Disability Press (Also available on: www.leeds.ac.uk/disability-studies/archiveuk/index).

Barnes, C., Morgan, H. and Mercer, G. 2001: ***Creating Independent Futures: An Evaluation of Services Led by Disabled People. Stage Three Report***. Leeds: The Disability Press (Also available on: www.leeds.ac.uk/disability-studies/archiveuk/index).

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