

# Direct Payments: Policy development across the UK (second draft)

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*[NB: draft work in progress – apologies for any inaccuracies – not for quotation without permission]*

## **Introduction**

Direct payments legislation across the UK was implemented in April 1997 in England, Wales and Scotland and a year later in Northern Ireland. The policy framework enabled local authorities and health and social service trusts to make cash payments to disabled people to purchase services on their own behalf rather than using those supplied and organised by the local authority. In order to qualify for a direct payment, an individual has to be assessed as requiring community care service. Access was initially restricted to persons between the ages of 18 and 65 (Department of Health, 1997/ National Assembly for Wales, 1997/Northern Ireland Order 1996 No. 1923/ Scottish Office, 1997), but has been increasingly extended to other groups. This paper details the initial policy development and outlines the key tensions and debates that have emerged through the legislative framework. Discussion includes an exploration of early campaigns by disability activists to secure change in their local areas and then moves to focus on amendments to the 1996 Act and findings from research studies. In doing this, commentary will focus both on broader themes and, where possible, those pertinent to each part of the UK.

## **Negotiating payments in the 1980s and early 1990s**

For the disability movement, implementation of direct payments has represented an important victory and the culmination of campaigning throughout the 1980s and early 1990s. The next section explores some of the activity prior to the emergence of direct payments on the statute. This begins by looking at the role of *indirect* payments in their various guises. Firstly, through the emergence of payments made through local alliances between disabled people and local authority planners and then through the development of Independent Living Fund (ILF) payments. Commentary then shifts to map the legislative path of direct payments and explore some of the key issues arising in the initial years of implementation through a focus on the research studies in this area.

## **Indirect routes: the development of local alliances**

Prior to the 1996 Act, confusion surrounded the legality of direct payments across the UK. Whereas under the 1948 Social Security Act in England and Wales, it was stipulated that a local authority could only provide services – not cash payments, the position differed slightly in Scotland. Indeed, provisions were made through the Social Work (Scotland) Act 1968, for local authorities to ‘give cash to...any person aged 18 or over who is in need, within the meaning of the Act, and requiring assistance in exceptional circumstances an emergency and where to do so would be more cost effective’ (Written answer from Lord Lindsay, Minister for Scotland, House of Lords, 25 January, cited in Rolls, 1996). However prior to the 1996 Act, the impact of this ruling was limited, with little knowledge of the ruling amongst local

authority planners (C Pearson, 2000) and only one local authority justifying payments through this route (Witcher *et al*, 2000).

During the 1980s and early 1990s, several areas sought to overcome the legal restrictions by administering payments *indirectly* to disabled people through a third party voluntary sector organisation or an independent trust in the area. These schemes were largely found in England with authorities such as Norfolk, Essex and Hampshire working with local disabled people to enable payments to be made. The only example of this type of approach in Scotland was set up in Lothian<sup>1</sup>; no similar moves were developed in Northern Ireland and Wales. Central to these schemes was the role of local disability activists who worked together with local authority planners sympathetic to the values of independent living promoted by the disability movement.

One of these first schemes was developed in Hampshire where a small group of disabled people persuaded the local authority to allow them to live independently by paying for personal assistance with money previously set aside to fund their residential care (Zarb and Nadash, 1994). It was agreed that the money could be allocated to the residential care home, which in turn, made payments available directly to each individual on behalf of the local authority. Whilst individual support for cash payments rested on the enhanced control and independence secured by employing personal assistants, the local authority's co-operation focused on the potential for a new 'marketised' model of service delivery offered by the change. Hence, it was the promotion of consumer markets, individual 'choice' and 'cost efficiency' enabled through cash rather than service provision that appealed to the Conservative-led authority (Priestley, 1999).

As Evans and Hasler (1996) note, throughout this time development of these type of indirect payments was slow, with only a few areas adopting the approach. Most areas were not keen to take on the scheme because they considered them either too risky or were wary of handing over control to disabled people. Consequently, where payments did emerge, the rationale for change strongly reflected collective negotiation and lobbying from disabled people and local authority planning views on service delivery where Conservative run administrations were keen to produce a more market-based approach. This established a concentration of schemes largely in southern English authorities where Conservative councils were more prominent.

### **Indirect routes: pursuing cash payments from the Centre**

Although at this time local disability activism proved to be an important factor in establishing initial indirect payment routes, other examples of cash payments for personal assistance were also in evidence. These originated from wider changes implemented by central government amidst a reorganisation of social security support for disabled people and the development of community care from the late 1980s (see Glendinning, 1992; Berthoud, 1998). Following implementation of the 1986 Social Security Act, the Independent Living Fund (ILF) was launched by the Conservative Government. This was set up with some co-operation with the Disability Income Group (DIG) in 1988 to compensate for the loss of additional domestic payments made to disabled people. The shift also came in response to concerns that the removal of the additional domestic assistance payments would result in some disabled people

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<sup>1</sup> This region was later disbanded amid local authority reorganisation in 1996.

being forced to enter residential care – an outcome that clearly conflicted with the push towards ‘care in the community’ being promoted at the time.

The launch of the ILF was only initially seen as a temporary measure to cover gaps prior to implementation of Community Care legislation in April 1993. However, its importance was perhaps more symbolic, in that it represented the first large scale opportunity for disabled people to use cash to meet their support needs, rather than relying on services provided by local authorities or families (Zarb and Nadash, 1994).

At the time of its introduction, the ILF attracted criticism from a number of disability groups and opposition MPs, angered by the replacement of legal entitlements to benefits with discretionary awards from a charity (Wood, 1991). Indeed, use of the term ‘independent living’ in this context was in itself questionable in that ILF was being brought in amid the broader shift to community care. From this stance, the principles of community care with its focus on ‘professional assessment’ were seen as incompatible with social model goals of choice and control over *who* and *how* support for disabled people is provided (Hasler *et al*, 1999). Indeed, writers such as Kestenbaum (1996) have emphasised the differences in interpretation around the concept of ‘independent living’ when promoted through community care policy. She argues that in focusing on the shift from institution to community, the provisions of equipment and adaptations or the employment of personal assistants, the power shift from service provider to the disabled person is not necessarily achieved. As a result, this serves to:

conceal the fact that there are some fundamental differences of view between disabled people and those who seek to ‘care’ for them.

Kestenbaum (1996, p.2)

However, implementation of the ILF proved to be remarkably successful and highlighted a number of benefits for users (Kestenbaum, 1992). As Zarb and Nadash (1994) note, although it was initially estimated that there would only be around 300 new awards per year (with a maximum of 1250 overall), these forecasts were soon overtaken by demand. Within the first year in 1989/90, applications were already being received at a rate of 900 per month and by November 1992, had risen to 2000 per month. The pattern across the UK for ILF users was particularly stark, with Northern Ireland showing a disproportionately high number of users (see Kestenbaum, 1995 for full breakdown of figures).

The experiences of persons using the ILF demonstrated that providing cash for people to organise their own support arrangements offered more choice, control and flexibility than direct service provision (Zarb and Nadash, 1994; Kestenbaum, 1993; Oliver and Zarb, 1992). Hence as a result of the ILF’s popularity, government plans to close the fund were reconsidered, and it was replaced with two – albeit much more restrictive - new charitable trusts. Existing users continued to receive payments through the Independent Living (Extension) Fund and the Independent Living Fund 1993 (ILF’93) was run alongside services provided or purchased by local authorities. This established a closer link between the ILF and local authority social service provision and was therefore intended to reinforce the key role given to local authorities in the implementation of the 1990 community care changes from April 1993.

Since its revision in 1993, the ILF' 93 has been primarily used to top-up local authority services to people living in their own homes where the services would otherwise exceed the cost of residential care. Although some features of the revised fund are similar to its predecessor, there are important differences which, in turn, dramatically impacted on user take-up. These included a shift in administration of the budget from the central fund to local authorities and a much more restrictive eligibility criteria (see Kestenbaum, 1995 for more details), which required users to be in receipt of services worth £200 per week and excludes new applicants over the age of 65. Whilst this framework kept the broad principles of cash payments in place, the new limitations meant that by 1994 fewer than 200 people in the UK were benefiting from payments and the national budget of £4 million was under spent (King, 1994).

Alongside the new ILF framework, a new allocation of money – the Independent Living Transfer (ILT) was made available to local authorities for a three-year period. This was a specific sum of money issued ahead of the implementation of community care and transition to the ILF'93 fund. In this context, its importance rested in its unique potential for raising the profile of independent living within social service departments/health and social service boards and for promoting more appropriate policies for services to disabled people (Kestenbaum, 1995).

Given the ILT's specific focus on restructuring services, DIG commissioned research to explore how this money was used by local authorities and whether, in fact, it had initiated a change in service delivery for disabled people (see Kestenbaum, 1995). As the title of the research - 'An opportunity lost?' - suggests the full potential for developing services based on the principles of independent living was not realised and considerable differences in approaches were identified across the UK. This saw a concerted effort to develop indirect payment schemes in English authorities such as Avon, Leicestershire, Merton, Norfolk, Nottinghamshire and Wiltshire. Other areas such as Birmingham, Essex, Kent and Sheffield also set up personal assistance pilots at this time. Likewise in Scotland, two local authorities – the former regional councils of Lothian and Strathclyde – also each allocated funds to indirect payment schemes. In the case of Lothian, funds were to extend the existing scheme, whereas in Strathclyde, a new structure was put in place.

Elsewhere in the UK local planners were, however, less innovative. In Northern Ireland, Kestenbaum found that monies had largely not been spent on their intended purposes. No indirect payment, personal assistance pilots or other intended aspect of independent living support was set up as a result of the ILT. Indeed, she highlights examples where funds were used for the development of a new day care centre. Similarly, no attempt to develop indirect payments in Wales were made, although at the time of Kestenbaum's research, three local authorities were looking into this option and other 'independent living options' were being considered (Kestenbaum, 1996, p. 22).

At this time, therefore, the emergence of indirect payment approaches through the ILF frameworks, the ILT and those instigated through agreements between disability activists and local planners, differed mainly through their funding sources. As discussed, ILF and ILT monies were allocated from central government to local authorities and were intended as a short-term measure to support the transition to

community care, whereas earlier indirect payments in areas like Hampshire, required payments to be made from existing local authority service budgets. Hence indirect payments made through the second route meant that local authorities were perhaps more prepared to take a 'risk' in allocating their own funds to users, whereas ILF monies were funded by central government. As such, local authorities could access an entirely separate pool of funding from their locally run services. However, despite these differences, the role of disability activists working *with* planners also needs to be highlighted as an important factor in the development of both frameworks. As Kestenbaum observed from her study findings:

The design of a personal assistance scheme requires the involvement of local disabled people and sometimes a lengthy period to develop proposals that fit local circumstances.

Kestenbaum (1995, p. 59)

### **Moving towards direct payments**

As stated, the dramatic reduction in the number of new ILF users with the shift to the '93 fund meant that the momentum for UK wide uptake of cash payments had lessened once again. Elsewhere, it was becoming apparent that the political affiliation of local authorities together with the campaigning role of local disabled people was a significant relationship in the establishment of indirect payment schemes. In contrast to Hampshire, where a working allegiance between political actors and disabled people was made, elsewhere these partnerships have been less easy to facilitate. For example, Priestley's (1999) work on developments in Derbyshire illustrates how conflict between user and planning positions could delay or impede progress. In this case, despite a public commitment by the local authority to the social model principles of integrated living from the early 1980s, open resistance emerged against proposals to replace existing public sector provision with integrated living networks controlled by disabled people. As in Hampshire, the link between Conservative members of the council who favoured a more consumerist framework of support services, and disability activists, proved to be a more sympathetic alliance to proposed changes than the then majority Labour controlled authority.

In other parts of the UK, progress with indirect payments remained patchy. In Scotland, Zarb and Nadash (1994) reported that 64 per cent of local authorities<sup>2</sup> were making cash payments at this time. This placed Scotland third in Britain, behind Greater London and the South of England, in terms of local authority availability of direct payments. As stated earlier in this paper, only one local authority at this time made payments through the provisions of the 1968 Act. As Witcher *et al* (2000) found in their study, there appeared to be widespread confusion within local authorities both as to the *availability* of payments and the *type* of approach offered. However, from Witcher *et al*'s study, it would appear that most payments made in Scotland prior to the 1996 Act were organised through the ILF. In Northern Ireland, progress was especially poor. Whilst a number of people employed their own staff using money from the ILF, there did not appear to be any significant demand from disabled people to extend payments more widely (NICOD, 1999). This will be returned to shortly.

### **Details to be added for Wales.**

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<sup>2</sup> The response rate for this survey was 64 per cent (see Zarb and Nadash, 1994, p. 27).

Therefore, by the mid-1990s the disability movement was becoming increasingly frustrated with restricted access to ILF. Furthermore, the position with regards to indirect payments made by local authorities was looking increasingly precarious and a number of legal challenges were put in place as the Department of Social Security took action over indirect payments being made by local authorities. Whilst cases were won, the actions raised the profile of these type of cash payments, thereby instigating the need for a more formal legislative path to be developed. Moreover, the DSS action provoked widespread concern over the legality of this type of arrangement in other areas, causing many to suspend development of their own schemes.

### **Policy on the statute: the 1996 Act**

As detailed in an earlier article (see C Pearson, 2000), prior to securing direct payments on the statute, a number of issues were outlined as to why policy would *not* be formally adopted by the Conservative Government. These centred strongly on ‘cost efficiency’ and ‘accountability’ of public spending together with wider concerns that personal assistants might exploit or abuse disabled people (Campbell, 1996). Despite the initial failure to secure parliamentary backing, it was clear that a significant growth in support was emerging as groups such as the Association of Directors of Social Services (ADSS) added their weight to the campaign (see Glasby and Littlechild, 2002). At the same time, the BCODP contracted the Policy Studies Institute to carry out research to highlight the cost implications of and effectiveness of direct payments (see Zarb and Nadash, 1994). Findings showed much higher levels of satisfaction for direct payments users and critically, for a government focused on issues of cost efficiency, the study found that support financed by payments was on average between 30 and 40 per cent cheaper than equivalent service-based provision. In emphasising these issues, the research became an important base to challenge the government’s position. Indeed, a week after its publication, it was announced that legislation for direct payments would emerge in the following session of parliament (see Glasby and Littlechild, 2002 for more details).

The Department of Health introduced a consultation paper in January 1996 on its proposals for direct payments (Department of Health/Scottish Office/Welsh Office/Northern Ireland Office, 1996). Alongside setting out how direct payments would operate, the consultation paper sought views on a number of key issues to be contained within the regulations and guidance (Glasby and Littlechild, 2002). This centred on a view that recipients should be ‘willing’ to receive payments instead of services and ‘able’ to manage them (Department of Health/Scottish Office/Welsh Office/Northern Ireland Office, 1996, p. 3). As a result of this stipulation, the Direct Payments Bill gave the Secretary of State powers to specify which groups of people would be able to receive a direct payment. These were defined in the following six categories as:

- (1) Adults who have physical impairments (including people with sensory impairments), who are under the age of 65 and are willing and able to manage direct payments (with help if necessary). This does not exclude people with both a physical impairment and another condition (such as learning disability [sic]). Those aged 65 or over who began to receive direct payments before age 65 could continue to do so after that age.

- (2) All disabled adults under the age of 65 who are willing and able to manage direct payments (with help if necessary). Those aged 65 or over who began to receive direct payments before age 65 could continue to do so after that age.
- (3) All adults under the age of 65 who are willing and able to manage direct payments (with help if necessary). Those aged 65 or over who began to receive direct payments before age 65 could continue to do so after that age.
- (4) All adults with physical impairments (including people with sensory impairments) who are able and willing to manage direct payments (with help if necessary), with no age limit. This does not exclude people who have both a physical impairment and another condition (such as learning disability [sic]).
- (5) All disabled adults who are able and willing to manage direct payments (with help if necessary), with no age limit.
- (6) All adults who are able and willing to manage direct payments (with help if necessary), with no age limit.

(Department of Health/Scottish Office/Welsh Office/Northern Ireland Office, 1996, p. 4-5).

From these categories, the consultation paper emphasised a preference to limit direct payments to the first group – persons with physical impairments under the age of 65. Yet as Glasby and Littlechild (2002) note, the government was particularly keen to consult on whether or not people over 65 with learning difficulties should be eligible for direct payments if they were willing and able to manage them (Department of Health/Scottish Office/Welsh Office/Northern Ireland Office, 1996, p. 4-5). In this context, it was emphasised that the inclusion of other groups could be developed at a later stage, but at the outset it was considered necessary to restrict the number of users. However, on-going lobbying by groups such as Values into Action meant that when the 1996 Community Care (Direct Payments) Act was finally passed, the policy framework included persons with learning difficulties alongside persons with physical and sensory impairments under the age of 65.

Also considered within the consultation paper was a restriction on using direct payments to employ partners or close relatives. This was justified by a desire to prevent existing informal care arrangements from becoming too formalised, to prevent the risk of exploitation and to prevent family members from feeling under pressure to become full-time carers (Glasby and Littlechild, 2002). However, it is likely that the costs of payment for informal care - which had been strongly promoted in the original 1990 NHS and Community Care Act - acted as the main check to this area of policy development. But as discussion later in this paper indicates, the inclusion of a wider range of users and carers (currently in England, Wales and soon to be implemented in Northern Ireland) has been an important pattern in more recent legislative changes.

The original policy guidance for direct payments (Department of Health, 1997/ National Assembly for Wales, 1997/Northern Ireland Order 1996 No. 1923/ Scottish Office, 1997) set out the framework for policy implementation. Central to its structure was its position as *enabling* legislation – presenting local authorities with the option

to allocate direct payments or maintain existing modes of service provision. As C Pearson (2000) argues, the policy model for direct payments fitted in with wider shifts to locality planning of services across the spectrum of social policy and more specifically through the promotion of 'local care markets' in the 1990 NHS and Community Care Act.

In allowing local authorities the choice as to whether they should develop direct payments or not, they retained discretion in a number of areas. These are listed by Glasby and Littlechild (2002) and cover the following issues:

- Whether or not to implement direct payments.
- For which services (if any) payments are available.
- Whether to arrange some services for users as well as making payments.
- Whether or not to offer someone a direct payment.
- How much flexibility individual recipients have over the way the money is spent.
- How much of a payment to make and what it is supposed to cover.

However, guidance stated that local authorities should not treat direct payment users any more or less favourably than persons receiving services and should therefore only be given to those assessed as needing community care services.

### **Changes since 1997**

Since implementation of direct payments in April 1997 in England, Wales and Scotland and a year later in Northern Ireland, a number of changes have been made to the original policy framework. This began in 1998 with publication in England and Wales of the White Paper, *Modernising Social Services* (Department of Health, 1998). This removed the upper age limit of 65 for direct payment users by permitting local authorities to offer schemes to older people. Similar changes were made in Scotland and Northern Ireland (SI 2000/183; SI 2000/1868 (W127); SR 2000/114).

Inclusion of older people was followed by the publication of new policy and practice guidance in England and Wales (Department of Health, 1999/2000a). Although the guidance was broadly similar to its predecessor, there were a number of key changes which seemed to indicate the government's intention to increase the availability of direct payments and to ensure that particular groups of service users were not excluded (Glasby and Littlechild, 2002). This included a specific focus on different types of impairment – notably persons with learning difficulties and sensory impairments, together with access to black and ethnic minority communities and different age groups (Department of Health, 2000a, p. 3). Furthermore, when deciding whether or not to offer direct payments to an individual, it was emphasised that local authorities should consider each case on its merits and treat all adult user groups equally (Glasby and Littlechild, 2002).

The focus on extending direct payments to a wider user population has been addressed in a number of subsequent pieces of legislation which have, in turn, instigated a different pattern of user access across the UK. This was initially addressed in changes outlined in the Carers and Disabled Children Act 2000 (Department of Health, 2001a), which gave payment access to parents or guardians who look after disabled children (Department of Health, 2001b); 16 and 17 year olds (Department of Health, 2001b) and 'carers' aged 16 or over (Department of Health, 2001c). Change was

followed through the Health and Social Care Act 2001, which set out the shift to mandatory implementation of direct payments across England and Wales from April 2003. Revised policy guidance was published in September 2003.

Similar legislative changes have been considerably slower to emerge in Scotland (C Pearson, 2004a) and Northern Ireland although it is clear from directives that both administrations intend to promote policy and encourage payment access to a more diverse user population. The main focus of change in Scotland was set out in the Community Care and Health (Scotland) Act 2002 with revised policy and practice guidance published by the Executive in June 2003 (Scottish Executive, 2003). At the forefront of this was the enforcement of a mandatory duty placed on all local authorities to offer direct payments to all disabled persons requesting them from June 2003. By removing the enabling feature of legislation, planners across the country have been obliged to develop schemes and offer this type of service option to disabled people (C Pearson, 2004a). Changes also brought in in June 2003 allowed parents of disabled children to receive direct payments to purchase services their children need. Furthermore, the Act set out a clause whereby service users are now able to purchase their 'care' services from local authorities, as well as other independent sector providers. An additional change, accessing direct payments to all community care groups was also set out. This would mean that all persons assessed as having 'care needs' because for example they were frail, receiving rehabilitation after an accident or operation, fleeing domestic violence, are a refugee, homeless or are recovering from drug or alcohol dependency, will become eligible to be considered for direct payments (Direct Payments Scotland, 2002). It was initially intended that this change would be made in April 2004, however, the Scottish Executive has since announced that policy extension to these groups would be deferred until April 2005 and then implemented gradually after piloting changes (Scottish Executive Circular No. CCD1/2004). The delay reflected broad concern from local authorities and support organisations highlighted in research carried out for DPS (see Direct Payments Scotland, 2003b; C Pearson, 2003) as to their capacity to cope with new user groups as many areas struggle to provide payments to their current cohort of users (C Pearson, 2004a; C Pearson, 2004b). But given the clear indication by the Scottish Executive to diversify user access, it is likely that a different pattern of payment use from the rest of the UK will emerge over the next few years.

In Northern Ireland, changes to the 1996 Act have been laid out in the Carers and Direct Payments Act (Northern Ireland) 2002. Like England and Wales, this outlines the extension of policy to carers, parents or guardians of disabled children and 16 or 17 year old disabled persons. The Act does not cover mandatory enforcement of direct payments (as in England, Wales and Scotland) as this was set out as a requirement in the 1996 Act. At the time of writing (March 2004), planners in Northern Ireland were awaiting the results of a review of direct payments conducted by the EHSSB before issuing guidance to implement the 2002 Act.

#### **Promoting payments: encouraging awareness and developing support structures**

In seeking to promote take-up of direct payments, two key initiatives have been funded and promoted by the Department of Health and Scottish Executive. This reflects the clear statement of intent from New Labour to extend direct payments across social care (see Department of Health, 2000; Northern Ireland Executive, 2002; Scottish Executive) and utilise independent sector agencies in facilitating this role

(this will be explored in more detail later in this paper). As the following section outlines, to date government department led directives focus specifically on encouraging uptake in England and Scotland, rather than the UK as a whole.

In Scotland, the Scottish Executive has sought to address the poor take-up of direct payments since April 1997 (see Witcher *et al*, 2000) through a series of measures. Central to this was the allocation of a £530,000 grant in 2001 to set up the development project 'Direct Payments Scotland' (DPS) (see C Pearson, 2004a; C Pearson 2004b). The remit of the project is to:

- Increase awareness of direct payments amongst users, local authority staff and service providers.
- Establish and develop user-led support organisations.
- Identify training needs amongst key personnel (Direct Payments Scotland, 2002)

In recognition of the work carried out by DPS in promoting direct payments across the country, an additional grant of £650,000 has subsequently been allocated to the project to support work from 2003-2006.

A similar approach to develop policy awareness was announced by the Department of Health in October 2002 through its proposals for a Direct Payments Development Fund in England. The package of £9 million, made available over three years, has been targeted at developing support structures through partnerships between local authorities and voluntary agencies (Department of Health, 2003). In July 2003, the successful bids were announced and 45 organisations were allocated funds to develop projects.

In Northern Ireland, progress in encouraging the take-up of direct payments has been focused on a more localised approach, based largely on work by the Centre for Independent Living (CIL) in Belfast. Following a review of policy in April 2000 by the EHSSB (EHSSB, 2000), recommendations were put forward to establish a support structure for direct payments. This instigated formation of a CIL steering group who were invited by the Board to submit a proposal to develop a CIL in Belfast. The proposal was submitted in Summer 2000, agreement was given in the autumn, with the CIL opening in March 2001.

Following its launch, the CIL was contracted by the EHSSB to specifically promote and support the take-up of direct payments and to deliver training to staff working in the Eastern Board area. This includes the following roles:

- information, advice and advocacy relating to direct payments and personal assistance;
- training to assist direct payment users to be good employers;
- support for the development of local networking of direct payment users;
- information and training to care managers and others to ensure effective take-up of the direct payment scheme; and
- research other areas relating to independent living which require action (EHSSB, 2003).

In focusing the remit of the CIL almost exclusively on direct payments, Belfast's role in providing support differs from other CILs and user-controlled support organisations, which have tended to assume a more diverse approach in providing a range of independent living services (see Barnes *et al*, 2000). Moreover, the allocation of funding from the EHSSB, without additional monies from the other three health and social service boards or the Department of Health, Social Services and Public Safety (DHSSPS) once again underlines the highly localised approach to direct payments in Northern Ireland.

Following a successful evaluation of the CIL in December 2003, on-going funding for the service has been made available. At the present time, there are no plans to include the other Health and Social Service Trusts into this arrangement.

To date in Wales, there is no unified support strategy to encourage take-up.

Having outlined the current legislative framework for policy, a number of issues are raised relating to differential access and entitlement to direct payments across the UK. Indeed, it is clear that policy development has been led from the Department of Health in England. Since 1997, policy has consistently been implemented at a faster rate than the rest of the UK. However, in terms of coverage and access of direct payments, there remain important differences in the directions taken by policy makers across the UK. Discussion now shifts to outline some of the broader patterns in policy implementation as highlighted in research studies to date.

### **Direct payment implementation: issues from research studies**

Whilst early studies examining the impact of indirect and early direct payment schemes reported high user satisfaction (see for example, Kestenbaum, 1993; 1996; Zarb and Nadash, 1994; NICOD, 1999) and a degree of enthusiasm from participating local authorities in accessing payments, the overall pattern of policy take-up across the UK has been acutely uneven. In examining these trends, this section details some of the broader patterns highlighted in research studies to date. This begins by examining some of the key trends highlighted in research carried out in each country. Findings presented at this stage focus largely on work commissioned by government and related agencies, with some additional commentary. Overall, this maps a brief overview of early policy take-up in different parts of the UK from survey data. This is followed by a focus on other patterns highlighted in research studies, more specifically in relation to the dominant policy discourses which, in turn, have impacted on user access. Within the framework of existing research, these have tended to have been explored through a number of themes by impairment group, age, the role of professionals and support organisations, alongside limited discussion of other social divisions such as ethnicity and sexuality. To date, there is limited commentary available exploring the impact of gender and none in relation to class and direct payment access and use. Additional discussion also refers to research findings on direct payments from European countries.

Given the relative success of direct payments in England compared with the rest of the UK, it is perhaps unsurprising that most of the empirical studies have been carried out here. A more specific focus of finding in relation to key themes will be returned to later in this paper, but at this stage discussion will offer an overview of the main research carried out in English localities.

The first substantive audit of direct payments in England since implementation of the 1996 Act was carried out in 1998 when the Department of Health issued questionnaires to all 150 local authorities (Auld, 1999). As Glasby and Littlechild (2002) detail, 135 (90 per cent) of authorities responded and findings indicated that 68 (51 per cent) of areas had established direct payment schemes. This covered 1404 users, the majority of whom were people with physical impairments. From the remaining 67 authorities not operating schemes, 59 (88 per cent) indicated that they intended to do so in the short term. As with the earlier pattern of indirect payments, it was clear from this early stage that there was a clear regional pattern to up-take with the majority of direct payments offered in the south and the least in central and northern areas.

A year later in 1999, the Social Services Inspectorate (SSI) carried out a national programme of inspections to examine the promotion of independent living within local authorities (see Fruin, 2000). Ten councils were chosen by the inspection team – Brighton and Hove, Calderdale, Enfield, Lincolnshire, Herefordshire, Lincolnshire, Middlesbrough, Oxfordshire, Poole, Stockport and Westminster. The findings of the SSI report presented a disappointing picture of independent living services and direct payments. As Fruin (2000) reported, the highest number of users in any of the areas was twenty and inspectors were particularly critical of the limited progress, lack of information and absence of specialised services such as peer support, self-help groups and voluntary sector input.

Following on from the SSI report, the ADSS's 2000 survey (Jones, 2000) covered both local authorities in England and Wales. At this stage, 80 per cent of areas were found to have introduced direct payments, with the remaining 20 per cent having plans in place. As such, the survey concluded that the total availability of direct payments for users between the ages of 18 and 65 looks to be an 'achievable goal' in the short term (Jones, 2000).

The first major study of direct payments in Scotland was carried out by Witcher, Stalker, Roadburg and Jones (2000). This research was commissioned by the Scottish Executive and confirmed the limited availability of direct payments, with only 13 out of the 32 local authorities having fully operational or pilot schemes, and a total of 143 users in Scotland. Although more recent figures show the current number of users at 532 (Scottish Executive, 2003), take-up is considerably lower than in England. Findings from Witcher *et al's* (2000) study also highlighted the imbalance in impairment groups with 125 (87 per cent) of the total users, against 17 (12 per cent) with learning difficulties and no persons with mental health problems. Whilst this pattern replicates the broader picture of payment use across the UK, in Scotland the trend has been more acute. Indeed, a follow-up study commissioned by the Scottish Executive (Ridley and Jones, 2002) focusing specifically on why direct payment access had been denied to persons with mental health problems highlighted five main barriers. These centred on the inflexibility of community care assessments; a general lack of knowledge and understanding of direct payments; uncertainties about eligibility and anxieties about people's ability to manage.

Many of the barriers to developing direct payments in Scotland have also been picked up in discussion by C Pearson (2004a). She argues that resistance to widespread

policy development has focused on two main issues. This has centred primarily on an anti-market discourse, whereby direct payments have been viewed by some senior planners as part of a broader drive to privatise social care services. In addition, a second major problem – a pervading ignorance surrounding the principles of independent living in many social work departments – has prevented many staff from actively promoting policy to users.

Whilst resistance to direct payments in Scotland has been viewed by a number of local authorities as a means of social service privatisation, reasons for low policy take-up in Northern Ireland appear to be less driven by market or anti-market discourses. To date, the limited impact of direct payments since 1997 has inevitably meant that very little discussion of policy has been documented. However, some of the wider problems have been discussed informally with key informants and access has been gained to several key planning reports, from which a number of observations can be made at this stage.

As indicated so far in this paper, the take-up for direct payments in Northern Ireland is considerably lower than elsewhere in the UK. Furthermore, planning and policy development has been highly localised with the EHSSB taking the lead. This began in 1997 with the establishment of the ‘Direct Payments Steering Group’, which included key staff from the Health and Social Service Trusts, voluntary organisations and disabled people (EHSSB, 2003). In April 2000, the Board commissioned a review of direct payments, incorporating the views of users and policy awareness and attitudes from service staff (EHSSB, 2000). At this time there were only eleven users in the country, therefore it was perhaps unsurprising that findings highlighted a clear lack of information about policy from both staff and potential users. Interviews with staff indicated that nearly a third were not adequately informed about policy and a number of misconceptions as to access and eligibility prevailed amongst key personnel. Likewise, knowledge was especially poor amongst those working with people with learning difficulties and mental health problems. Although those receiving direct payments reported increased control and flexibility in their day to day lives (EHSSB, 2000), most indicated a lack of clear information about the scheme and wider aspects of independent living. Indeed, it was this aspect of the review which initiated the main recommendation from the Review – the development of an advice and support service for direct payments based on the approaches on other CILs within Britain (EHSSB, 2000). As previously mentioned, this became the starting point for the establishment of the CIL in Belfast.

Earlier discussion in this paper also highlighted the role of the Personal Assistance Support Project in establishing a role for direct payments in the Province. Since this time no empirical studies have been carried out on policy implementation, although at the time of writing the EHSSB are conducting a substantive review of direct payments ahead of implementation of changes set out in the Carers and Direct Payments (Northern Ireland) 2002 Act. This is due to report at the end of March 2004.

In Wales, an evaluation of the Independent Living Scheme (ILS) and the implementation of direct payments in Cardiff and Vale was carried out by Stainton and Boyce (2002). The research was completed over a two-year period from April 1999. At this time although the 1996 Act had been in place for two years, the impact of direct payments had been minimal in Wales. Cardiff and Vale was therefore chosen

for evaluation as it represented both the first and most fully developed scheme in Wales.

The project focused largely on the impact of the ILS and direct payments and reported high levels of satisfaction from disabled people using either scheme. Alongside the focus on increased user control and independence, Stainton and Boyce (2002) also highlighted the aspects of cost efficiency achieved through the shift. However, the report did highlight difficulties from the local authority in administering payments and the need for awareness training for social work staff. Moreover, it was clear at this stage that access was limited overwhelmingly to persons with physical impairments.

Having detailed some of the broader patterns of findings outlined from the wider body of research, discussion shifts to highlight some of the more detailed overviews. This begins by drawing on the categorisations used within the legislation and exploring research findings raised for the following groups: persons with physical and sensory impairments, persons with learning difficulties, persons with mental health problems, older people, persons with HIV/AIDS, and disabled children. Discussion then shifts to provide a more detailed overview of the impact of direct payments for users from black and minority ethnic communities and issues around sexuality. The paper concludes by focusing on the role of support for policy users and then moves to examine the international impact of direct payment and/or personal assistant support schemes.

### **Persons with physical and sensory impairments**

It is clear from the pattern of direct payment use across the UK that the largest group of users are persons with physical impairments. This is perhaps unsurprising given the historical development of policy and wider role of disability activism. Indeed, as earlier discussion indicates, in areas like Hampshire, Essex and Edinburgh, the impetus to offer cash payments came initially through the efforts of people with physical impairments dissatisfied with their service arrangements. Discussion has also shown that the initial agreement to develop policy from central government focused largely on supporting the needs of this group, often to the exclusion of other disabled people – notably persons with learning difficulties and mental health problems. Although revised guidance began to address this issue (this will be explored in the next section) the disproportionately higher take-up for persons with physical impairments has remained a dominant feature.

Indeed, this has been picked up in some of the research studies. Dawson (2000) in particular, highlights some of the wider problems with the structure of service planning which, in turn, has focused support on physical impairments. For example, she found that staff involved in direct payments planning came from physical impairment teams and often documentation was not sent to corresponding staff for other user groups. Likewise, she noted a widespread assumption from planning staff that persons with learning difficulties or mental health problems would be unable to cope with a direct payment. Again, this will be returned to in the next section.

Whilst the figures for direct payments (and other areas of support for disabled people) have combined the categories of physical impairment with sensory impairment, evidence from the research suggests that persons with sensory impairments have not secured widespread access to direct payments. Likewise, there is limited research

discussion in this area. However, commentators such as J Pearson and Sapey (2003) confirmed in their study that policy access for this group was indeed restricted. More specifically, this focused on the role of voluntary organisations as ‘gate-keepers’ to information and service change. As the main information point for many people with sensory impairments in the study, they were often excluded because organisations remained unconvinced of the suitability of direct payments.

### **Persons with learning difficulties**

Direct payment access for persons with learning difficulties has been met with a number of obstacles from the policy planning stages through to implementation across the UK. As indicated earlier in this chapter, this began during the debates for the Community Care (Direct Payment) Bill 1996, whereby attempts were made to exclude any users with learning difficulties. As a result of intense lobbying by groups such as ‘Values into Action’ and People First, this was overturned. Consequently, Department of Health guidance emphasised that local authorities should avoid blanket assumptions that assume whole groups of people are unable to manage direct payments (Department of Health, 1997a, 2000a). However, the clause stipulating that direct payments should only be offered to those ‘...able to manage them (alone or with assistance)’ (Department of Health, 1999, para. 19) has caused concern for many commentators writing in this area. Holman and Bewley (1999) for example, argue that many social service managers and social workers continue to have difficulty in visualising how people with learning difficulties could use a direct payment and therefore this type of clause is considered unhelpful in persuading local planners to widen payment access.

Efforts have been made in policy guidance to encourage take-up for this group. For example, in Scotland calls to widen access were outlined a national review of services for persons with learning difficulties in Scotland (Scottish Executive, 1999). This acknowledged a greater role for policy and stipulated that ‘by 2003, any one who wants a direct payment should be able to have them...’ (Scottish Executive, 1999, p. 24).

### **Persons with mental health problems**

It is clear from the pattern of users for direct payments that payment use for persons with mental health problems has remained marginal. As Glasby and Littlechild (2002) suggest, the neglect of mental health issues has been apparent since the outset of policy development. This began with the 1996 policy consultation paper, where no reference was made to the needs of people with mental health problems, aside from the exclusion of persons detained under mental health legislation. Specific attempts were also made to exclude all persons with mental health problems (Beresford, 1996) during the parliamentary debates. Publication of the 1997 policy and practice guidance across the UK also gave only limited references and failed to acknowledge any of the barriers that might be faced (Glasby and Littlechild, 2002). Revised guidance in 2000 and 2003 (Department of Health, 2000b, 2003) also failed to address any of the substantive issues.

Findings from Witcher *et al*’s (2000) study showed that there was only one person in Scotland with mental health problems using a direct payment. As mentioned earlier in this paper, the Scottish Executive commissioned a follow-up piece of research to explore the reasons for this. The study (Ridley and Jones, 2002) found that little

progress had been made since the initial findings (Witcher *et al*, 2000). Professionals in both voluntary and statutory sectors were found to have a number of reservations as to the benefits of direct payments and questioned the capability of persons with mental health problems to cope with them in view of fluctuating or worsening conditions. Likewise, they raised concerns as to what they perceived as an increased risk of fraud and exploitation. Potential direct payment users also expressed anxieties about becoming employers and dealing with aspects such as paperwork.

Elsewhere in UK, the uptake of direct payments for people with mental health problems has been equally poor. As Glasby and Littlechild (2002) document, by September 1998, the number of users in this group stood at 13 and was spread over seven social service departments (Auld, 1999). Essex has been highlighted in the literature as being the leading authority in this areas – both in the UK and on a European level (Brandon, 19998).

Like Ridley and Jones' (2002) study, other work in this area (see Maglajlic, 1999; Maglajlic *et al*, 1998) has underlined the lack of knowledge about direct payments, amongst both potential users and staff. Similarly, concerns around the capacity of individuals to cope with payments also feature prominently in the studies to date.

There is also important work in this area currently being undertaken by the Health and Social Care Advisory Services. This project – due for completion in May 2004 – aims to examine the gaps in professional knowledge about the operation of direct payments for persons with mental health problems through a series of focus groups. Work is being specifically targeted at black and minority ethnic service professionals.

### **Older People**

As detailed earlier in this paper, implementation of the 1996 Act initially excluded persons over the age of 65. This restriction was put into place to limit the number of users, thereby reflecting concerns from the then Conservative Government that policy implementation would lead to excessive rises in public spending (Means and Smith, 1998).

Despite these concerns, lobbying from groups such as Age Concern and NCIL were made and policy was extended by New Labour within their first year in office (see earlier discussion). Since then, direct payments for older people have been promoted by government as an integral part of the modernising agenda for social care. This has been reiterated in subsequent policy documents such as the *National Service Framework for Older People* (Department for Health, 2001) and *Fair access to care services* (Department for Health, 2002). Indeed, to some extent the enthusiasm to promote direct payments from the Department of Health has been reflected in the uptake for this group in key localities. Analysis of figures from this study shows a considerable growth in the number of users over the age of 65 in many English authorities and a total population of 2700. Other parts of the UK fare less well, notably uptake in Wales is especially poor.

Early research in this area suggested that older people may face specific barriers to direct payments, but that these may be overcome with appropriate support (see Zarb and Oliver, 1993; Barnes, 1997; Hasler *et al*, 1999). More recently, concerns have been addressed in a study by Clark, Macfarlane and Gough (2004). They found that

although older people receiving direct payments reported feeling happier, more motivated and having an improved quality of life, there remain a number of problems in the organisation and wider access payments. As such, the role of support services were highlighted as being critical in enabling older people to use their payment effectively. This was particularly important for users from minority ethnic communities where language was often found to be a major barrier. However, it was reported that direct payments were still not being routinely offered as a mainstream service option and were therefore not considered to be part of the 'culture of care management'.

### **Direct payment users with HIV/AIDS**

Glasby and Littlechild (2002) also provide a useful overview of some of the issues raised for users with HIV/AIDS. Available data for this group from the Department of Health's study (see earlier section) showed that in 1998, there were 13 people with HIV/AIDS in receipt of a direct payment (Auld, 1999). As Glasby and Littlechild (2002), note, these figures are too small to provide conclusive findings, but they point to preliminary work undertaken by NCIL and the National AIDS Trust which suggests that direct payments may be a particularly useful option for people with HIV/AIDS (Grimshaw and Fletcher, nd). For Grimshaw and Fletcher, the success of combination therapy is likely to impact on the availability of specialist HIV/AIDS teams within social service departments. Therefore, the availability of a direct payment to buy in individualised support may alleviate this problem. Current direct payment users with HIV/AIDS have also suggested that the flexibility of payments fits in well with the fluctuating nature of their conditions (Glasby and Littlechild, 2002).

### **Younger people and disabled children**

To date, there has been very limited empirical research focusing on the impact of direct payments in this area, although some general commentary has appeared in the literature. For example, the impact of direct payments on disabled children has been addressed in an article by Leece (2002). This paper discusses the experiences of adult payment users – both between the ages of 18-65 and over - as a basis for examining the potential benefits for younger users. From this, Leece highlights their advantages in terms of encouraging socialising and wider aspects of participation, control and independent living amongst younger people.

Policy extension to 16 and 17 year olds has been more directly addressed in a project carried out at the University of Bristol (see [www.bris.ac.uk/Depts/NorahFry](http://www.bris.ac.uk/Depts/NorahFry)). This project was set up with a view to produce a resource to highlight the main issues facing young disabled people. Once again, it was found that information access for direct payments was a key concern. Furthermore, the project showed that whilst some young disabled people saw direct payments as a potentially significant means to achieving greater autonomy and control, many remained concerned about the barriers in trying to access them. Indeed, a similar level of concern was reflected by social service managers who were unsure as to how well younger disabled people would manage their payments.

### **Issues around sexuality**

As Glasby and Littlechild (2002) document, for gay men and lesbians direct payments raise a series of issues which have been neglected by the vast majority of

commentators. Prior to implementation of the 1996 Act, Killin (1993) addressed some of the practical issues faced by gay and lesbian personal assistance users. These include homophobic attitudes from personal assistants and the disclosure of sexual orientation of the disabled person to neighbours. Since 1997, many of these complexities have been addressed in Policy Studies Institute (PSI)/National Centre for Independent Living (NCIL) guidance to local authorities (Hasler, 1999) and the NCIL publication, *The rough guide to managing personal assistants* (Vasey, 2000).

### **Issues around gender**

Whilst to date, there has been no specific discussion of the specific experiences of direct payments for disabled men or women, earlier discussion by Rae (1993) highlights a number of important issues. She argues that there is a fundamental contradiction for women as personal assistance users through the construction of female 'care' roles. For disabled women this role is used to exclude them from some roles, for example the risk of parenting a physically or intellectually impaired child, but is reversed in the assessment of 'care' needs. In such cases, Rae (1993) maintains that there is an assumption that disabled women can sustain a number of support roles either individually or for a disabled partner, whereas disabled men are often more varied and comprehensive packages.

### **The experiences of black and minority ethnic communities**

For the Conservative government, implementation of the direct payments legislation was framed within the context of the wider restructuring of welfare (C Pearson, 2000). As such, the policy framework drew strongly on the rhetoric of 'needs-led' planning promoted in the 1990 NHS and Community Care Act. In this context, both the Griffiths Report (1988) and the White Paper *Caring for People* (1989) recognised the fact that people from black and minority ethnic communities might have specific needs. Similar issues were also raised from within the disability movement whereby commentators such as Hasler *et al* (1999) suggested that direct payments may be a useful means of meeting more diverse support needs. However despite these early proclamations, it is clear from the pattern of research that payments have not been readily available across black and minority ethnic communities. In their study of the views of young black disabled people on independent living, Bignall and Butt (2000) found that, despite being in contact with social service departments, there was practically no knowledge of direct payments amongst their respondents. A similar pattern was reported by Vernon (2002) in her study of community care amongst Asian communities.

Poor access and take-up has also been highlighted in some of the larger studies of direct payments. In Scotland, Witcher *et al's* (2000) study found that there were no users from black and minority ethnic communities. Indeed, it is clear from voluntary sector organisations working within different communities that lack of accessible information and general concerns about the suitability of payments remain as key barriers to enhanced take-up (C Pearson, 2004b). A similar pattern has been replicated in research from other parts of the UK even where densities of black and minority ethnic communities are considerably higher. Maglajlic *et al* (2000), for example, found that in the London borough of Tower Hamlets none of the members of the local organisation of disabled people were from minority ethnic groups.

Other research such as Clark *et al* (2004) found more positive outcomes in highlighting examples of some of the benefits of direct payments. Indeed they found that access to direct payments for Somali older women interviewed for the study had enable them to secure culturally relevant services, where social care agencies had previously failed. By removing the language barriers through employment of a Somali-speaking personal assistant, participants in the study were found to be more in control of support and less reliant on family members.

### **The role of professionals: social workers and support organisations**

Throughout the research to date, it has become clear that professional roles, both through social workers and support organisations, have played a central role in the effective implementation of direct payments. As Sapey (2001) states, the predominant attitude of social workers continues to be one of viewing disabled people as incompetent and therefore in need of having decisions made for them. In turn, he suggests that direct payments are an important means of challenging this type of ‘culture of welfare’ across social service departments. This is an area addressed by Dawson (2000) in her report of direct payment implementation in Norfolk. Whilst the report highlights the positive impact of direct payments in the area, Sapey (2001, p. 507) notes that, ‘there are some very important messages for social workers which go to the heart of certain problems that exist between disabled people and state welfare’. For Dawson, one of the most important deciding factors as to whether a disabled person gained access to a direct payment was the approach of their care manager/social worker. Sapey (2001) also refers to his own experiences where he suggests that some social workers have policed the use of direct payments by altering assessments when their client has succeeded in obtaining better services. Likewise, a similar practice of policing has been evident at an institutional level where the notion of equity is used to try and restrict the improvements that disabled people are gaining from them.

This is also an area picked up in some of the research studies elsewhere in England (see Carmichael and Brown, 2002; Leece, 2000; J Pearson and Sapey, 2003) and in Scotland. Witcher *et al* (2000) were first to highlight the views of social workers as an important influencing factor on disabled people’s access to a direct payment. This was reiterated by C Pearson (2004a) who found a pervading ignorance surrounding the principles of independent living amongst many staff charged with the responsibility to access information to potential users.

There is also concern about the availability of personal assistants and the development of a ‘market’ of service provision. Much has been written in this area surrounding the problems with recruitment of personal assistants (see for example, Clark *et al*, 2004) and also through the gendered impact on the poor pay and conditions offered by these jobs. Although writing prior to implementation of the 1996 Act, Ungerson (1997) in particular raised questions over the impact of personal assistance and the deregulation of ‘care’ provision for many women taking on these roles. This perspective was confronted by Morris (1997) who argued that access to personal assistance must be seen as a civil rights issue and primarily in terms of the choice and control offered to disabled people in terms of moving away from rigid modes of service provision. As such, she suggests that other areas of work such as cleaning are equally susceptible to exploitation by non-disabled and disabled people alike, and therefore Ungerson’s

argument negates the important role direct payments play in promoting genuine empowerment for users.

Another important role in the successful policy implementation has been identified through the role of local user-controlled support organisations. Indeed this has been emphasised from both the disability movement (see Hasler *et al*, 1999; Evans, 2000) and policy planners across the UK (see Department of Health, 2000b; Scottish Executive, 2003b; Northern Ireland Executive, 1998). Likewise, the value of this support has been acknowledged by users across a range of studies (see for example, Carmichael and Brown, 2002; Clark *et al*, 2004; Dawson, 2000; Holman with Bewley, 1999; Maglajilic *et al*, 2000; Stainton and Boyce, 2002). However despite recognition of this role in facilitating payment packages, local authorities are not obliged to meet the costs as part of the assessment. Therefore as C Pearson (2004b) found in her study of user-controlled support organisations in Scotland, many of these groups have found themselves in a precarious position, where it is assumed that they are willing and able to support an expanding and increasingly diverse user population, but without additional funding.

Whilst CILs and other user-controlled support organisations have traditionally been viewed as the main centres of expertise for direct payment support, there has also been a growth in other local support groups over the past few years (C Pearson, 2004b). However, as Barnes *et al* (2000) have observed, these services have assumed a number of different forms, many of which have not developed from a 'user-led' framework promoted by the disability movement. As analysis from this study shows, a number of local authorities across Britain are developing support network out with the disability movement. Likewise as C Pearson (2004b) observes, although many of these organisations promote an active role for users in their constitutions, interpretations of this involvement varies considerably and often includes any kind of engagement. As Robson, Begum and Lock (2003) found, users only really value 'user-centred involvement' where service users objectives and priorities become the focus of the organisation's work. With this in mind, C Pearson (2004b) suggests that a shift away from this framework will inevitably push direct payments away from its independent living roots and towards a more welfarist model of service provision.

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