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Money Talks?: *Direct Payments and Competing Policy Discourses*

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Abstract

IMPLEMENTATION OF THE Community Care (Direct Payments) Act 1996 in April 1997 enabled local authorities to make cash payments to service users under the age of 65 with physical and sensory impairments, learning difficulties and mental health problems. This gave users control over money spent on meeting their community care needs rather than receiving services arranged for them by the local authority. The policy is often represented as a victory for the disability movement and as a push towards independent living and social justice. However, direct payments also need to be understood as part of a wider market discourse prominent in the restructuring of welfare. Therefore, a growing culture of localised care markets led by local authorities with increasing ideological diversity may ultimately erode the scope for independent living, choice and control.

This thesis examines the impact of these policy discourses informing the planning constructions and user experiences of direct payments in two contrasting areas – one in England and one in Scotland. A third authority – also in Scotland – is examined where direct payments have yet to be implemented and an indirect payment scheme remains in place. In the English authority – 'East Anglia' – findings show direct payments promoted both as part of a wider marketisation of community care and development of independent living services. Implementation has seen a relatively rapid promotion of policy but this is found to be located within wider New Right confines of cost efficiency and accountability. Like East Anglia, the Scottish authority – 'East Scotland' - has also demonstrated a long-term commitment to independent living services and has worked in partnership with the local disability movement to establish a momentum for policy change. However, wider policy use is shown to be restricted by a more dominant *anti*-market discourse. Similarly for the second Scottish authority in the study – 'West Scotland' - planning fears of service privatisation coupled with limited disability activism and a chaotic aftermath of service reorganisation has resulted in non-implementation of direct payments.

By focusing on the impact of these discourses alongside wider controls made by central government, this research examines user experiences of direct payments in East Anglia and East Scotland and indirect payments in West Scotland through a series of semi-structured interviews. Additional information is generated through a discourse analysis of key policy documents and discussions with planners. Whilst findings highlight an overall enthusiasm for both direct and indirect payments, user experiences are shown to be strongly influenced by market and independent living discourses in each area. This has implications not only for individual user constructions of independence but draws more widely on an understanding of collective disability identities.

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Declaration

I declare that this thesis has been composed by myself and has not been presented for any other degree. All quotations are differentiated from my own work and all sources of information have been acknowledged.

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Chapter I: Introduction

Introducing direct payments

THE COMMUNITY CARE (Direct Payments) Act 1996 gave local authorities across Britain[i] the powers to make cash payments to disabled people. Implementation in April 1997 initially restricted access to those under the age of 65 (Department of Health, 1997/Scottish Office 1997) although more recently they have been extended to older people (Department of Health, 1999/Scottish Executive Circular No. CCD4/2000). Allowing individuals direct access to cash payments to purchase their support services represents an important shift in the restructuring of welfare. Previously, although these types of schemes existed, any allocation of cash payment was legal only if social (work) services used a third party (usually a well-established voluntary sector organisation) to facilitate monies indirectly on their behalf[ii] (Means and Smith, 1998, p. 60). Across other policy areas direct payment of cash or a voucher from the state to an individual for them to purchase welfare services had only been advocated by some on the political right (see for example, Joseph, 1975). However, attempts in recent years to apply this model to contemporary social policies – through vouchers for nursery education - have not been sustained over the long term. Direct payments may therefore be seen as a unique example of empowerment through cash. Given this exemplary position, policy discussion requires an understanding of the discourses informing this legislative change.

At one level, this policy gives users control over money spent on meeting their community care needs rather than receiving services arranged for them by the local authority thus empowering service consumers and reducing that of providers. At another level, direct payments are often presented as a victory for the disability movement and as a push towards independent living, user empowerment and social justice. However, they are also underpinned by a wider market discourse informing social policy change over the last decade. The market in social care has been based on the idea of local 'mixed economies' with public, private and voluntary sectors competing with each other to offer services which are more suited to the needs of

individual service users and are also cheaper (Pearson, 2000). Direct Payments, therefore, are a form of service delivery which may appeal equally to the left and right, but for different reasons. This thesis explores the legitimating discourses used by planners and users to justify the adoption of direct payments in two local authorities. A third authority - where direct payments have not been implemented but an indirect scheme is in place - is also examined and similarities and differences in policy are drawn out. However, before detailing the layout of this thesis, an initial explanation of terms used is given.

Discussing discourses: *an explanation of terms used*

So far in this introduction the term 'discourse' has featured a number of times. However before developing ideas further in this study, brief explanations and definitions of this and other key terms used and their context, need to be laid out. For the purposes of this research, the term discourse is based on ideas initially outlined by Michel Foucault (1972, 1976, 1979). For Foucault, two issues are important in understanding discourses: their means of *organising knowledge* and the *power relations* that inhabit this process. In turn, he suggests that discourses are structured around central themes and connections which define the terms in which statements can be made, investigations conducted and conversations take place (Clarke and Cochrane, 1998, p. 35). More recently, a number of commentators (see for example, Clarke and Cochrane, 1998; Watson, 2000; Williams and Popay, 1999; Williams, 1996) have drawn on Foucault's ideas on discourse and used them in understanding and analysing developments in social policy. As Clarke and Cochrane (1998, p. 35) explain, 'discourses shape and become institutionalised in social policies and the organisations through which they are carried out'. Similarly, Williams and Popay (1999, p. 173) suggest that the utility of the term lies in the way it allows us 'to consider the structural and ideological influences upon people's lives in one frame'.

Discourses are therefore frameworks which structure thought and action throughout society. Whereas within Marxist thinking ownership of the means of production determines power relations, Foucault felt that ideas have power independent of the economic base. Foucault believed, however, that certain groups in society have more control over frameworks of thought or discourses because of their access to material,

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cultural and political power. However, because the power of a particular discourse is not solely economic, the control of dominant groups is always open to challenge by subordinate groups through the power of discourses they employ.

By focusing on constructions of direct payments by different interest groups, the thesis examines struggles over the meaning and future direction of the policy. The following section introduces some of the key ideas reflected in direct payment policies which will be revisited throughout the thesis.

Direct Payments as a means of achieving independent living

Over the past twenty years collective action by disabled people has gained an increasing momentum and profile in the policy making process. The development of a disability movement has centred on a rights-based agenda. Central to this agenda has been the rejection of disability as a tragic problem occurring for isolated, unfortunate individuals for whom the only appropriate social response was medical treatment. Instead, disability is located within the social model as collective institutional discrimination (C. Barnes, 1991) Throughout the 1960s disabled people campaigned for a comprehensive disability income. As will be shown in chapter II and III, although this demand was not met, it established civil rights on the campaigning agenda and introduced the idea of making cash payments to disabled people to buy in support. From the 1970s and through the 1980s and early 1990s, attention shifted to attaining the broader goal of 'independent living'. In the 1970s, there was a move away from a focus exclusively on material inequalities to information deficits. A number of early initiatives like the setting up of the Disablement Information and Advice Line (DIAL) by activists in Derbyshire signified an important shift in accessing information about services and provision to disabled people, thereby representing a milestone in the development of the local disabled people's movement across the UK (Davis and Mullender, 1993). Moreover, news of the American Independent Living Movement began to filter through to disabled people in Britain and act as a stimulus to change. As Barnes and Oliver (1998, p. 83) note, this was particularly important because developments in the USA provided evidence of what disabled people in the UK knew already; that the obstacles to their self-fulfilment were the direct outcome of living in hostile physical and social environments and that current services were inhibiting rather than empowering.

In Britain, the first centres for independent living (CILs) were set up in the early 1980s by disabled people in Derbyshire and Hampshire. From the outset, a fundamental goal of these local organisations and national groupings such as the British Council of Disabled People (BCODP) has been to challenge the basis of control of services for disabled people. This included the development of early cash payment schemes in some areas allowing disabled people to 'buy in' the services they need (see chapter III). Indeed, the focus of the campaign for independent living has advocated the need to transform both the economic and cultural inequalities in service provision and state support for disabled people (these areas are addressed in chapters II and III). Direct payments have been identified as one of the main ways of breaking down these inequalities (see for example, Zarb and Nadash, 1994) and have been used by the disability movement as a touchstone for its progress towards citizenship. Whereas the policy of direct payments has different implications for different groups of disabled people, it is seen as a largely progressive measure by the disability movement.

Direct payments as an instrument of the market

Since the late 1980s, social policy provision has been subjected to a series of dramatic changes. These centred on an attack on the monopoly of publicly run services, considered by many on the right to be inflexible, unaccountable, costly and led by the needs of service professionals rather than the users themselves. Whilst these ideas were not exclusive to the New Right (see chapter III), this was the first time they received a high policy profile. Therefore, as Bartlett, Roberts and Le Grand (1998, p. 1) describe, across nearly all areas of welfare provision, new institutional arrangements were introduced, designed to extend the principles of the market (Bartlett, Roberts and Le Grand, 1998, p. 1).

In community care, use of quasi-markets became fundamental to the 1990 reforms. As M. Barnes (1997, p. 35) remarks, 'the Act was as much about making services 'customer-focused' as it was about securing a shift in services from institutional to community bases'. These changes centred on recommendations from the influential Griffiths Report (1988) which advocated a transformation in the role of social (work) service departments, stating that they should be reorganised as 'arrangers and purchasers of care services – not as monopolistic providers' (Griffiths, 1988, para.

3.5). This new role assumed a dual function for local authorities in both designing service packages tailored to meet the needs of individuals and securing their delivery by developing a diverse network of providers in a 'mixed economy of care'. Both the White Paper on community care (Department of Health, 1989, p. 4) and the subsequent practitioner guidance stressed that 'the rationale for this reorganisation is the empowerment of users and carers' (Department of Health/Social Services Inspectorate, 1991, p. 7). In these terms, direct payments fitted easily into the new conceptualisation of a welfare state geared to the interests of consumers rather than providers. Within this conceptualisation of a modern welfare state, consumers are envisaged as diverse individuals with differing needs, rather than a collective with very similar needs. However, these differences are to do with individual preferences rather than social, economic and political diversity.

Whilst empowerment remains a highly contested concept in policy discussion, several commentators have drawn on Hirschman's (1970) notions of 'exit' and 'voice' to conceptualise the empowerment approaches adopted in community care (see for example, Taylor, Hoyes, Lart and Means, 1992). Similarly, Hirschman's ideas provide a useful framework to understand the use of direct payments in the creation of customer-focused services. Hirschman's idea of 'exit' suggests that users are empowered by choosing between alternative service providers. If dissatisfied with a particular service, the consumer will be able to change provider and then if a large number of consumers make the same decision, that provider will be punished for their inefficiency and go out of business (Means and Smith, 1998, p. 83). As Means and Smith note, opportunities to apply these principles in community care are limited. This is because services are largely funded by the state, and it is not possible for the user to 'shop around' (see for example, Lewis and Glennerster, 1996). Furthermore, direct choice inevitably becomes by-passed because of the role of a care manager, who usually organises provision on the user's behalf. An important departure from this pattern, however, came through the introduction of the Independent Living Fund (ILF) in the late 1980s. As will be explained in chapter II, this gave disabled people sums of money to buy care services and represented a small but important example of how exit in social care might be used. Within this scheme, assessment of need remained controlled by government, but users were given a cash benefit to buy the services they wanted. Research conducted into the experiences of ILF users

(Kestenbaum, 1992) showed that they were able to use their ILF money for a support package which met their needs in a way that heightened their independence. Perhaps more importantly, additional research commissioned by the BCODP (Zarb and Nadash, 1994) indicated that this type of provision was up to 40 per cent cheaper than direct service provision – thereby fitting in with market doctrines of cost efficiency as well as increased individual choice. As such, the ILF experience was used by the Conservative Government and proponents of the market to justify the development of 'exit' models of empowerment (Means and Smith, 1998, p. 85) and formed an important basis to eventual adoption of direct payments.

Also contained within the community care reforms were a number of 'voice' options for empowerment. Firstly, social (work) service departments were required to seek the views of users before deciding on the overall strategic direction of policy. Secondly, through the care manager, users were able to demand appropriate and flexible care packages (Means and Smith, 1998, p. 88). However, the effectiveness of 'voice' approaches like consultation has been subjected to widespread criticism in a number of research studies on the grounds that users do not have any real power to change decision making in policy (see for example, Glendinning and Bewley, 1992).

Direct payments draw directly on the principles informing the ILF. Allowing disabled people to purchase the service they required, the policy allows them to exercise the power of exit. If dissatisfied with a local authority service, a direct payment user could simply purchase another service from the voluntary or private sector. Direct payments also afford opportunities for disabled people to exercise the power of voice. They could negotiate directly with the service provider rather than using the care manager as intermediary. If change did not take place, they could seek a new service. Like the proponents of marketised public services, disability movement advocates of direct payments emphasised the diversity and difference of service users, demanding individually tailored rather than mass-produced services. More general commentary in the field has also recognised some of the structural differences. For example, Oliver (1990) draws on Marxist analysis to outline some of the material inequalities faced by disabled people and Morris (1991) highlighted the exclusion of gender and disability from policy research.

Understanding direct payments: *issues of diversity and difference*

So far, this introductory discussion has shown the appeal of direct payments both for advocates of independent living and the market and how these discourses need to be understood in policy analysis. The policy of direct payments may be justified in terms of offering disabled people enhanced control over their daily lives *or* as a means of developing a quasi-market model in social care. Both arguments may be deployed tactically. For example, a group of disabled people may argue that direct payments offer both greater autonomy and better value for money, even if their major concern is with disabled people's freedom. A central aim of this thesis is to understand how three authorities justified their approach to direct payments. The study examines the extent to which each authority drew on a market or independent living discourse to justify their actions and to what extent these discourses shaped the direct payments scheme adopted. Finally, the extent to which different 'versions' of direct payments were experienced differently by service users is examined. As noted earlier, both versions of direct payments reflect a view of service consumers as diverse individuals requiring a range of personalised services. This view of the modern welfare state is in line with the Citizens' Charter and more recently, the Modernising Government Programme (Stationary Office, 1999).

It is also in line with Williams' (1996, 1994) view that the modern welfare state reflects changes in the organisation of production and consumption in the wider global economy. Use of cash instead of services may be seen to represent a shift from rigid, 'service-led' public sector provision (a 'Fordist' era) to a more individualised, pluralistic, flexible and 'needs-led' ethos of planning (a 'post-Fordist' era). However, as Williams argues (1994, p. 66) this type of analysis tends to envisage consumers as atomised individuals, failing to take into account the way in which people's lives are structured by wider social and economic forces based on gender, 'race', sexuality, class, age and disability. Williams suggests that for services to be genuinely attuned to individual needs, the service user should be understood not just as a consumer but as an individual negotiating a subject position rooted in multiple identities. A major concern of this thesis is to consider whether direct payments as a mode of service delivery was capable of recognising these complexities, or reflected a more one-dimensional view of the service consumer.

Examining direct payments: *layout of the thesis*

In the following section the structure of the thesis is described. Chapter II begins with an historical overview of the wider framework of social policies for disabled people and highlights a number of ideas informing service development. This begins by highlighting the construction of disabled people as part of the 'deserving poor' and the establishment of segregationist policies during the early industrial era. This shifts to an exploration of the more sustained network of support developed by central and local government from the post war era onwards. Whilst central government provided access to cash benefits, from central government, local authorities provided 'care' services. Policy developments for disabled persons from the 1970s to the 1990s are traced through this 'cash and care' divide. Finally, direct payments are introduced at the end of the chapter as a significant break with this pattern, since they involve the provision of cash by local government.

Chapter III examines the position of direct payments more specifically in the wider restructuring of welfare, noting the shift from the positioning of service users as passive clients to a new conceptualisation of them as active citizens. At a structural level, discussion centres on organisational changes in service delivery through the emergence of a 'mixed economy of welfare'. As these concepts became central to policy change instigated under the third Thatcher administration, their application is examined through the reorganisation of social (work) services in the 1990 NHS and Community Care Act. The introduction of local 'care markets' driven by cost-efficiency is discussed. At the same time, this highlights a shift in user identities from clients to consumers with services drawing on the rhetoric of 'empowerment', 'control' and 'needs-led' planning. Although the New Right sought to restructure user identities through a consumerist discourse and ultimately presented direct payments as part of this process, the chapter further examines a parallel push for policy change from the disability movement, which advocated user control, choice and empowerment as a means of achieving independence rather than promoting the market. The eventual adoption of direct payments is presented as an example of an alliance of interests between the New Right and the disability movement.

The aims of chapter IV are two-fold. Firstly, attention is given to examining how the values informing research production have shifted in the light of wider policy changes. More specifically, the growth of a cohesive disability movement has influenced both service planning and the nature of research. Discussion examines the debates surrounding the inclusion and representation of disabled people throughout the research process. Those involved are no longer viewed as 'research subjects' and instead participate and are represented more fully in the process and products of research. The second part of the chapter therefore links key theoretical and methodological ideas and illustrates how these are reflected in the research design.

In designing the research as a comparative study, it was anticipated that local authorities would implement direct payments in different ways. Therefore in order to understand this localisation of policy making, three main stages of data collection are described: analysis of policy documents on direct payments produced by central government and the local authorities, semi-structured interviews with key informants and local policy planners and semi-structured interviews with direct payment users in two areas and indirect payment users in the other. A more detailed outline of the local issues affecting policy planning for the cash payment schemes used in this study is given in chapter V. As negotiations for direct and indirect payments have emerged since the early 1990s, commentary explores how dialogue between local disability activists and local authority planners led to the adoption of direct payments in two of the areas whilst indirect payments remained in the third. Chapter VI focuses on user's accounts of direct payment schemes. Once again, drawing on the key ideas informing direct payments, this chapter examines how and why users in each of the areas transferred to direct/indirect payments and the role of service professionals in facilitating this shift. This is followed by an examination of issues surrounding changing disability identities as users assume the role of 'being an employer'.

Direct payments require a fundamental shift in the subject position of the disabled person from client to employer. Chapter VII begins by providing a more in-depth appraisal of the different versions of direct/indirect payments used in each area. Drawing on interviews with service users, perceptions of how local planners have framed policy are analysed. Did they see it as a means to encourage independent living through participation in employment, education and/or social activities, or

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simply as an alternative mode of organising support services for personal care in a home setting? The different experiences of users with physical impairments and those with learning difficulties are also explored This is followed in the second half of the chapter by a discussion of users' own conceptualisations of their independence and the way this was shaped by the receipt of a cash payment.

As a relatively new policy, local and central planning for direct payments has changed since implementation in April 1997. With this in mind, chapter VIII provides an update to the study by examining the key changes at both these levels occurring since completion of the main fieldwork stage. At central government level, New Labour has promoted wider access to direct payments by groups such as older people, 16 and 17 year olds, parents of young disabled children and carers. At the same time, the differing pace of change between England/Wales and Scotland has been accentuated through devolution. Therefore variation in local implementation of direct payments is being more marked over the longer term. Reactions to the series of changes instigated by central planners in the three local authorities are explored. As direct payments are promoted to more users and gain a higher policy profile, their purpose may become more disputed.

Chapter IX brings together the main ideas developed in the thesis. In doing this, discussion returns to the key research findings and examines these changes in a wider context of welfare restructuring.

Notes

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[i] Legislation differed in Northern Ireland where implementation of direct payments was mandatory.
[ii] At this time, the legal position regarding indirect payments in Scotland differed slightly. This is detailed in chapter III.

Chapter II: State support for disabled people: *cash versus care*

Introduction

THIS CHAPTER OUTLINES the development of state support for disabled people, providing the legislative background for the introduction of direct payments. Discussion draws on a number of themes replicated throughout policy development. Historically, there has been a differentiation between working and non-working populations and disabled people have been regarded as a 'deserving poor'. At the same time, they have tended to be segregated and stigmatised by social policies. The chapter also draws attention to two trends: the dependency of many disabled people on means-tested social assistance and the privatisation of income maintenance provision, whereby the growth of occupational and private schemes has excluded many disabled people.

The emergence of a more interventionist welfare state in the post-war era initiated a gradual shift towards including disabled people in benefits systems and local authority service provision. Commentary focuses upon two main levels of intervention - through central and local government - and introduces some of the ideas underpinning developments. Policies from central government broadly relate to cash paid through the benefits system. Income maintenance systems developed during the twentieth century were characterised by major inconsistencies and inequalities *between* different groups of disabled people, depending on the circumstances and causes of impairment. In these terms, some disabled people were constructed as being 'more deserving' than others. This continued division between disabled people introduces two areas of interest which will be returned to throughout the thesis. Firstly, it is evident that the interests of some groups of disabled people have been served better than others. Secondly, the emergence of a hugely complex system of state support for disabled people indicates long-term confusion over the exact role and coverage of benefits.

Whilst campaigning for a rights-based disability income in the 1960s was unsuccessful, recognition of the extra costs associated with disability led to the emergence of separate benefits for disabled people in the 1970s. An ad-hoc and incoherent policy framework developed, establishing a long-term need to restructure provision. For both Conservative and New Labour governments, this has linked in with wider concerns over 'welfare dependency' and eligibility for state support. A redefinition of a 'deserving poor' through a more stringent use of medical assessment of impairment has taken place. Although Conservative restructuring of disability benefits in the early 1990s began a process of narrowing eligibility, the introduction of the Independent Living Fund (ILF) represented an important symbolic shift in state support. Initially developed as a short term measure to cover gaps in provision prior to implementation of community care, the ILF was the first opportunity for disabled people to receive cash to buy in their own support. It is argued that the ILF was used to link in with local authority service provision – thereby breaking with traditional 'cash and care' boundaries between central and local government.

The theme of 'dependency' is touched on briefly in the second half of the chapter when state support is examined through local authority provision of 'care' services. Commentary begins by highlighting some of the key issues surrounding the notion of 'care' in policy analysis. This is followed by an overview of services available in the post-war period then looks at the emergence of a formal policy of Community Care in the early 1990s. Implementation of the 1990 NHS and Community Care Act sets out a number of themes subsequently developed in the policy framework for direct payments and throughout this thesis.

The chapter concludes by introducing direct payments into the network of state provision for disabled people. Having shown a broad separation of support between 'cash' and 'care' allocated from central and local tiers of government, direct payments are introduced as a significant break from this pattern and part of a wider restructuring of social welfare.

Establishing a role for state support: a historical overview of disability and welfare

The current policy framework of welfare for disabled people requires a broad understanding of the role of the state. A number of interpretations have been developed, however Oliver and C. Barnes (1998, p. 25) suggest that throughout recorded history a consistent cultural bias against people with impairments has existed. Whilst this section does not intend to provide a detailed historical analysis of understandings of disability (see Drake, 1999, pp. 45-67; C. Barnes and Oliver, 1998, pp. 25-35; Oliver, 1990, pp. 25-39 for more comprehensive accounts) a number of themes may be identified. Structural analyses of disability suggest there is a direct link between the rise of industrialisation and waged labour and the exclusion of disabled people. Participation in paid work is a key factor in determining the direction of state support for disabled people. The role of medical intervention in assessing 'ability' becomes more prominent and support for disabled people shifts from the family to an institutional setting. Furthermore, a process of differentiation between groups of disabled people is set in place. Together these changes not only introduce a new, more interventionist, role for the state but instigate a process of stigmatising disabled people.

Disability and industrialisation

From the beginning of the eighteenth century major economic and cultural changes signified the onset of industrialisation in Britain. Economically, this involved the shift to more intensive land and agriculture practices and the spread of waged labour. Concurrently, the emergence of the Enlightenment gave rise to a critique of established religions, an emphasis on the value of reason and 'science', a commitment to social progress and increased value to individuality (Oliver and C. Barnes, 1998, p. 29). Together, these economic and cultural changes provided the rationale for developing more exclusionary policies for persons with impairments. As Finkelstein (1980) notes, whilst not underplaying a general antipathy towards impairment, prior to this time, disabled people were more readily accommodated within the pastoral life of feudal society.

Consequently, industrial change – mainly through the spread of waged labour – compounded the difficulties faced by people with impairments. As Oliver and C. Barnes describe (1998, p. 30), cyclical economic depression created large numbers of dependants in families solely reliant on waged labour. Moreover, the Elizabethan system of localised Poor Law relief was increasingly unable to meet the needs of the growing free-market economy. Hence, waged labour accentuated the distinction between the 'able-bodied' and 'non-able bodied' poor because local domestic relief interfered with the need for labour supplies.

Conversely, a shift to segregation proved to have many advantages over domestic relief as it acted as a major deterrent to the able-bodied worker. In turn, these principles were reflected in the 1834 Poor Law Amendment Act. Forming one of the first major social policy interventions in the UK, the 1834 Act introduced key principles for state welfare policy: national uniformity and removal of relief outside an institution, both underpinned by the principle of 'less eligibility' (ensuring that a pauper's situation was less comfortable than that of the lowest paid labourer). Thus, as Oliver and C. Barnes (1998, p. 30) note, exclusion through both physical and ideological means became a major force in nineteenth century social policy.

Constructions of disability – categorising a 'deserving poor'
Nineteenth century reform was also underpinned by an upsurge in Christian morality, philanthropy and humanitarian values which were also to have a profound effect on the lives of disabled people (Oliver and C. Barnes, 1998, p. 31). These ideals encouraged a process of differentiation which not only separated people with impairments from other disadvantaged sections of the community, but also divided them up into specific categories and groups with differing treatments for each of them. In keeping with Poor Law reform, policy required workhouses to separate the incarcerated population into four different groups: able-bodied males; able-bodied females, children and the deserving poor and the 'aged and infirm'. This last group were housed separately and sub-divided according to newly established 'medical' categories of the 'aged and infirm' – those with chronic illness and/or permanent impairments, the 'sick' – anyone with acute, temporary or infectious diseases, the 'insane' – those defined as 'idiots', 'lunatics', the 'mad' or 'persons suffering from

brain diseases and 'defectives' – persons with sensory impairments such as blindness, deafness or lack of speech (Stone, 1985).

Towards the end of the nineteenth century, pressures to incarcerate these groups increased dramatically. Oliver and C. Barnes, (1998, p. 32) link this to three main occurrences. Firstly, the transition from relatively light industries such as textiles to much heavier capital goods industries such as iron and steel emphasised the importance of physical fitness as a criterion for finding work among working people. Secondly, welfare policies particularly with regard to outdoor relief were severely tightened during the 1870s and 1880s because of escalating costs caused by rising unemployment. This put more pressure on local authorities to apply the 'workhouse test' to anyone seeking welfare. Thirdly, there was a further expansion of segregated institutions for the deserving poor following public scandals and government enquiries exposing their appalling conditions in workhouses. As a result, the numbers of disabled people consigned to these institutions rose significantly – a rise sustained until the 1950s (Humphries and Gordon, 1992).

As Oliver (1990a, p. 34) notes, the success of the institution did not mean that all or even a majority of disabled people ended up in them. With the rise of capitalism, the family remained the setting in which the majority of disabled people lived. However, partly due to the change in the ideological climate created by institutional segregation, disability became highly stigmatised. In particular, for many working class families already under pressure from the new capitalist social order, caring for a disabled family member often proved too much. Disabled people were placed in institutions, away from the community, wider society as a last resort when the families were unwilling or unable to cope. Consequently, the increasing separation between work and home, led the boundaries of family obligations towards disabled people to be redrawn. This distinction between care in the family and the institution remained into the twentieth century as the state became more interventionist and the welfare state developed.

Disability support and the welfare state

State involvement in disabled people's lives has increased steadily since development of the welfare state in the post-war era. Throughout this period, Oliver and C. Barnes (1998, p. 3-4) maintain that understanding of disability has changed radically. In the past twenty years, this has shifted from viewing disability as a tragic problem occurring only for isolated, unfortunate individuals for whom the only appropriate social response was medical treatment, to seeing it as a situation of collective institutional discrimination (C. Barnes, 1991) and social oppression (Abberley, 1987) to which the only appropriate response is political action (Campbell and Oliver, 1996; Oliver, 1990) Oliver and C. Barnes suggest that the welfare state lies halfway between these positions – based neither wholly on personal tragedy theory nor fully embracing social oppression theory. On the one hand, policy has begun to acknowledge some of the specific costs and needs incurred through disability, yet support still remains underpinned by a medical model and discourses of dependency. The remainder of this chapter outlines the main welfare policies affecting disabled people. This focuses mainly on developments from the 1970s onwards when a more targeted policy agenda has emerged.

Locating 'central-local' roles and introducing discourses of dependency

The network of state support for disabled people can be broadly explored at two levels: through central and local tiers of government. Many commentators have criticised the complexities surrounding this structure (see for example, Dalley, 1991; Fitch, 1995; and Rowlingson and Berthoud, 1996), arguing that separate assessment and administration produces unnecessary waste and contradictions. From this division, a more specific boundary between *cash* and *care* has been broadly sustained between the allocation of direct cash benefits through the social security system and support for 'care needs' from local authority social work (service) departments (Fitch, 1995). This type of division not only underlines differences in administering support for disabled people, but introduces two discourses of dependency underpinning provision. Since the late 1980s, support through the social security system has been criticised by Conservative and New Labour Governments on the grounds that it promotes a 'dependency culture'. In turn, residualisation of disability benefits has formed part of a wider attack on benefit dependency from both Conservative and New

Labour governments. On one level, this has seen a more rigid use of the medical model of disability in defining impairments and accessing benefits. Conversely, more recently policy has shifted towards more inclusive initiatives out-with the benefits system. Through the introduction of tax credits and employment based support with the 'New Deal', current policy presents a much stronger emphasis on work as an alternative to benefit dependency for *all* groups.

An alternative dependency discourse operates around the notion of 'care'. This has been established through a long term assumption that disabled people are dependent and in need of 'care' (Priestley, 1999, p. 43). However, it is clearly inadequate to present this view uncritically. Therefore, at this stage some of the wider debates surrounding care are introduced as a preface to some of the issues raised later in this thesis. Indeed, the concept of care has been the subject of wide ranging policy analysis over the last fifteen years and more specifically since implementation of the 1990 NHS and Community Care Act (see for example, M. Barnes, 1997; Morris, 1993a; Twigg and Atkin, 1994). This has given way to a range of different, and often competing definitions of 'care'. More specifically, the concept of 'care' in legislation, practice and research has raised some problematic issues for a number of disability rights commentators. Morris (1993c) for example, has drawn attention to the work of feminists such as Finch and Groves (1985) and Dalley (1988) whose critiques of the way in which women perform the majority of care tasks led to their demand for more residential care. As Morris argues, this type of analysis not only ignores the rights and views of disabled people, but fails to acknowledge that women can also be disabled people. Similarly, Shakespeare (2000, p. 56) highlights how the carer movement has redefined care in a way which ignores the needs of disabled people by focusing solely on the single dimension of 'being a carer' and the associations of dependency related to this role (see for example, Pitkeathley, 1989). In these terms, Shakespeare puts forward an alternative view – one which moves beyond crude contestations between carers and disabled people. This has been reflected in a number of research studies. For example, Keith and Morris' (1995, p. 45) work focused on the *social barriers –* such as poverty, disabling environments and services – which make a disabled parent reliant on the support of a young carer. Hence, Shakespeare highlights the need to understand dependency as a consequence of wider structural constraints.

Shakespeare's (2000) ideas become important to the discussion of care raised in this thesis. He supports the position of the independent living movement – promoted as a central platform of campaigning for direct payments – that individuals receiving help should be offered as much control as possible over the way in which that help is delivered. At the same time, he emphasises the importance of inter-dependence in human relationships. Shakespeare (2000, p. 64) states, 'disabled people and others still often depend on good will and mutual aid, as all people do. The danger comes when disabled people have no choice and no alternative, and are reliant on unresponsive services or demeaning charity which renders them marginalised and dependent'.

Cash from the centre: the social security system and disability

It is only since the mid-1970s that the social security system has recognised disability as a particular subject for consideration. Prior to this time, disabled people could claim benefits if they were unable to work through the same route as those who were unemployed or retired. Support was also given through special schemes to compensate people whose capacity to work had been impaired while at work or in the armed forces. In this context, it is important to note that an early challenge to the material inequalities faced by disabled people came in the 1960s. This centred on campaigning for a national comprehensive disability income by the then newly formed Disablement Income Group (DIG) (Oliver 1997 p. 244). The policy was promoted by the group as the way to ensure that disabled people were able to share in the affluence of the period and as the way to ensure their inclusion into society. As Oliver and C. Barnes (1998, p. 79) describe, 'if poverty was the problem disabled people faced, giving them money was perceived as the solution'. This was clearly a radical initiative at the time and the DIG organised a major rally in Trafalgar Square in 1968 in support of their campaign (Campbell and Oliver, 1996, p. 152). However, the campaign also attracted the attention of a number of non-disabled experts and organisations controlled and run by non-disabled people. Whilst a small group of mainly non-disabled DIG experts began lobbying parliament on the incomes issue, the majority of its members remained largely passive. Some limited success was achieved – notably the introduction of Attendance Allowance (this is discussed shortly) – but a fully comprehensive national disability income was not embraced (Oliver and C.

Barnes, p. 80). Therefore although the idea failed to secure mainstream political support, it is important in the context of direct payments as an initial demand for cash from disabled people.

However, during the 1970s a series of mainstream benefits for disabled people was introduced. This shifted the policy objective away from the notion of injury compensation in the post-war period to wider objectives of meeting needs through recognition of some of the extra costs associated with disability and the provision of earnings replacement. Development of disability benefits also needs to be explored in the wider ideological context. Indeed, whilst disability has established its own policy agenda, reform has been used by both Conservative and New Labour as a means of playing out wider ideological concerns in welfare restructuring.

State support for disability: policy trends in the post-war period

Social security provision has been traditionally framed around two distinct principles: compensation, emerging from legal concepts of common law liability, and insurance, to provide income maintenance. Walker and Walker (1991, p. 22) document the evolution of this framework, highlighting the first recognition of disabled people's rights to financial compensation through the introduction of disablement pensions in 1917. This was followed by the post-war Labour government's implementation of long term disablement benefits under the National Insurance (Industrial Injury) Act 1946. The tradition of compensation for work-related injuries continued throughout this period. However, provision ignored disabled people who had not been injured at work or had never been in work and therefore could not rely either on insurance cover or personal savings (Drake, 1999, p. 56). This was initially addressed in the Beveridge Report (1942) through plans for means-tested social assistance, covering what Beveridge termed 'the inability of a person of working age, through illness or accident, to pursue gainful employment' (cited in Drake, 1999, p. 56). But in doing this, major inequalities *between* different groups of disabled people with the same levels of disability were established. Therefore, differentiation served to characterise certain groups of disabled people as more or less 'deserving' than others.

Although the needs of disabled people for additional support were acknowledged in part, assistance led to very low levels of income. Similarly the organisation of benefits through social assistance rather than 'rights-based' social insurance maintained earlier stigma associated with state support for disabled people.

Developing disability benefits: the 1970s

During the 1970s, policy moved to develop separate benefits for disabled people. Although this initiated recognition of the differing needs and extra costs experienced by disabled people, benefit levels remained low - seldom exceeding 20 per cent of the average male wage (Drake, 1999, p. 56) - and reliant on medical 'testing' of impairment. Furthermore, benefits were not part of a planned framework, but emerging in an ad hoc manner, resulting in a long-term need for reform. Researchers have continually emphasised this need for reform (see Berthoud *et al*, 1993; Walker and Walker, 1991). As Rowlingson and Berthoud (1996, p. 19) state, 'to call it a 'system' of benefits may...give a false impression of coherence'.

In 1971, a general attendance allowance (AA) was introduced. This was defined as 'a comprehensive universal benefit not based on the compensation, but on evidence of severe disablement, however caused, which requires attendance' (DHSS, 1974, p. 8). It was, therefore, the first new benefit ever to recognise the costs of disablement for those whose disability originated outside war or industry (Baldwin, Bradshaw, Cooke and Glendinning, 1981, p. 94-95) However, the status of AA is somewhat ambiguous in the overall network of cash and care support for disabled people. Indeed, although attendance needs are the criteria by which severity (and therefore eligibility) is assessed, the allowance is widely recognised by users and local authorities as a means of meeting care needs rather than the extra costs of disability. Thus it is commonly taken fully into account in local authority assessments for home care and other services. AA was followed by the introduction of a non-contributory invalidity pension (NCIP) in 1975. Paid at 60 per cent of the contributory pension, it was aimed at people of working age, such as those with congenital disabilities, who were unable to work but did not qualify for the invalidity pension owing to insufficient national insurance contributions. Married women who were incapable of work were initially excluded from receiving NCIP on the grounds that they were likely to be at home

anyway regardless of whether they were incapable of work or not (Walker and Walker, 1991, p. 24).

Development of the NCIP was followed by introduction of a mobility allowance. This was phased in over three years from 1976 for different groups between the ages of 5 and 65 and was available to those who were unable or virtually unable to walk because of physical impairment. It is perhaps useful to note that the introduction of this mobility allowance led to the discontinuation of the 'invalid tricycle' (a vehicle designed specifically for civilian disabled people in the 1960s and 1970s). The tricycle was criticised not only because of its inconvenience as a single seated vehicle which made no concessions to the family or social life of its owner, but also because of its poor safety record (Baldwin *et al*, 1981, p. 102). Therefore, by offering these disabled people cash instead of welfare in kind, this may be seen as an early example of the 'marketisation' of welfare through the extension of 'consumer choice' to a wider group by offering money instead of services[i].

In 1976, invalid care allowance (ICA) was implemented for those unable to work because they had to stay at home to care for a severely disabled person. Initially, this was only available to men and single women but was extended to non-relatives in 1981 and married women in 1986 after a ruling by the European Court of Justice (Walker and Walker, 1991, p. 24). The final benefit introduced at this time was the housewives' non-contributory invalidity pension (HNCIP) in 1976. This signified an acknowledgement by government – albeit reluctantly and inadequately - that married women with disabilities had a need for income (Loach and Lister, 1978).

Despite the emergence of separate disability benefits, the system of support for disabled people developed in an ad hoc manner rather than a systematic way. Wide ranging eligibility criteria applied and some groups of disabled people were excluded. As Walker and Walker (1991, p. 25) note, this has resulted in a system which pays vastly different sums to people facing similar degrees of disability. There has been a steady increase in claimants – resulting in a four-fold growth in spending since 1978/79 (Berthoud, 1998). However, research suggests that this growth relates to an increase in the length of time individuals remain on benefit (Berthoud, 1998), rather than generosity of provision. In turn, the structure and cost of benefits have led both

Conservative and New Labour administrations to target disability benefits as part of their respective social security reforms. The following section documents these changes.

Extra costs and cost cutting: policy change in the 1980s

Election of the Conservative Government in 1979 brought with it a commitment to providing 'a more coherent system of cash benefits to meet the costs of disability' (Conservative Party Manifesto, 1979). As Glendinning (1992, pp. 89-90) notes, reform was underpinned by the more general New Right aim to reduce the role of the state and 'targeting' welfare on the poorest and most 'deserving'. Whilst earlier analysis has traditionally placed disabled people in this category, the Conservative reforms instigated a long-term process of narrowing eligibility.

The commitment to reforming disability benefits was delayed in the early 1980s when the government argued that there was too little information on disability (Walker and Walker, 1991, pp. 44-45). In turn, alongside the announcement of the Fowler social security reviews in 1984, the (then) Department of Health and Social Security commissioned the Office of Population, Censuses and Surveys (OPCS) to carry out a number of nation-wide surveys of disabled people (Glendinning, 1992, p. 92). The surveys were carried out between 1985 and 1988 and published in a series of six reports between 1988 and 1989. They reiterated a link between disability and financial need, showing incomes of households containing working aged disabled people to average only 72 per cent of the general population. Incomes of disabled pensioners were even lower than those of pensioner households in general (Martin and White, 1988, p. 33). From these figures, the Disability Alliance estimated that this amounted to a total 'income gap' of nearly £8 billion between the incomes of disabled and non-disabled persons (Disability Alliance, 1990, pp. 11-12).

The Conservative Government's response to the OPCS findings was eventually laid out in the White Paper *The Way Ahead* (DSS, 1990). The policy focus determined by the review aimed support at 'those disabled early in life, for whom disability is financially more disruptive' (DSS, 1990, p. 6). In turn, those of 'working age' were targeted as a priority. As Glendinning (1992, p. 93) argues, whilst these needs were important, the strategy ignored some of the highest levels of deprivation and

disadvantage revealed by the OPCS survey. In particular, the incidence of disability in old age and inequalities *between* disabled people on grounds which have nothing to do with impairments or other social circumstances (Walker, 1990).

Changes to the disability benefits structure proposed in the White Paper and enacted in the 1990 Disability Living Allowance and Disability Working Allowance Bill, combined the former attendance and mobility allowances into a single benefit – DLA - with new lower rates for those under 65 with less severe attendance or mobility problems. Commentators were highly critical of the changes made. For Glendinning (1992, p. 94) and others (see Large, 1991; Walker and Walker, 1991), reform failed in two main aims by neither simplifying nor 'targeting' benefits effectively. In terms of administration, some harmonisation of assessment, decision-making and appeal systems occurred, but the overall structure still included eleven different benefit combinations with nine different impairment criteria (Large, 1991, p. 117). The structure of the new allowance was justified on the grounds that the existing mobility and attendance allowances were targeted on those with either the severest disabilities or highest costs (Walker and Walker, 1991, p. 44). However as Glendinning (1992, p. 94) reiterates, evidence from the OPCS surveys questioned this assertion. For example, over a quarter of older people in OPCS's 'most severe' category of disability were not receiving attendance allowance; nor were 15 per cent of the most severely disabled people of working age (Martin and White, 1988). For both benefits, almost half of the adults not receiving them said that they had never heard of them (Martin and White, 1988) – therefore making it debatable whether these benefits were even 'targeted' effectively on those with identifiable needs.

As stated, the review of disability benefits coincided with a wider review of social security in the mid 1980s. Although the then Secretary of State for Health and Social Security, Norman Fowler, had claimed in his Green Paper that 'the review...has not included benefits specifically for disabled people' (DHSS, 1985, p. 39), the established link between low income and disability meant that it was inevitable that disabled people would be affected by the comprehensive changes made to means-tested supplementary and housing benefits (Glendinning, 1992, p. 96). Through a process of 'simplification', the shift to Income Support (IS) removed 'additional requirement' payments. These covered provision such as extra heating, special diets

and the costs of private domestic assistance up to the costs of a live-in helper –
provision used by an estimated 300,000 disabled people (Glendinning, 1992, p. 96).
When the system changed, these extra payments were consolidated into fixed weekly
'disability' and 'severe disability' premiums. Whilst even Government figures
estimated that around 80,000 'sick and disabled' people would lose out by this shift
(Glendinning, 1992, p. 96), it was envisaged that part of the loss would be met by
payments made through the introduction of the Independent Living Fund (ILF).

Establishing a link between cash and 'care': the Independent Living Fund

Following implementation of the 1986 Social Security Act, the ILF was launched by
the Conservative Government in co-operation with DIG in 1988 to compensate for the
loss of the additional domestic assistance payments made to disabled people.
Furthermore, the ILF was also a response to alleged risks that the removal of the extra
assistance payments would result in some severely disabled people having to enter
residential care - an outcome that would clearly conflict with the push towards care in
the community being promoted at that time. Therefore, although initially seen as only
a temporary measure – to cover gaps in provision prior to implementation of the
community care reforms in April 1993 – its importance was also 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 their local authority or
families (Zarb and Nadash, 1994, p. 6).

Although the ILF assumed a 'service' based rationale, its position differed from
mainstream local authority provision of services in that it was a national charity,
covering the entire UK and was originally designed with no connection to local
services. Establishing the ILF as a charity enabled the structure to be set up quickly,
thereby eliminating the delay that would be entailed in drafting and passing
legislation. This followed the format used previously for other government funded
support for designated groups. Notably the Family Fund established in 1973 drew on
this framework and it was considered for the Social Fund between 1986 and 1987.
Payments from the Fund were at the discretion of the Trustees although eligibility
criteria were later tightened in order to keep demand in check (Roll, 1996, p. 11). In
keeping with earlier policy pledges, access has been 'targeted' on those with either the
severest disabilities or highest support costs. In turn, those qualifying for

consideration had to receive AA; to have resources at or below IS level; to live alone or with someone else unable to care for them; to be severely restricted in their ability to perform normal personal care or domestic tasks without extensive help; and to be on income support, or have income and capital below income support levels after they had met the costs of essential personal care and domestic help. As suggested, excess demand led to a tightening of criteria and the exclusion of those in receipt of the lower rate of AA and people under 16 or over 75. Over 75s were then readmitted although trustees eventually limited awards to people receiving income support (Roll, 1996, p. 11).

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, p. 201). However, implementation proved to be remarkably successful and highlighted a number of benefits for users (Kestembaum, 1992) As Zarb and Nadash (1994, p. 6) note, although it was initially estimated that there would only be around 300 new awards per year (with a maximum of 1,250 overall), these forecasts were soon over-taken 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 (Kestenbaum, 1993).

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, p. 7; Kestenbaum, 1993; Oliver and Zarb, 1992). As a result of the ILF's popularity, government plans to close the fund were reconsidered, replacing it with two new charitable trusts. Existing users continued to receive payments through the Independent Living (Extension) Fund and the Independent Living Fund (1993) was run alongside services provided or purchased by local authorities. Establishing this closer link between the ILF and local authority social (work) service provision was intended to reinforce the key role given to local authorities in implementation of the 1990 community care changes from April 1993.

Shifting cash from the centre: local authorities and the ILF

Since its revision in 1993, the ILF (now known as the ILF (1993) fund) is 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 new fund are similar, there are important differences. For example, it remains funded by central government, payments are made at the discretion of trustees and are not treated as income for means-tested benefit purposes (although initial access to the fund itself is subjected to a means-test). However, whereas applications were made directly to the fund, local authorities are now charged with this responsibility and both budget and eligibility criteria are much more restrictive (Roll, 1996, p.11). Alongside the shift in ILF administration, a clearer link has been made between payments and use of local services. As such, applicants are now required to be in receipt of services worth £200 per week. Although ILF payments can be used to purchase additional support to supplement local services, the cost of support is strictly cash limited to £560 for the total cost of payments and services.

The development of the ILF (and its successor) represents an important shift in the framework of state support for disabled people. Part of its importance was perhaps the symbolic shift in providing cash for disabled people to 'buy-in' services. In making cash available for users to purchase 'care', a break with the traditional separation of 'cash and care' between national and local tiers of government was made. This will be returned to in chapter VI and explored alongside local authority roles in the provision of 'care' services and the introduction of direct payments into this framework.

Income maintenance and disability

In detailing state provision of disability benefits from central government, discussion shifts to provide an overview of 'income maintenance' benefits for disabled people through the social security system. Unlike the previous focus on benefits designed to meet some of the extra costs associated with disability, this group relates more specifically to payments made in relation to employment, as support is aimed to compensate absence of earnings or low pay.

All social security claimants of working age who are not in work are categorised by the social security system into one of three main groups. The definition of

'unemployed' refers to those capable of work and therefore requires them to be actively seeking and available for work. A second group are categorised as 'unavailable' for work because they have other responsibilities, as in the case of a lone parent caring for their children. Finally, a third group is defined as 'incapable' of work. Those in either of the last two categorises are not required to be actively seeking or available for work, but nevertheless may be so (Rowlingson and Berthoud, 1996, p. 19). This framework, although broadly sustained, has been subjected to redefinition over the past decade. Whereas disabled people have been traditionally placed in the third group as 'incapable' of work, policy change from both Conservative and New Labour governments has narrowed this category.

Earlier discussion in this chapter has already shown how the Conservative Government in the 1980s and early 1990s included disability benefits as part of their reform of the social security system. The process began with 'targeting' benefits broadly associated with the extra costs of disability in the early 1990s and then shifted to income maintenance support by the middle of the decade. Re-structuring focused on two main areas - contributory benefits for those deemed unable to work (incapacity and related benefits) and in-work benefits (the disability working allowance).

As suggested, the need to reform what was then invalidity benefit (IVB) fed into a wider agenda to 'target' benefits on the most needy and avert what was increasingly being seen as a 'dependency culture' of benefit claimants (Moore, 1989). Although disabled people continued to be perceived as part of a 'deserving poor' (Taylor-Gooby, 1991), concern mounted over a trebling of IVB claims between 1975 and 1995 (Berthoud, 1998). Commentators such as Berthoud (1998) argue that the main reasons for this rise link in with wider changes in employment patterns. These have resulted in a gradual shift down the severity scale, so that men and women with middle-severity impairments who would have been employed in the 1970s are now out of work and receiving incapacity benefits. However, the Conservative's response to this rise was to introduce tighter and more rigid medical assessment criteria in April 1995 when incapacity benefit (IB) replaced IVB. As Rowlingson and Berthoud (1996, p. 21) note, until then general practitioners, who had main responsibility for deciding who was incapable for work, had some discretion over the factors they took into

account. This was replaced with the introduction of a points system of 'objectively defined impairments', subject in most cases to an examination by a Benefits Agency doctor (Bethoud, 1998). Therefore, if the claimant had a sufficiently high severity of impairment score they were deemed 'incapable' of work (Bonner, 1995).

This shift to a heightened focus on the medical model of disability has been criticised widely (see Bonner, 1995). In designing a test based solely on functional ability, wider interactions between impairments and other relevant criteria – such as age and previous experience – are negated (Rowlingson and Berthoud, 1996; Berthoud, 1998). Moreover, the success of this shift has been debatable, with fewer people than expected disallowed benefit. As Berthoud (1998) states, preliminary evidence suggests that very few of them found a job – raising the question of whether they were, in fact, 'capable of work'. However, the number of people beginning a period of claim fell substantially after the reform – implying that a more stringent test may have achieved its objective of cutting spending.

Incapacity Benefit and New Labour: tightening definitions

Whilst Conservative changes to incapacity benefit made in the mid-1990s resulted in some cost savings, New Labour have taken reform and cost cutting a stage further. Implementation of the Welfare and Pensions Act (1999) introduces a means test and tougher eligibility criteria for all persons claiming incapacity benefit. This means that anyone with a private pension of £85 per week or over will start losing their weekly IB payment at a rate of benefit loss of 50 pence in the pound, with complete removal when pensions reach £11,362 per year. Also, new claimants will not qualify for benefit if they have not made the equivalent of one year of national insurance contributions in the last four years (The Guardian, 2 November 1999).

Interestingly, the new changes were originally proposed in 1993 by the then Treasury Chief Secretary, Michael Portillo, but were rejected by Peter Lilley, Secretary of State for Social Security at the time. New Labour have presented the changes as part of their overall strategy for welfare reform. This has extended New Right rhetoric of 'dependency culture' to include disabled people, with Tony Blair promising to end 'the something for nothing culture' (cited in The Guardian, 2 November 1999).

Moreover, these changes link in with two wider goals in welfare reform pursued in recent years. Firstly, New Labour's focus on work as the primary means of tackling social exclusion (policy change in this area is returned to later in this section) and secondly as part of a broader drive towards the privatisation of income maintenance provision.

In-work benefits: the introduction of Disability Working Allowance (DWA).

Part of the Conservative's re-organisation of disability benefits in the early 1990s focused on a wider strategy to develop in-work benefits to improve incentives to take up low-paid work. In line with the implementation of Family Credit (FC), the DWA was introduced to act as a 'top-up' supplement to the earnings of disabled people in low paid jobs. However like FC, DWA also involves a detailed means-test resulting in a marginal tax rate of up to 94 per cent. This marks a key distinction from 'extra costs' benefits, such as DLA, which can be claimed whether people are in work or not. All the well documented difficulties associated with family credit – low take-up, poverty traps, on-going changes in the circumstances of many claimants – became transferred to DWA claimants (Glendinning, 1992, p. 95). Furthermore, new claimants have been required to find a job before they can apply for the benefit (Witcher, 1991). Perhaps unsurprisingly then, DWA has had a much smaller impact than was hoped. Research suggests that financial incentives made little difference to the prospects of people who cannot find a job in the first place (Berthoud, 1998).

Changes under New Labour: the introduction of tax credits and the New Deal

Given the problems associated with the DWA and the limited advantages offered by the policy, New Labour moved to abolish the benefit, replacing it with the Disabled Persons Tax Credit (DPTC) from October 1999. Government guidance underlines the main advantages of this shift, stating that it will offer lower income tapers, higher earnings thresholds and improved help with child care costs (DSS, 1999a, p. 5). Whilst it is too early to gauge the impact of this move, the change may once again be more symbolically important. Its shifts state support for disabled people outside the boundaries of the social security system and social (work) service departments, and instead uses the Inland Revenue as the administrator. This removes direct associations

of 'dependency' and 'care' associated with social security and local authority provision.

The New Deal for Disabled People

As part of New Labour's 'welfare to work' policy drive, disabled people have been included as a key constituent of the New Deal agenda. Although the initiative is based largely on developing information and advice services outwith the benefits system, its inclusion in this section does provide a brief insight into the direction of policy.

Government figures suggest that there are around a million unemployed disabled people who would like to work (DSS, 1999a, p. 3). In conjunction with the Department for Education and Employment's work focussed programmes, the DSS has introduced a number of work incentive measures. Personal advisors have the dual task of informing people of employment opportunities and benefits. (DSS, 1999a).

Again, it is unclear how successful the initiative will be, but it does mark a significant shift from a sole focus on medicalised conceptions of disability dominating disability policies, towards more ability-centred policies (Berthoud, 1998). To date, New Labour policies for disabled people show both a continuation and break with Conservative initiatives. On one level, changes made to IB indicate a strengthening of the Conservative focus on 'targeting' benefits. However, a wider appraisal of Blair's attack on a 'dependency culture' has resulted in more inclusive policies – such as introduction of the DPTC. This inconsistency is underlined in a statement by Social Security Minister, Stephen Timms:

> We need to stop writing disabled people off to a life on benefits and doing nothing to help them achieve their ambitions and become more independent. We need to ensure that help goes to the right people. We need to provide extra help for disabled people with the greatest needs.
>
> DSS (1998).

To summarise, this section has documented key changes in central government's role in supporting disabled people. This began with a shift from the post-war welfare state

where disability support was largely through means-tested social assistance to the development of specific benefits from the 1970s onwards. Discussion has also focused on a changing ideas of disability and dependency. Disabled people continue to be constructed through a medical model as dependent but at the same time there is an ideological attack on a 'dependency culture' in the social security system. The following section moves onto examine support through the notion of 'care'. This is introduced by tracing state support organised through local government.

'Care' in the community: provision for disabled people at the local level

In contrast to the development of cash benefits made through the social security system in the 1970s, local authority responsibilities to provide 'care services' for disabled people developed much earlier. This section gives a brief overview of provision, highlighting a legislative patchwork in the post-war era towards more formal re-organisation of responsibilities through the 1990 NHS and Community Care Act. Whilst changes culminating in the 1990 Act represented a long term push towards supporting people in a home environment, an exhaustive history of community care in Britain is not given here (for further details, see Means and Smith, 1998, pp. 16-46). In turn, the shift to more community-based service provision for disabled people is linked to wider attempts to 'roll back the boundaries of the state', going beyond the process of de-institutionalisation. This introduces some of the issues which will be explored in more detail in the next chapter, as policy discourses are examined more thoroughly in the context of the overall restructuring of welfare. Accordingly, discussion at this stage explains how direct payments fit into the framework of state support for disabled persons. This sees policy breaking with the traditional 'cash and care' divide between central and local tiers of government.

Care provision in the post-war period

Earlier discussion in this chapter focused on how disability policies have traditionally been framed around medical interventions. Support from central government has generally focused on providing cash benefits to support assessed needs. Conversely, at the local level, major policy programmes have been organised through health and social (work) services and framed around the notion of 'care'. Although these bodies deliver domestic services, historically their main roles have been to develop an

increasingly diverse range of segregated projects such as day care centres, social clubs, residential homes, workshops and long-stay institutions (Drake, 1999, p. 69).

Initial duties for local authority service provision were laid out in Section 29 of the 1948 National Assistance Act. This was followed by primary enabling legislation for local authority providers in Section 12 of the 1968 Social Work (Scotland) Act and Section 2 of the 1970 Chronically Sick and Disabled Persons Act in England and Wales, which places a duty on social services authorities to provide particular kinds of support to disabled people where they have been assessed as needing them. As Priestley (1999, p. 39) notes, many of these responsibilities are concerned with practical help, adaptations and the provision of information about services. Additionally, Section 21 and Schedule 8 of the 1977 National Health Service Act gives social services departments the power to provide certain other kinds of support (such as laundry services and home help). District health authorities are also empowered to provide community care services by Section 3 of the 1977 National Health Service Act. This followed provisions also set out in Section 14 of the 1968 Social Work (Scotland) Act. Requirements for health and social services authorities to provide care services to some people with mental health problems are outlined in Section 117 of the 1983 Mental Health Act in England and Wales and Section 4 of the 1984 Mental Health (Scotland) Act.

Post-war legislation focused largely on giving local authorities discretionary, enabling powers rather than mandatory obligations to support disabled people in the community (Priestley, 1999, p. 39). Despite the fact that the provision of some services followed automatically from an assessment of need, there was no requirement to assess those needs in the first place. Therefore, implementation of the 1986 Disabled Persons (Services, Consultation and Representation) Act represented a significant shift in that it outlined local authority duties to assess service needs under the 1970 Act. This duty was reinforced in Section 47 of the 1990 NHS and Community Care Act (Scottish Office Circulars: SW11/91 and HHD/DGM(91) 40 – see McKay and Patrick, 1998 for more details) which required local authorities to assess users where it appeared that support services might be needed.

Changing agendas: Care provision in the 1990s

The legislative patchwork of community care services in the post-war era highlighted the need for a cohesive framework for policy. For the Conservative Government, this was accentuated by an escalation in the costs of care throughout the 1980s. The main contributor to these rising costs was a DHSS ruling made in the early 1980s which made it easier for residents of private and voluntary homes in receipt of supplementary benefit to claim their fees from the social security system. This meant that public subsidy of individual support was based solely on an assessment of financial entitlement and not a need for such care. Although this focused largely on the provision of residential care for older people (see Means and Smith, 1998, p. 50), it added considerable impetus to policy change across all user groups. For younger disabled people, the closure programme of long stay institutions and gradual emergence of independent living projects (see Priestley, 1999, p. 71) at this time contributed to broader changes in support. As a result, the government commissioned a series of reports to examine why community care policy had remained so disjointed over such a long period of time. The first of these - the Audit Commission Report (1986) *Making a Reality of Community Care* – noted that whilst the policy of successive governments had been to promote and foster community care, local authority services were still highly dependent on institutional and hospital-based resources. It reported slow and uneven progress in achieving a shift towards community-based services and recommended organisational, staffing and funding changes as a basis for a more formal policy transition.

In response to the Audit Commission's findings, the then Secretary of State for Health and Social Security, Norman Fowler, commissioned the Chief Executive of Sainsburys, Sir Roy Griffiths, to develop proposals for reorganising community care. Publication of Griffiths' findings in 1988 signified an important departure in the direction of local authority service provision for disabled people. By addressing the long term mis-match between community care services and resourcing, Griffiths stated that local level responsibilities between health authorities, social (work) service authorities, housing authorities, the voluntary and private sectors were poorly co-ordinated. Central to his proposals was the creation of local mixed economies of care whereby services were to be provided through private and voluntary sectors. Whilst

promoting voluntary and private groups as integral service providers, a key role was given to informal care. Use of this group linked in with two main areas of New Right thinking: cost efficiency and traditional family roles. Consequently, a strong emphasis on a discourse of 'care' emerged in the context of reform. As suggested earlier, for the disability movement this focus has been especially problematic (see Morris, 1991; 1993a; 1993b) and is therefore a theme that will be re-visited later in the thesis.

Overall, these changes were designed to largely remove the local authority role from provision and redefine it as an 'enabler' or facilitator of services (Griffiths, 1988, p. vii). In these terms, packages of care for individual users were to be framed on a 'needs-led' basis (Griffiths, 1988, p. 6) and assessed through a care manger. This addressed what Griffiths considered to be a 'service-led' tradition in local authorities where 'activities tend to be dominated by the direct management of services which take insufficient account of the varying needs of individuals' (Griffiths, 1988, para. 4.7). Furthermore, the focus on individual 'need' drew also on an aim to limit the aforementioned escalation of social security subsidies of residential care occurring since the early 1980s. A more detailed discussion of the thinking informing these changes is given in chapter III.

Griffiths' key proposals – the development of 'local care markets' and the provision of 'needs-led' services through individual care assessments - were adopted in the White Paper *Caring for People* (1989) and the subsequent NHS and Community Care Act (1990). In outlining the Government's commitment to community care, the White Paper defined this as 'providing the services and support which people who are affected by problems of ageing, mental illness, mental handicap or physical or sensory disability need to be able to live as independently as possible in their own homes, or in 'homely' settings in the community' (Department of Health, 1989, p. 3). Therefore, local service provision for disabled people became formalised as part of a wider network of 'care' services.

Since implementation of the 1990 Act, several legislative changes have been made – drawing on many of the policy discourses outlined in the original policy framework. The first of these was implementation of the 1995 Carers (Recognition and Services) Act. This gave persons providing informal 'care' on a regular basis the right to a

separate assessment. In turn, social (work) services became required to take their views and the results of their assessment into account when deciding what services to provide to the person being 'cared for'. More recently, provision of services for carers has gained a higher policy profile as direct payments look set to be extended to this group. The other significant change to the framework of community care adopted by the Conservatives was implementation of the 1996 Community Care (Direct Payments) Act.

Challenges to the 'cash and care' divide: introducing direct payments

Whilst the background to the legislative shift to direct payments is explored in chapter III, at this stage discussion highlights the emergence of policy in the context of the overall network state support for disabled people. In these terms, direct payments form part of the remit of services offered through local authorities. As will be detailed in chapter III, the 1996 Community Care (Direct Payments) Act is enabling legislation – therefore initial access to a payment is determined by the decision of the local authority to offer the policy or not. Otherwise, users are assessed through the same route as mainstream community care services and are given an equivalent payment to secure the relevant services (Department of Health, 1997, para. 5). Therefore, it is emphasised that 'local authorities should not offer direct payments to people who do not meet their usual eligibility criteria for community care' (Department of Health, 1997, para. 7; Scottish Office, 1997, p. 7).

In line with ILF payments, direct payments are not means-tested or classed as taxable income[ii]. Therefore, entitlement to other social security payments remains unaffected. However as will be shown in chapter VII and VIII, users *are* constrained both indirectly - through payment interaction with ILF packages - and directly - through local authority charging policies. Earlier discussion of eligibility for the ILF (1993) Fund showed the establishment of a clearer link between payments and use of services. This requires users to be in receipt of £200 worth of services per week when making an application to the fund. Hence for direct payment users, those with greater needs will be required to apply for ILF funding for services over the £200 limit. Whilst this gives users in receipt of both payments a larger cash sum to buy in their

required support, means-testing of the ILF component means that either employment earnings or personal savings are restricted.

Furthermore, given that direct payments fit into the wider framework of community care assessment and eligibility, central policy guidance 'enables the local authority to require the individual to make a financial contribution to the cost of his or her care' (Department of Health, 1997, para. 44). Therefore as will be shown in chapter VIII, in areas where local authorities levy a means-tested service charge, direct payment users may become penalised through earnings and/or savings.

One of the themes highlighted in this chapter has been the broad separation of 'cash and care' in support for disabled people between central and local government. Clearly, two policy changes: the introduction of the ILF and emergence of direct payments challenges this divide (alongside the ambiguity surrounding AA). Writing prior to development of direct payments legislation, Fitch (1995, p. 24) argues that the advent of consumerism across public services poses a fundamental challenge to the 'cash and care' divide. Moreover, he suggests that the introduction of direct payments would create intense pressure to unify central and local systems of support. This pressure has yet to manifest itself, but for local authorities proceeding with direct payments, users may increasingly find themselves in receipt of several cash sums from central and local government to purchase and cover their day to day living expenses. Therefore, the implications of this shift in state support is one of the broader themes returned to later in this thesis.

Also, in light of the push towards a model of cash payments pursued over the last forty years, it is interesting to consider why the struggle for a comprehensive *rights based* disability income was unsuccessful yet the campaign for direct payments met with some success. Part of the reason for this may be that the disability movement itself has always been ambivalent on the position of benefits. Hence, it is argued that they fail to cover the full costs of living with an impairment and create and socialise disabled people into dependency (C. Barnes and Oliver, 1998, p. 97). At the same time, the previous Conservative Government and New Labour have framed disability benefits as a safety net to unemployment. In many areas, direct payments are subjected to means-tested charging policies and are seen as a basis of providing

services to meet assessed needs. However, they offer more individual autonomy through their cash status and may be seen as half-way between a disability benefit and a rights-based income. Hence, these attributes allow them to be supported by government and the disability movement. These are issues that will be returned to in chapter III as the background to the disability movement's campaign for direct payments is explored in more detail.

Conclusions

This chapter has provided an outline of the network of state support available to disabled people and discussed how direct payments fit into this framework. In doing this, discussion has focused on the broad separation of support from central and local government levels and introduced a number of themes which will be returned to throughout the thesis. In the nineteenth century, disabled people were first constructed as a 'deserving poor'. Subsequently, they were redefined into sub-groups as income maintenance developed in the twentieth century, establishing inequalities *between* different groups of disabled people. The unsuccessful campaign for a disability income and the increased reliance on means-tested benefits underlined an inherent tension between 'rights' and dependency. The focus of the next chapter provides a more in-depth appraisal of some of these issues as direct payments are examined in the context of a wider restructuring of welfare.

Notes

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[i] Thanks to Caroline Glendinning who provided this analogy.
[ii] A more detailed appraisal of the interaction between direct and ILF payments is given in chapter VI, in the sub-section entitled 'Cash and care: direct payments and the ILF'.

Chapter III: Direct payments and the restructuring of welfare: *changing frameworks, changing subjects.*

Introduction

DISCUSSION IN THE last chapter outlined the provision available to disabled people and introduced direct payments into the framework of state support. Whilst a broad division of support between central and local government was highlighted, direct payments were shown to break with the 'cash and care' divide established between these levels. However, the emergence of policy draws strongly on many wider issues in the overall restructuring of social policy. Central to this shift is an attack on the 'universal post-war welfare state'. This attack may be broadly located at two levels which, in turn, will be focused on throughout the chapter. Firstly, through organisational changes in the nature of *service delivery*, policy has shifted from an emphasis on uniform, universal and centrally organised state provision of welfare services to a more decentralised, residual, pluralistic and 'consumer-led' framework. This links to a second area where representation of the *service user's demands* in policy has moved from the assumption that a service user is a white, able-bodied and male head of household to a recognition of key social divisions such as gender, 'race', class, age, sexuality and disability.

Presenting direct payments as a product of both structural reorganisation in service delivery and user negotiation, requires understanding of change at both these levels. Changes in the delivery of social policies reflect the shifts towards 'welfare pluralism' or a 'mixed economy of welfare' emerging from the mid-1970s onwards from voices across the political spectrum. Whilst the development of a mixed economy of welfare is usually viewed as a key part of New Right social policy reform during the late 1980s and 1990s, support was introduced under the previous Labour Government. This chapter begins with a focus on the concept of 'welfare pluralism', employed first by commentators on the centre-left in the 1970s and then revisited in the late 1980s by the New Right through the increasing use of 'quasi-markets' in education, housing, health and social services. By looking at changes to

social service delivery determined through the 1990 NHS and Community Care reforms, attention is drawn to the formation of local 'care markets' and the accompanying discourse of consumerism. Policy change not only altered the structure of service provision through its emphasis on alternative providers, decentralisation and cost-efficiency, but redefined the social service user as well. In this sense, the rhetoric of *user empowerment, control, choice* and *needs-led provision* became integrated into service planning and delivery. This instigated a more individualised focus on the user role, transforming it from that of 'passive recipient' to 'active consumer' of services.

Attention is then focused on a parallel impetus for policy change from the Disability Movement. Drawing on the experience of traditional 'new social movements' including feminist, anti-racist and gay and lesbian rights groupings, collective action emerged to place civil rights for disabled people onto the policy agenda. Although much has been written on the position of disability as a new social movement (see for example, Shakespeare, 1993; Oliver, 1990), commentary here focuses on the emergence of Centres for Independent Living (CIL). However, examples of the growing influence of disability activism are shown through two main policies put forward since the late 1980s: anti-discrimination legislation and the introduction of direct payments. As discussion will show, lobbying for anti-discriminatory measures first highlighted gaps between the demands of the disability movement and the limits imposed by government. Therefore, whilst collective action may be seen to be highly important in securing change, the boundaries in which such influence operates are shown to be rigidly controlled by central government.

The development of direct payments is discussed in the context of 'market' and independent living frameworks outlined in chapter I. On one level, direct payments may be seen as part of a more pluralistic, cost-efficient and decentralised network of service delivery where it is envisaged that individual consumption dictates the pattern of provision. However at the same time, their emergence represents a victory for the independent living movement and a push to gaining genuine user empowerment and control. This section explores the initial interaction of these two impulses for change by tracing the specific evolution of direct payments and early responses to the legislation.

The chapter concludes by briefly revisiting some of the issues surrounding policy development described in chapter I.

Changing agendas, changing structures: *reorganising service delivery and the birth of the welfare consumer*

Since the 1970s, there have been challenges from across the political spectrum to the structure of the welfare state framed in the post-war period. This section considers the key shifts occurring over the past thirty years. Discussion begins with calls for change and then focuses more specifically on ideas developed in the 1970s when a 'welfare pluralist' agenda first emerged from commentators on the centre-left of the political spectrum. Paradoxically, a more left-wing critique also emerged at the time from some academic quarters and public sector activists (see for example, Clarke, 1979; Bailey and Brake, 1975). Whilst all these ideas placed the notion of a more diverse and localised network of welfare service provision and a more involved welfare recipient on the policy agenda, it was not until the third Thatcher term of government that similar ideas gained any influence. Therefore, as commentary shifts to policy change in the 1980s and 1990s, the principles of quasi-markets in social policy are discussed with the impact of changes for social (work) services. In turn, this introduces a more direct focus on the plans laid out in the 1990 NHS and Community Care Act.

Changing agendas: the 1970s

Throughout the post-war period, all major political parties in Britain subscribed to the goal of a state-funded welfare system in which the bulk of welfare goods and services were delivered by either central or local state institutions (Ellison and Pierson, 1998, p. 32). By the mid-1970s, this Beveridgian settlement appeared to be increasingly difficult to sustain. Cross party concern emerged over the increasing costs of welfare services, coupled with accusations of bureaucratic paternalism and professional self-interest within welfare institutions.

There were growing calls from across the political spectrum for solutions to the 'welfare crisis'. It was alleged that the welfare state was wasteful, overly bureaucratic, insensitive to user needs and run for the benefit of service providers. However, it was not until the mid-1980s that a fundamental restructuring of the

provision and consumption of services took place. Concern over welfare costs and inefficiency were of particular resonance within social services, whose spending formed the second largest item in local authority budgets (Cochrane, 1993, p. 71) and whose work exemplified New Right concerns that the welfare state had become a 'nanny state'. In these terms, the political pressures were established to encourage a move away from direct state provision towards eventual development of 'enabling' authorities in the late 1980s (Ridley, 1988). This structural change had two main aims: to push welfare recipients away from passive dependency on state provision and to 'enable' other non-state organisations to deliver social services. Together these arguments formed the basis of a framework of welfare consumerism which dominated change across the welfare state. This period of reform will be returned to shortly.

Although the discourse of consumerism is more widely equated with New Right social policy reform during the late 1980s and 1990s, support originated under the previous Labour administration through the work of the Wolfendon Committee 1978). This focused largely on discussion around the concept of 'welfare pluralism' (Johnson, 1987) and its application to social services. Central to this mode of reorganisation was a shift away from a state monopoly in the provision of services towards a mixed economy where voluntary and private sectors would be included as key providers.

Whilst Wolfendon's work was halted by the election of the Conservatives in 1979, commentary from the 'centre-left' continued to develop in the early 1980s. In 1981, Hadley and Hatch (1981) espoused the benefits of a more pluralistic framework in organising and providing social services. Their main focus reiterated the contention that centralised social services from 1940s onwards had failed, mainly because they had developed into large, rigid, unaccountable bureaucracies, which alienated consumers. As a way forward, they proposed an alternative structure. The key features of this structure focused on developing a role for alternative providers, with a main role for the voluntary sector role working in partnership with state services. This emphasised the need to decentralise services, thereby encouraging a community orientation to provision. Similarly, it was envisaged that accountability should be structured through contractual rather than hierarchical means - thus both attacking

the dominance of professionals and encouraging participation and representation of users. Furthermore as mentioned earlier in this section, a left-wing attack on public service structures also emerged during the 1970s.

Although these ideas failed to enter the mainstream of policy thinking through this framework, key themes re-emerged in the late 1980s in a more substantive restructuring of the welfare state.

Changing agendas: the 1980s and 1990s

As suggested, despite the apparent ideological incompatibility of a welfare state with the principles of Thatcherism, social policy structures remained largely in place throughout the first two Conservative administrations (Le Grand and Bartlett, 1993). However, from 1988 a series of radical reforms was introduced across the main welfare areas of education, housing, health and community care. Whilst the framework for reform integrated many of the 'welfare pluralist' ideas – the removal of state monopoly in the provision of services, decentralised planning and increased user participation and choice in services – there were key differences. The private sector was promoted as a key service provider whilst state provision was given only a residual role. Furthermore, use of contracting facilitated a more marketised and competitive framework.

In light of these changes, Le Grand (1990) coined the term *quasi-market* to describe the Conservative Government's framework for welfare pluralism. As outlined in chapter I, by introducing market principles into welfare provision, a radical new structure was set in place. Although services remained largely funded by the state, the public monopoly in providing local services was replaced through the development of a variety of private, voluntary and public providers. These service providers were invited to compete with each other through a system of contracting organised through the state's new role as a *service enabler*. This ensured that public services were delivered, but not directly by the state (Deakin and Walsh, 1996, p. 33). Other key differences emerged, distinguishing quasi-market frameworks from a pure market approach. For example, given the nature of welfare provision, it was clear that not all providers would seek or be able to achieve profit maximisation as

some areas would obviously be less lucrative than others. Likewise, 'purchasing' would not usually be facilitated through cash, instead a voucher or ear marked budget confined to a specific service would be used. Moreover in many of these 'welfare transactions', this purchasing decision could be delegated to a third party – i.e. a service professional such as a social worker or general practitioner.

Application of quasi-markets to the social services became an integral part of community care policy developments in the 1990 Act. As suggested, reform focused on two main areas – service provision and the role of the service user. Together these changes underlined the centrality of consumerism and the market in policy change. By introducing 'care markets' into local authorities, the separation of 'purchasing' and 'provider' roles transformed social (work) service departments, which moved from being total care service providers to facilitating 'market development' from private and voluntary sectors. Acute variation in the speed of local authority adoption of these purchaser/provider splits emerged (for England and Wales see for example, Lewis and Glennerster, 1996; Hoyes *et al*, 1994 and for Scotland, Maxwell and Titterton, 1996). Although this led to the development of 'mixed economies of care' at different speeds throughout the UK, central government still secured tight overall checks over policy direction. Indeed, implementation of community care was accompanied by extensive guidance and regulation from the centre and local authority funding was controlled from local and central sources.

In the UK as a whole, differences emerged between England/Wales and Scotland. Through the 1990 Act English and Welsh authorities were required to purchase 85 per cent of their services from the independent sector whilst in Scotland this ruling did not apply (see for example, Perkins *et al*, 1997 for England and Curtice and Fraser, 2000 for Scotland). Therefore, the speed at which the 'care market' was embraced largely reflected the political complexion of the local authority. For example, the Conservative London borough of Wandsworth maximised private and voluntary sector provision of care services (Daniels, 1997) whilst many 'Old Labour' authorities in the north of England and Scotland resisted extensive use of outside agencies.

Focus on the new 'welfare user' or 'consumer' also extended into a more participatory role in service planning. Government enthusiasm for this shift became evident across welfare reform and in broader policy drives such as the 'Citizen's Charter'. This was highlighted in 1991 by the then Home Office Minister, John Patten who predicted that 'participation' was the big unsung idea of the late 1980s, arguing that it would do for social policy in the 1990s what privatisation had done for the economy (cited in Cochrane, 1993, p. 74). This introduced notions of *user empowerment* and *control* to the discourse of consumerism.

Throughout the reform of Community Care, the terms user empowerment, choice and control have been reflected at two different levels of planning. As shown in chapter I, these can be broadly categorised through the notions of 'exit' and 'voice'. To re-cap, 'exit' suggests that users are empowered by choosing between alternative service providers through the care manager role. 'Voice' strategies are based largely on the requirement that local authorities seek the views of users before deciding the overall strategic direction of policy. This requirement appeared to frame the concepts of user empowerment, choice and control more directly as local authorities became obliged to draw up their care plans in consultation with users (Department of Health, 1989, p. 6). In line with the discourse of consumerism and 'needs-led' planning, this provision sought to highlight user involvement in the policy planning process. The impact of this change may be seen as more symbolic than real. This line was implied by ministers in the Major government, one of whom suggested that the new agenda for participation required 'rather more opportunity and effort than money' (Patten, 1991 cited in Cochrane, 1993, p. 74). Indeed, the effectiveness of this requirement appears to be intrinsically determined in practice by local authority willingness to involve and represent user's views in plans (see for example, Glendinning and Bewley, 1992) as well as central government budgetary restraints affecting the overall pattern of services (Means and Smith, 1998).

Furthermore, in line with the introduction of care markets local authorities became required to assess potential service users on a 'needs-led' basis. By representing user needs more specifically through an 'individualised' care package, users may be seen to gain more control through their support. Whilst this policy shift attacked the 'service led' conceptualisation of social work assessment advocated by welfare

pluralists from both right and left, acknowledgement of individual difference has still remained within the limits of professionally defined categories and budgets (Williams, 1994). Indeed a key example of the limits of 'needs-led' planning became apparent in a High Court judgement on the provision of services by Gloucestershire County Council soon after implementation of the 1990 Act. In this case, Gloucester withdrew services from a user in light of social services budget cuts. Having had the decision upheld, this established a precedent for resources to be taken into account when assessing need (Thompson and Dobson, 1995). Consequently, it became clear that statutory obligations only extended to local authorities *defining* rather than *providing* for needs.

Indeed although commentators such as Barnes and Prior (1995, p. 54) maintain that individual empowerment through increased opportunities to increase choice is a worthwhile policy goal, they are critical of the effectiveness of these type of policy claims. In particular, they focus on the concept of choice and argue that far from being empowering, it can often be experienced as a risk:

> Individuals make choices with little confidence that the outcome will provide them with what they want, unsure if the choice will 'rebound' negatively on them at some future date.

As discussion of 'exit' and 'voice' approaches in chapter I and this chapter indicate, implementation of empowerment strategies in community care are limited. These are themes also picked up on by Barnes and Prior. In these terms, they argue that, 'empowerment through enhanced user influence means giving attention to the relationship of users to the whole public service process' (Barnes and Prior, 1995, p. 58). For them, central to this process is to address the inequities of policy-making, resource allocation, planning, organisation and management as well as the consumption of services. This extends into a more collective goal of the empowerment of citizens. These are issues that will be revisited later in the thesis in the context of extending user choice and control through direct payments.

In short, changes across the welfare state have transformed the language, structure and rhetoric of the policy environment. More specifically, this has seen an

increasingly localised and consumer based structure emerge where a more active role for the user has been constructed. Whilst policy guidance has defined the identity of the welfare user operating in the new market culture in individual and consumerist terms (see for example, Department of Health, 1990), around the same time growth in collective and individual activity for specific groups has seen the emergence of an agenda of their demands. The following section highlights some of the attempts that have been made to articulate these needs and influence policy.

Changing structures: *policy change and provision for disabled people*

For disabled people, the past fifteen years have witnessed a growth in collective action, individual awareness and lobbying for policy change. More recently at policy level, some of these demands have been developed through legislative change. Two key examples of this emerged from the mid-1990s with the passing of the Disability Discrimination Act (1995) and the Community Care (Direct Payments) Act (1996).

The development of anti-discrimination legislation provides a useful background to outlining a number of issues surrounding the emergence of direct payments, and some of the conflicts for the disability movement in trying to achieve social change through legislation. Firstly, campaigning for civil rights represented a key issue in the evolution of the disability movement. Having detailed the background to group action in chapter II, through calls for a national disability income, discussion at this stage returns to focus on the articulation a 'rights-based' or independent living agenda. This extends into a second area where the representation of these demands in policy are shown to have been restricted by more dominant 'market' discourses of cost-efficiency and individualisation.

The changing nature of disability activism and the emergence of Centres for Independent Living

The disability movement grew from a gradual recognition by disabled people that neither party politics nor charitable and voluntary organisations were serving their interests appropriately or well (Oliver, 1997, p. 245). Additionally, external influences from the civil rights movement and feminism (both of which had succeeded in getting discrimination outlawed on the grounds of 'race' and gender under statute) added to the impetus for change. As Oliver notes, this aided the

emerging consciousness of disabled people who began to recognise the problem of disability as an external issue; thus societal exclusion became framed as a human rights issue.

As mentioned in the last chapter, political activism by disabled people gained momentum in the 1960s through the campaign for a national disability income. Although this established a rights-based agenda for disabled people, division over the long-term focus of this agenda led to division within the emerging movement. Oliver differentiated between two competing tensions, one emphasising *income* and one emphasising *oppression*. This distinction formed the basis of new groupings, so that the Disability Alliance (DA) was assembled to take on the problem of income and the Union of the Physically Impaired Against Segregation (UPIAS) became the focal point of a wider challenge to social conditions. Differentiation between the groups extended to control in that the Alliance was run by non-disabled 'experts' whilst the UPIAS was restricted to disabled members only (Oliver, 1996, p. 136).

For Oliver, group control became a defining issue in transforming attitudes towards disability throughout the 1980s, where groups run and controlled *by* disabled people increased significantly in number. Indeed by 1990, representation had been established at a number of levels. Globally, the Disabled People's International (DPI) had been set up and national co-ordination was facilitated through the BCODP. This was matched by the emergence of over a hundred constituent BCODP organisations, most of which were local coalitions of disabled people or centres for independent living (CILs).

The first recognised CIL was established in Berkeley, California in 1973. The scheme operated under the control of its users and was founded around issues of housing, personal assistance, accessible transport, access and peer counselling (Priestley, 1999, p. 71). As Shakespeare (1993, p. 250) notes, a large element of the disability movement in North America stemmed from consumerism and self-help. Notably, therefore, in the development of American CILs, consumerism has played a large part in the working ethos of organisations. This has drawn strongly on US traditions of self-reliance and individual rights. In contrast, early attempts to establish independent living projects in the UK met only with limited success and were often

not under the control of disabled people themselves. However by the early 1980s, real change began to be achieved through the struggles of disabled people themselves with collective living projects appearing in Derbyshire, Edinburgh, Rochdale and Gillingham. As Priestley (1999, p.72) notes, these early projects not only provided tangible lived experiences of barrier removal but also demonstrated the potential for an alternative mode of self-organised welfare production.

Significantly for Shakespeare (1993, p. 250) the development of CILs and the wider disability movement in the UK has tended to focus more on the notions of political autonomy and democratic participation. This contrasts with the more individualised and market-oriented US approaches. Whilst the growth of CILs in the UK have been seen as significant in the *collective* representation of disabled people, implementation of direct payments may encourage more individualised and consumer-base roles.

In search of rights: lobbying for anti-discrimination legislation

In line with the growth in disability activism from the early 1980s onwards, a sustained push for comprehensive anti-discrimination Civil Rights Bill for disabled people gained momentum. A total of fourteen attempts were made, culminating in the Disability Discrimination Act (1995). Demands for legislation centred on the removal of institutional discrimination across all aspects of social life. They included areas such as fully accessible public transportation, equal opportunities in education, employment and training, access to non-segregated housing coupled with full inclusion and participation in daily life, thereby also challenging cultural and attitudinal barriers (Evans, 1996).

Despite the continual failure to integrate fully comprehensive legislation, a strong cross-disability lobby emerged working in pursuit of this goal. Individual politicians from across the political spectrum were included and more directly from the Committee on Restrictions Against Disabled People (CORAD). The Committee was established by the then Labour government in 1979 and examined a wide range of institutional and structural issues surrounding disability (Oliver and C. Barnes, 1998, p. 88). Despite initial optimism, the changing political climate following the election

of the Conservative government in 1979 curtailed any chances of gaining a meaningful anti-discrimination bill (Davis, 1996).

By the mid-1980s, the formation of the Voluntary Organisations for Anti-Discrimination Legislation committee (VOADL) represented a key shift in bringing together organisations of disabled people such as the BCODP, alongside more traditional groupings such as the Royal Association for Disability and Rehabilitation (RADAR). As Oliver and C. Barnes, (1998, p. 89) note, this coalition was important because it signified the public conversion of several of the larger organisations for disabled people to the idea of civil rights legislation. Alongside increased lobbying in the UK, international changes in disability law formed an important influence to instigating change. For example, the passing of the Americans With Disabilities Act (ADA) in 1990 following a long and vigorous campaign by disabled Americans, added considerable impetus to the continuing struggle for equal treatment in the UK (Oliver and C. Barnes, 1998, p. 89).

Representing rights: the limits of the official policy framework

From the mid-1980s, a major check to the development of anti-discrimination legislation hinged on three arguments put forward by the Conservative Government. It was maintained firstly that there was no evidence of discrimination against disabled people, secondly that the cost of implementation was too expensive, and thirdly that such a law would be unworkable (Evans, 1996, p. 4). Together, these arguments underlined key New Right concerns over the role of government in securing *collective* rights for minority groups and the related *costs* in maintaining these interests.

In gaining funding to develop a research base, the assertions were challenged in the BCODP report, *Disabled People in Britain and Discrimination* (C. Barnes, 1991). This provided the most extensive quantitative and qualitative research on the extent of discrimination against disabled people in the UK yet produced. As Oliver and C. Barnes, (1998, p. 89) note, governmental denial of disability discrimination still prevailed up until the launch of the study. However, five days after publication in a House of Commons debate during the tenth attempt to get anti-discrimination

legislation through the Parliament, Nicholas Scott the then Minister for Disabled People, admitted for the first time that 'discrimination against disabled people is widespread' (Hansard, 1992).

By the mid-1990s pressure to develop anti-discrimination legislation had gained increased momentum. Alongside lobbying from organised groups, direct action from disabled people added to their campaigning role. Part of the effectiveness of this strategy rested in media interest. As Evans (1996, p. 2) notes, historically it had always been problematic getting publicity for and media coverage of disability issues to the wider general public, but through direct action demands took a much higher public and political profile. An additional dimension to campaigning came through the formation of the 'Rights Now Group' – a group set up in 1992 as an extension of VOADL, specifically to organise and co-ordinate events around campaigning, promoting and publishing the need for legislation. In turn, organisation integrated both group and individual representation *of* disabled people and also those *for* – i.e. traditional charities who had joined together with the sole purpose of attaining legislation (Evans, 1996, p. 3). Again activity through Rights Now was substantiated by a research base, this time challenging the Government assertion – that an anti-discrimination law would be too costly to implement.

In light of the growing profile of disability activism, the Conservative Government came under intense pressure to bring in rights-based legislation. This came at the end of 1994 with the introduction of the Disability Discrimination Bill – later forming the Disability Discrimination Act (1995). However despite the legislative shift, the provisions have been widely criticised (see for example, Oliver and C. Barnes, 1998; Evans, 1996). This criticism has centred on the minimal protection afforded and the terms of reference in which policy has been framed. In its original form, the Act only offered limited protection from direct discrimination in employment, the provision of goods and services and in the selling or letting of land. Moreover, these conditions were framed around a highly *individualised* approach. Whilst this type of thinking links in with wider New Right conceptualisations of 'rights' it invokes two main areas of conflict with a rights-based (or social) model of disability. This will be returned to shortly.

Primarily, for Oliver and C. Barnes (1998, p. 90), the fundamental flaw in the Act rests in its medicalised conception of disability. This is explored throughout earlier commentary by Oliver (1990, p. 46) who has directly linked individualisation with the medical model. By drawing on Foucault's work on madness (Foucault, 1965), Oliver has applied a similar approach to constructions of disability. Implicit in Foucault's analysis is the rejection of 'madness' as an individual problem. Therefore, the focus of his discussion is the role of the professional, in this instance the psychiatrist, and meanings placed on what is considered to be 'pathological behaviour'. For Foucault, psychiatry as an organised professional activity only becomes possible when madness has been transformed from a diverse set of social valuations to a uniform category of pathology. This leads 'the mad' to be excluded from normal social life and isolated into a specialist domain. In short, Foucault argues that there can be no such thing as madness without the idea of 'unmadness'. Oliver's application of this thinking to disability invokes the idea of disablement as an individual pathology only when placed alongside the idea of 'individual ablebodiedness'. Again, drawing on materialist discourse and returning to some of the ideas outlined in chapter II, he argues that this is sustained through the rise of capitalism and the development of wage labour. To re-cap, Oliver (1990, p. 147) argues that disability became individualised through capitalism as disabled people could not individually meet the demands of wage labour and so became controlled as a group through exclusion.

In adopting the individualised nature of consumerist discourses operating throughout welfare restructuring, the Disability Discrimination Act put forward by the Conservatives assumed that the policy structure, wider society and all disabled persons were suitably placed for discrimination to be challenged effectively. Consequently, this type of privatised conceptualisation of the 'disabled consumer' became magnified through the original legislative provisions, where no enforcement mechanism - enabling decisions to be challenged - was established.[i] This extended to the exclusion of those considered to be 'incapable' of articulating themselves without additional support, thus legislation failed to include some people with learning difficulties and mental health problems.

Commentators such as Clarke and Newman (1997, p. 108), have argued that it is the *individualised* focus of consumerism established through New Right thinking that presents fundamental problems in its application to social policies. In this sense, whilst both consumerist and 'independent living' discourses emphasise the centrality of 'choice', 'control' and 'empowerment', the focus of consumerism rests on individual rather than collective realisation of these goals. Hence, it becomes too limited to attack the broader inequalities associated with discrimination. More specifically, this is emphasised by Gooding (1994, p. 173) who argues that 'for an anti-discrimination law to have any real capacity to achieve its goals it must be the product and instrument of a powerful collective movement'.

Essentially, the background to the 1995 Disability Discrimination Act provides an example – albeit limited – to show how 'independent living' and 'market' discourses interacted to achieve *some* policy change for disabled people. Although a similarity in the rhetoric of 'choice' and 'control' was apparent in both government's broader ideological goals and the aims of the disability movement, it is the differences in the realisation of these concepts through 'rights-based' legislation that underlined irreconcilable goals. In short, it was the New Right emphasis on securing rights solely through individual action that was incompatible with the disability movement's calls to achieve civil rights, equal opportunities and independent living at a collective level.

Whilst the development of anti-discrimination legislation highlights a clear conflict between individual and collective conceptualisations of 'rights', the emergence of direct payments differs in that it offers much clearer opportunities for potential conflict *and* co-operation between 'market' and 'independent living' discourses. In these terms, policy integrates a dual empowerment agenda: one which assumes market or consumer-based interests by encouraging diversity and choice in service provision laid out through the framework of quasi-markets, and another which fosters the development of individual and collective control of services. With this in mind, the next section outlines some of the key debates surrounding the emergence of direct payments on the statute.

In search of independence: calls for direct payments

For the Disability Movement, implementation of direct payments has represented an important victory in the push for independent living (see for example, Kestenbaum, 1996; Kestenbaum, 1999). Whilst the roots of independent living lie in demands made by disabled persons who want to leave long-stay institutions, the Independent Living Movement has developed to embrace more comprehensive issues of choice and control (Kestenbaum, 1996, p. 2).

Although direct payments were not adopted as a formal policy until the 1996 Act, various indirect cash payment schemes have been used in some localities since the early 1980s. This required any allocation of a cash payment for services to be facilitated from social (work) service departments to the user through a third party – usually a well-established voluntary sector organisation (Means and Smith, 1998, p. 60). These early schemes underlined two main issues, which in turn, became the focus of the BCODP's Independent Living Committee's campaign for Direct Payment's legislation in 1989. Firstly, the experiences of those disabled persons receiving cash payments indicated that giving money directly in order to recruit and employ their own workers was the key to satisfying personal assistance needs (see for example, Zarb and Nadash, 1994; Kestenbaum, 1996). Secondly, that the availability of existing payment schemes was determined largely by the political will of individual local authorities. By examining reasons behind local development of these schemes, discussion indicates how 'market' and 'independent living' discourses in policy planning for direct payments may conflict and co-operate. From localised experience of early payment schemes, this shifts to a focus on these issues nationally through campaigning to secure formal adoption of policy.

Cashing in early: negotiating payment schemes in the 1980s and early 1990s

Prior to the 1996 Act, confusion surrounded the legality of direct payments. 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 where, through the Social Work (Scotland) Act 1968, local authorities were able to 'give cash to...any person aged 18 years or over who is in need, within the meaning of the Act, and requiring assistance in exceptional

circumstances constituting 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 1995, cited in Rolls, 1996). However, there remains limited knowledge of this provision amongst Scottish local authority personnel and no evidence of cases where it has been applied.

As stated some authorities avoided these constraints by administering payments *indirectly* to the disabled person through a third party voluntary sector organisation or trust in the local area. The first indirect payment schemes in the UK were set up in the early 1980s. As Evans and Hasler (1996, p. 1) note, throughout this time development was slow and only a few areas adopted the approach. Most areas were not keen to take on the schemes because they considered them either too risky or were wary of handing over control to disabled people. In turn where payments did emerge, the rationale for change strongly reflected collective negotiation and lobbying from disabled people and local authority planning conceptualisations of service delivery.

One of the first schemes was developed in Hampshire. As a pioneering authority in the evolution of direct payments, Hampshire's experience provides an initial example of how 'independent living' and 'market' discourses can co-operate in policy planning. The primary impetus to proceed with direct payments came from the actions of a small group of disabled people in Hampshire who persuaded the local authority to allow them to live independently by paying for personal assistance with money used previously to fund their residential care (Zarb and Nadash, 1994, p. 5). The money was allocated to the residential care home which, in turn, made payments directly to each individual on behalf of the local authority. Whilst user support for cash payments in the area rested on the enhanced control and independence secured by employing personal assistance, local authority co-operation focused on the potential for a new 'marketised' model of service delivery offered by the change. In this sense, 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, p. 117).

In contrast, Priestley's (1999, p.117) discussion of integrated living policy development for disabled people in Derbyshire illustrates how conflict between user and planning positions can delay or impede progress. Indeed, despite a public commitment by the local authority to social model principles of integrated living as far back as 1981, open resistance emerged against proposals to replace existing public sector provision with integrated living networks controlled by disabled people. Perhaps surprisingly, local disability activists received more enthusiasm from individual Conservative members who were able to accommodate the idea of self-managed support within their own agenda for increased plurality, competition and consumerism. Therefore in this example, two broad political positions of 'social justice' clearly conflicted. This centred on planning conceptualisations of service delivery and the traditional political affiliations of 'left' and 'right' associated with this role. Hence use of a service provider base out with the local authority was seen by Labour members to directly conflict with 'state collectivist' roles in the provision of welfare. In turn, it was the *rejection* of a 'market' discourse by the local authority that initially impeded policy development. These are themes picked up more specifically in chapters V and VIII as similar conflicts re-emerge in the context of this research.

Negotiating change: challenges from the Centre

Whilst Conservative-led authorities such as Hampshire viewed cash payments as an innovative means of service delivery in line with their own political ideals, nationally the Conservative Government was less convinced. The already ambiguous legal position of direct payments worsened in 1992 when the then Minister for Health, Virginia Bottomley, issued a circular to local authorities running schemes stating that Direct Payment schemes were illegal. As a result of the ruling, many existing schemes were withdrawn by local authorities.

Akin to the development of the Disability Discrimination Act (1995), the formal adoption of direct payments on the statute highlighted a significant shift in thinking for the then Conservative Government. Prior to policy acceptance, a number of issues were outlined as to why policy would not be developed. Again, in line with arguments advocated against civil rights legislation, these hinged largely on 'cost

efficiency'. This was emphasised by the then Minister for Health in the House of Lords, Lady Hooper who stated that difficulties related to 'the proper control of public expenditure and the need to ensure that the local authority is accountable for the expenditure it makes' (House of Lords Debate, 18 June 1990, cited in Rolls, 1996). Rejection of policy on grounds of 'cost efficiency' may also be related to wider themes of 'welfare abuse' articulated in social policy reform from the late 1980s. In turn, 'accountability' and 'efficiency' in welfare have been underpinned by the notions of 'scroungerphobia' that dominated social security reform from the late 1980s onwards (see Cook, 1993; Finn, 1987). Therefore by allocating cash instead of services, direct payments may be framed by some on the Right as by-products of the benefits system and therefore as a medium for potential user abuse. Again this is another theme re-visited later in the thesis.

Lobbying for direct payments drew on the same tactics as those used to achieve anti-discrimination legislation and thus formed an integral part of disability activism at the time. In adopting a campaign strategy in the early 1990s, BCODP's Independent Living group joined together with the Spinal Injuries Association to promote change. Additionally, by utilising the experience of existing indirect payment users, targeting key parliamentary allies and raising awareness through the mainstream and disability press, a heightened profile of activity was gained. Key support came from the Conservative Member of Parliament, Andrew Rowe. Through his work with a constituent using a payment scheme, he became an influential supporter of proposals and a means of accessing a parliamentary voice. This led to the submission of two (failed) Private Members Bill legislating for direct payments. After these initial attempts, the BCODP once again used a research base to substantiate policy demands. This was facilitated through the Policy Studies Institute (PSI) (Zarb and Nadesh, 1994) where the experiences of disabled persons using services were compared with those using cash payments to employ their own personal assistance. As suggested earlier, the research found much higher levels of satisfaction for cash payment users - a finding linked specifically with increased choice, control and flexibility. Furthermore, mainstream service users reported much higher levels of unmet need than payment users. Cost analysis of services also showed stark differences between types of service provision as cash payments were on average between thirty to forty per cent cheaper than equivalent mainstream service based

provision (Zarb and Nadash, 1994, p. 5). In emphasising the issues of cost and quality, the research provided an important base for challenging the Government's position and getting direct payments onto the statute. A week later after publication of the BCODP/PSI findings, it was announced that legislation for direct payments would emerge in the following session of parliament. The change of view was announced in November 1994 by the then Secretary of State for Health, Virginia Bottomley. Having had concerns over accountability and cost efficiency negated, the Government's new rationale for policy support now centred on a re-defined consumerist discourse through the promotion of user participation. In these terms, direct payments were described as 'a logical extension of the citizen's charter' (House of Commons Debate, 24 November, 1994, c333W).

Freedom at last?: direct payments on the statute

The policy framework for direct payments adopted through the 1996 Community Care (Direct Payments) Act may be viewed as evolving from the original Community Care legislative framework (Department of Health, 1990). At this stage of discussion, direct payments policy could be seen as an off shoot of 'local care markets' established by the 1990 Act. Through 'market' discourses of 'individual consumption' and 'locality planning', the idea of *enabling* legislation to achieve direct payments was justified. This gives local authorities the power to allocate direct payments or maintain existing modes of service provision. It is, therefore, important to note that this signifies a key difference from the 1990 Community Care changes. As stated, although the development of local care markets emerged at different speeds across the UK – with particular difference between England/Wales and Scotland – tight overall control from central government was set in place.

However, by presenting local authorities with choice in implementing direct payments, policy immediately conflicts with one of the main aims of the disability movement's campaign for change, as access to a payment remains determined primarily by locality and *not* user choice. Similarly, in line with the development of 'care markets' and points raised earlier in this chapter with reference to research by Priestley (1999), decisions to implement policy still seem likely to draw predominantly on ideological conceptualisations of service provision. Indeed, early

responses to the direct payments legislation would appear to support this supposition, as many local authorities in the North of England have viewed direct payments policy with suspicion and as a means to further erode public sector provision of social services (Zarb, Hasler, Campbell and Arthur, 1997). Similar concern has been expressed in many Scottish authorities. Therefore, as the framework for this research is set out in the next chapter, a need to explore the issues surrounding conflict and co-operation between 'market' and 'independent living' discourses in local policy implementation becomes an implicit goal. However as a precursor to this, the last section of this chapter begins to address how research into direct payments might be understood, by exploring how direct payments may be analysed in the context of the wider restructuring of welfare.

Conclusions

This chapter has explored the emergence of direct payments on the statute in the context of the restructuring of welfare over the past fifteen years and the growth of collective action by disabled people. Challenges to the post-war welfare settlement eventually culminated in a more localised, pluralistic and market-led framework of social policy provision. Around the same time, the growth of the disability movement, led to a more representative policy agenda. However, as lobbying for civil rights legislation showed, influence has been strictly circumscribed within the parameters offered by central government, resulting in only limited change.

In contrast, the emergence of direct payments on the statute has provided more scope for co-operation between central government and the disability movement. The New Right saw legislation evolving as a means of achieving choice and diversity in service provision through a growing network of 'local care markets', established through the 1990 NHS and Community Care Act. Conversely for the disability movement, implementation of direct payments represented an important victory in the push for independent living. However, despite the convergence of policy goals, some points of tension remained. Notably, the failure to make implementation mandatory immediately denies access to many disabled people. Similarly, the question may be raised as to whether local authorities will use policy only as another means of delivering personal care in a home setting or to encourage independent living for users.

Notes

[i] Since implementation of the 1995 Disability Discrimination Act, a Disability Rights Commission has been set in place from April 2000 with the remit to 'to ensure that the laws removing and preventing discrimination against disabled people are enforced'. For more information see http://www.drc-gb.org/drc/default.asp

Chapter IV: Direct payments and the restructuring of research: *changing values, changing structures.*

Introduction

DISCUSSION IN CHAPTERS II and III has broadly centred on the changing *structure* and *user* roles in disability provision and the position of direct payments as part of this process of change. In chapter II, this was explored through the historical development of state support for disabled people. Early state interventions showed a number of key themes replicated throughout policy development. These include:

- Differentiation between a working and non-working population.

- The establishment of disabled persons as a 'deserving poor'.

- Segregation and stigmatisation of disabled persons through medical assessment of impairment.

Throughout the development of the post-war welfare state, these themes have been shown to feature strongly in the organisation of state support for disabled persons. Moreover, by focusing on a division of 'cash and care' between central and local tiers of government, two discourses of dependency have been highlighted at these levels:

- A 'dependency culture' through increasingly residualised cash payments made through the benefit system.

- 'Care dependency' through a shift to community care and greater reliance on familial support as a key welfare provider.

In challenging these two ideas and breaking with the 'cash and care' divide, direct payments are introduced as a fundamental shift in state support for disabled people. A number of issues related to both wider restructuring and re-

negotiation of the user role in social policies and became the main focus of discussion in chapter III. The changes discussed were located in two main areas:

- Organisational change from uniform, universal and centrally organised state provision of welfare to a more decentralised, pluralistic and 'consumer-led' framework.

- Changes in policy representation of the service user - from an assumed white, able-bodied and male head of household to inclusion of social divisions of gender, 'race', class, age, sexuality and disability.

These shifts have been shown to be underpinned by two dominant discourses: one led by 'market' or 'consumerist' interests and a second by independent living and 'social justice' concerns. In documenting the development of direct payments, policy has been shown to integrate both discourses. At an organisational level, direct payments link in with existing 'local care markets' developed through the 1990 NHS and Community Care Act. Conversely for the disability movement, there has been a significant shift towards independent living and securing genuine user empowerment and control.

Challenges to the notion of a 'universal' welfare state have led to a reassessment of the parameters of policy analysis. Discussion in chapter I introduced this idea through the work of Fiona Williams. To re-cap, Williams suggests that for services to be genuinely 'needs-led', the service user needs to be understood not just as a consumer but as an individual with multiple identities. Hence, research into direct payments needs to consider whether policy is capable of recognising diversity or merely reflects a more one-dimensional view of the service consumer. The first half of this chapter explores some of the wider issues pertinent to the restructuring of social policy research – and more specifically in the area of disability.

Part of the shift in understanding disability and the restructuring of welfare over the past two decades relates to a need to reconsider the values framing research production. These provide the structure within which research is undertaken (Oliver,

1992, p. 102). In focusing on the independent living and market discourses underpinning direct payments, this section explores how research has dealt with change at both these levels. Firstly, discussion centres on the shift in disability research – highlighting the inadequacies of positivist and interpretive traditions and emphasising a push towards an emancipatory paradigm. This links to a second area where over the last decade, a body of social policy research has been developed under the guise of 'user empowerment' (see for example, Hoyes *et al*, 1994; Le Grand and Bartlett, 1993). Whilst often presenting a critical appraisal of the consumer role in welfare services, this genre of research has emerged ignoring the role of new social movements in generating policy change. As discussion moves to examine how direct payments should be researched, this type of single dimension policy analysis is rejected in favour of a wider appraisal of user and structural roles. The second half of this chapter begins by outlining the research questions addressed in this study. Discussion then shifts to raise some of the practical and theoretical issues that emerged throughout the stages of data collection and analysis.

Research and representation: *changing agendas for disability research*

Akin to wider historical constructions of disability outlined in chapters II and III, the major critiques of disability research have centred on the conceptualisation of disability as an individual pathology, a medical problem to be treated or a personal tragedy to be pitied (Stone and Priestley, 1996, p. 701). In turn, academics working within these frames have often cast themselves as 'experts' – a role that by implication suggests that the knowledge and experience of disabled people does not count. As Oliver (1992, p. 105) argues, this occurrence has led disabled people to view research as 'a violation of their experience, as irrelevant to their needs and as failing to improve their material circumstances and quality of life'. The following sections document some of the key issues surrounding the challenge to this research paradigm. This draws not only on well-rehearsed critiques of positivist social research, but also focuses on problems within the interpretist tradition. Discussion concludes by laying out the parameters for emancipatory research, from which key principles are drawn for this research design.

'Research as Alienation'

Writing in the early 1990s, Oliver (1992, p. 103) addresses the recent history of disability research through the concept of alienation. He draws on commentary by Rowan (1981, p. 93) who argues that research alienation occurs by 'putting a person into the role of 'research subject' and only then permitting a very restricted range of behaviour to be counted'. In turn, this becomes alienating because 'it is using the person for someone else's ends – the person's actions do not belong to that individual, but to the researcher and the research plan'. As Oliver notes (1992, p. 105), this is not an experience exclusive to the disabled population – similar sentiments have been presented across a number of groups – notably through feminist and anti-racist writers (see for example, Finch, 1986; Jenkins, 1971).

Oliver's critique links into wider debates over the nature and production of research in the social sciences. In attacking both the research *structure* and the role of the research *subject*, he rejects both positivist and interpretist paradigms. As he suggests, (Oliver, 1992, p. 106) the attack on positivist assumptions – that the social world can be studied in the same way as the natural world; that uniform methods can be applied to both the natural and social sciences and that knowledge obtained from such research is independent of the assumptions underpinning and the methods used to obtain it – has been well documented from within the social sciences (Cicourel, 1964; Giddens, 1979; Hindess, 1980) and the natural sciences (Kuhn, 1961; Popper, 1962). This led to the development of interpretive or qualitative approaches. Central to this shift is a view that knowledge is socially constructed and a product of a specific historical context. Unlike positivism, such approaches draw on a number of opposing principles: a rejection of any unity of method; an understanding that research should attempt to explore the meaning of events – not its causes; acknowledgement that research inherently reflects the researcher's view and can never be independent and that the research subject is active and not passive. Critics of interpretive paradigms draw on a range of perspectives – from positivist researchers to critical theorists, Marxists and active research subjects (Oliver, 1992, p. 106). Whilst these accounts are not documented here, as Oliver notes, it is criticism from active research subjects that has led to a reappraisal of disability research.

Attacking interpretism: changing the paradigms of disability research

The advantages of interpretive or qualitative methods over more scientific quantitative approaches have been well developed over the past few decades. As C. Barnes (1992, p. 116) suggests, these techniques are especially suited to small-scale studies where the researcher gets to know the social world being studied first. Moreover, they allow a commitment to the idea that full and adequate knowledge of social behaviour cannot be sought until the researcher has understood the symbolic world in which the subject lives. This invites much greater flexibility in research design than more rigid quantitative techniques such as a large-scale social survey in which hypotheses are tested. However, as Oliver (1992, p. 109) notes, whilst there have been some attempts to undertake disability research within the interpretive paradigm (Blaxter, 1980; Borsay, 1986; Oliver, Zarb, Silver and Moore, 1988), criticisms centre on the failure of this kind of work to have any serious effect on services for disabled people and their quality of life. More specifically, this has left the researcher cast in the role of the 'expert' and the disabled person has been treated as the 'passive research subject' (Abberley, 1987, p. 141) – a role that implicitly maintains that the knowledge and experience of disabled people does not count (Stone and Priestley (1996, p. 701). Together the limitations of both positivist and interpretive research paradigms have led a number of commentators (see for example, Abberley 1987; Oliver 1992; C. Barnes, 1992; Stone and Priestley, 1996) to advocate an *emancipatory* paradigm in order to make disability research more relevant to the lives of disabled people.

Developing an emancipatory paradigm for disability research

As suggested earlier, the process of re-evaluating the values of social research production emphasises a need to focus on both structure and subject. Implicit to both these areas is a recognition of and confrontation with power dynamics (Oliver, 1992, p. 110). These are addressed by Stone and Priestley (1996, p. 702) who advocate a number of key principles required for emancipatory disability research. Central to this framework is commitment on the part of the researcher both to a social analysis of disablement and to the development of the disabled people's movement. In these terms, they highlight the importance of their activity in providing a *de facto* redefinition of social research. Touraine (1981, p. 145) re-iterates this point by arguing that research intervention in social movements is a means of 'raising their

capacity for historical action and hence increasing the strength and elevating the level of their struggles'. This has relevance to research for oppressed groups such as disabled people – a key criticism of positivist and interpretive paradigms. In addressing this issue, Stone and Priestley (1996, p. 703) argue that, 'the political standpoint of the researcher is tied to political action in challenging oppression and facilitating the self-empowerment of disabled people'. The researcher's position changes from one of merely 'monitoring from the sidelines' to a level of engagement determined *by* the disabled person. Implicit to this role is what Stone and Priestley (1996, p. 703) term 'a radical reversal of the social relations of research production' – in other words, recognising that disabled people as a group are in an oppressed position and that research has been traditionally conducted within a wider context of oppressive social relations built on the privilege and power of non-disabled people.

Disability research and the non-disabled researcher

So far, the key issue underpinning the development of an emancipatory paradigm for disability research has centred on seeking redistribution of power between researcher and subject. For some commentators, a pre-requisite for this shift is to exclude non-disabled researchers from the field. Branfield (1998, p. 143), for example, argues that whilst non-disabled people can respond positively in actions and thoughts to the disability movement, 'their values, their policies, their culture, are objects of the analysis of our [disabled people's] subordination'. In turn, she contends that ''non-disabled people' are not where we are and can never be'.

As a non-disabled researcher working in the disability field, making a counter argument to Branfield's assertions may immediately appear defensive. However, rejection draws in debate from both the disabled and non-disabled academic communities and relates to a wider theoretical focus on identity. This is underlined by Duckett (1998, p. 625) who in direct response to Branfield maintains that her argument simply sustains a 'discourse of binary oppression'. Separation of disabled from non-disabled people, he suggests, simply serves to link in with other binaries - for example, female/male, black/white, child/adult, where one binary is 'preferred' to the 'other' and afforded socio-economic and political privileges in the process (through employment, income, social status, voting rights etc.). For disability, Duckett

suggests that this type of discourse aids support of the practice of segregated education and employment opportunities - presenting disabled people as the 'other' and different from the mainstream.

On another level, Duckett (1998, p. 626) is highly critical of Branfield's rigid focus on a disabled identity. This can be related to Williams' (1996, p. 70) notion of 'totalising identities', where she argues that in focusing on one part of a person's identity, other facets become frozen into one category of 'difference'. In these terms, she argues that although campaigns around the collectivising of an identity have been successful in countering negative and devaluing representations in dominant welfare discourses, this type of grouping runs the risk of fixing people into single unitary categories. Indeed, both Duckett (1998, p. 626) and C. Barnes (1992, p. 121) emphasise the fluidity of a disability identity in that non-disabled people regularly become disabled just as disabled people can become non-disabled. Moreover, Duckett notes that it has often been argued that the disability movement itself has been non-inclusive towards older, working class, black people and people with learning difficulties, instead privileging a 'white, male, spinal injured elite'. This is reiterated further by C. Barnes (1992, p. 121) who suggests that having an impairment does not automatically give someone an affinity with the disability movement nor an inclination to do disability research. For him, the cultural gulf between researchers and researched has as much to do with social divisions like class, education, employment and general life experiences as with impairments. In turn, rather than framing disability research as research solely *for* disabled people carried out *by* disabled people, he argues that emancipatory research is about the 'systematic demystification of the structures and processes which create disability, and the establishment of a 'workable dialogue' between the research community and disabled people in order to facilitate the latter's empowerment' (C. Barnes, 1992, p. 122).

Emancipation, participation or representation?: issues and values for 'doing disability research'
Debates surrounding the values underpinning emancipatory research require a wider focus than simply examining the role of the disabled versus the non-disabled researcher. On one level, writers such as Zarb (1992, p. 125) argue that a clear distinction between participatory and emancipatory research needs to be made. In these terms, he argues that the emancipatory paradigm should be viewed more as a set

of loosely defined principles rather than a framework of established rules for doing disability research. This implies a more evolutionary process in developing a new paradigm – a process which requires continual critical evaluation by and accountability to disabled people. Zarb (1992), draws on Oliver's work (1990, p. 13-14), who argues that in order to change the social relations of research production researchers have 'to learn how to put their knowledge and skills at the disposal of their research subjects, for them to use in whatever way they choose'. In turn until this process is fully achieved, Zarb (1992, p. 128) argues that research should be described as participatory and not emancipatory.

Conversely, Shakespeare (1996) suggests that the debate over 'ownership' and 'accountability' of disability research *by* the disabled people and the wider movement needs to be less rigid. Whilst C. Barnes (1992) has argued in similar terms to Zarb (1992) against the notion of an 'independent researcher', Shakespeare (1996, p. 117-118) maintains that that some form of 'academic independence' is both desirable and inevitable. This moves from earlier debates on 'objectivity' and value freedom within the social sciences (see for example, Sayer, 1992) towards a more direct focus on the theoretical 'ownership' of research. In articulating his reservations over the concept of emancipatory research in disability studies, he makes some important parallels with feminist research. Attention is drawn to the diversity in positions adopted from this perspective and the informal and unilinear relationship between feminist academia and the women's movement (Shakespeare, 1996, p. 115-116). Therefore he argues that like feminist work, disability studies needs to be wary of the risk of establishing an 'orthodoxy' within the discipline which serves to marginalise or ignore dissenting voices. More specifically, this links with post-structural theories which challenge the notion of framing research within a singular, unitary set of truths (Shakespeare, 1996, p. 116; Williams 1994; 1996; 1999). As an academic, Shakespeare differentiates between accountability to research subjects and to the disability movement. Whilst emphasising the need to equalise the relationship with research participants and give some control over the process, their participation and the representation of their voice, he suggests that to present this as a totally equal relationship is both naïve and ultimately impossible. Likewise, scrutiny for accuracy, effectiveness and consistency for researchers working in the disability field comes from at least two monitoring processes: academic colleagues and the wider disability movement. By framing these

relationships more loosely, Shakespeare (1996, p. 117) argues that a more independent and reflexive line can be taken – often allowing issues to be raised that may be over-looked in more heated political debates *within* the disability movement.

Shakespeare's argument underlines some important issues for researching direct payments. Primarily, it lessens many of the concerns over the boundaries of emancipatory research. In this sense, Shakespeare is perhaps more realistic in his appraisal of the role of research; sceptical of viewing it as a means of delivering major change, but seeing it as important as part of a longer-term process of developing ideas and representing experiences.

Indeed, whilst this study has sought to fairly represent and engage with the views of disabled people using direct payments, it self-evidently fails to meet the full 'emancipatory criteria' laid out by Oliver (1992), Zarb (1992) and others. This is not only due to time and financial constraints but also because the study seeks also to examine the extent to which planners in the three areas drew on a discourse of the market or independent living, as well as the user response. However, this should not negate its potentially emancipatory value as a means of raising important issues for disabled people with regards to policy delivery.

By drawing on post-structural analysis, Shakespeare (1996, p. 117) advocates a less rigid labelling of research. In these terms, research into direct payments need not be seen only in a framework of 'disability research' but also as a contribution to a wider discussion of policy change and restructuring of welfare.

Research and representation: 'empowerment', the 'welfare consumer' and 'policy research'
The debate surrounding how 'disability research' is conducted needs also to be briefly presented alongside the wider network of 'policy research'. As welfare provision in the 1990s increasingly adopted the language of consumerism and empowerment, a new genre of research and discussion emerged within the discipline of social policy reflecting this change (see for example, Baldock and Ungerson, 1994; Hoyes *et al*, 1994). However, for writers such as Beresford (1997), use of the term 'empowerment' by many within this research community is highly problematic and ultimately

*dis*empowering for groups like disabled people. This centres on the presentation of users or related groups solely as 'individualised welfare consumers'. Whilst this has shifted user identities away from that of 'passive welfare recipients' – drawing heavily on a medicalised rhetoric of impairment - Beresford (1997, p. 207) argues that consumerism must be explored as part of a dual process of empowerment. This brings in the emergence of new social movements for disabled people, psychiatric survivors, people with learning difficulties, older people and other groups who are the direct subjects of social policy. In line with many of the critiques of disability research detailed earlier in this chapter, Beresford (1997, p. 209) argues that much research and wider debates in social policy have little or nothing to say about the social movements of welfare service users and have failed to engage with their aims and activities. Indeed, he suggests that often the movement's ideas are misunderstood or misrepresented, whereby a quest for greater control and involvement in services is lodged within a narrow pre-occupation with the service system (see for example, Spicker, 1995, pp. 175-176). This clearly contrasts with the far broader issues of control, rights and independent living integral to the disability movement.

More recently, social policy research has developed more extensively – integrating a wider understanding of empowerment. For example, M. Barnes, Harrison, Mort and Shardlow (1999) explore the role of user groups in mental health and disability through a conceptual understanding of both consumerism *and* citizenship. In these terms, this type of policy appraisal highlights the need for research to explore the transient nature of user identity in policy development. For direct payments, although policy implementation represents a significant move in the collective goals of the disability movement, its impact in the individual lives of users is less clear. Whilst CILs assume an important role in the development of disability politics, their position in the implementation of direct payments draws on a background of both collective action in promoting the goal of individual living *and* individual support within the framework of the policy in place. In these terms, although CILs have traditionally lobbied for service change for disabled people, many local authorities developing either direct or indirect payment schemes have drawn on these organisations to provide support services for users. As a result, although lobbying still forms an important role for CILs, direct payments has created opportunities for CILs to work in *partnership* with local authorities.

By returning to the independent living and market discourses underpinning direct payments, discussion in the following sections shifts to show how these issues can be explored through empirical research.

Exploring policy implementation: *a focus on structural and user roles*

Having outlined the market and independent living discourses underpinning direct payments and a shift in thinking surrounding disability research, discussion moves to integrate these ideas into a research design. As shown in chapter I, the concept of discourse has featured strongly in mapping the theoretical and policy background to direct payments. Therefore in focusing on how direct payments can be understood both as a means to achieve independent living *and* as an instrument of the market, these ideas become an important feature of the research questions addressed in this thesis. Consequently, the following research questions are applied comparatively as policy implementation is explored in three different areas:

(i)   How are direct payment schemes being implemented and understood by those involved?

(ii)   How are independent living and market discourses reflected in policy implementation?

(iii) How are direct payments understood and utilised by service users?

In order to address these questions, it is necessary to understand how each local authority has justified its approach to direct payments and how this has impacted on users. Clearly this could not be achieved through quantitative methods and therefore draws implicitly on a qualitative methodology. As Jones describes, using qualitative methods for this type of study allows a far more thorough examination of views:

> To understand other person's constructions of reality we would do well to ask them...and ask them in such a way that they can tell us is their terms (rather than those imposed rigidly and a priori by ourselves) and in a depth which addresses the rich context that is the substance of their meanings (rather than

through isolated fragments squeezed onto a few lines of paper). (Jones, 1985, p. 46)

Although Jones appraisal of qualitative methodologies invokes flexibility for the interviewee to define their experiences, earlier commentary suggests that use of qualitative or interpretative methodologies alone do not amount to an adequate framework to carry out disability research. Accordingly, a number of the values associated with the emancipatory paradigm need to be brought into the research design. Again, previous discussion highlighted a number of different roles and meanings associated with this approach. However, for the purposes of this research three core values exist:

- An understanding and application of the social model of disability throughout the research process.

- Consultation with disabled people in the research design.

- Honest representation of user views and making research findings available to interested parties (either informally or through discussion papers and publications).

From these positions, two main stages of research design were adopted and used in three localities. These focused on:

- Exploring how policy planning for direct payments reflected independent living and market discourses.

- Exploring the user experience of direct payments

Methods and issues arising from each of the stages are detailed in the following sections.

Stage I: Exploring policy planning for direct payments

Locating direct payments: choosing the areas, comparing experiences

As demonstrated in chapter III, one of the defining characteristics of direct payments as part of a wider process of policy restructuring is its position as enabling legislation. To re-cap, this has given local authorities the option of whether to adopt direct payments or not. Earlier commentary suggested that decisions to develop policy linked in with the role of local disability activism in promoting independent living and/or the political views of the local authority. This discretion in implementing policy means that one of the main issues determining receipt of a direct payment is locality and *not* individual choice. In turn, these levels of local ideological diversity needed to be reflected in the research design.

Methodologically, this is reflected through a comparative approach. As suggested previously, May (1997, p. 186) also argues that one of the main advantages of carrying out this type of research is to understand diversity and difference in the implementation of policy. In turn, this enables a wider understanding of the macro-factors which influence social and political change and the micro-factors peculiar to each setting. By examining direct payments comparatively, this approach contributes both to an understanding of policy restructuring through the development of more localised, small-scale forms of welfare and the representation of disability as part of this process. Implicit to a comparative design is a hypothesis that policy implementation and outcomes *will* be different in each location. For direct payments, this assertion reflects commentary in the last chapter which underlines the differences among local approaches to independent living across the UK, and the development of care markets since implementation of the 1990 Community Care legislation.

Having already determined a clear link between ideology and practice in the implementation of direct payments – both through local disability activism and the local authority - choice of areas used in the study sought to integrate a number of factors relating to the role of these influences. This process was reflected through theoretical sampling. Mason (1996, p. 93-94) describes this as 'a means of selecting groups or categories to study on the basis of their relevance to your research

questions, your theoretical position…and most importantly the explanation or account which you are developing'.

In turn, selection focused on a Scottish and an English authority where direct payments had been developed with (apparent) user involvement in the planning process, but with contrasting political traditions. Meeting these requirements was aided by drawing on research by Zarb *et al* (1997) on initial local authority responses to the direct payments legislation and through discussions with one of the authors – also a Co-Director of the National Centre for Independent Living. This proved to be a particularly useful point of reference in choosing areas where research had not been carried out. Although research into direct payments is a new area, earlier studies on disabled people's experience of indirect payments (see for example, Zarb and Nadash, 1994) have drawn on 'showcase' examples of these projects. As suggested in chapter III, these areas have been particularly pro-active in developing direct payments. However for those using and planning these schemes, there is a risk of being 'over-researched' – therefore willingness to become involved in another study may have been limited. Similarly, the timing of the fieldwork – approaching a year after the implementation of direct payments – meant that some areas were starting to develop their own research to gauge initial responses to local changes and were seeking users to participate in their own work.

A third area was chosen as an example of where direct payments had yet to be implemented but indirect payments were in place and offered as a service option to disabled people. Inclusion of this additional area represented what Silverman (2000, p. 107) terms a 'deviant case' in theoretical sampling. In this sense, exploration of *non*-implementation of direct payments and the reasons underpinning this decision was considered to be equally important to the research questions. Therefore, both planners and indirect payment users were integrated into the research sample.

Choice of areas also included a number of practical considerations. These centred largely on geographical, financial and time constraints. As shown in chapter III, use of independent living schemes and eventual development of direct payments in Scotland have occurred at a much slower rate than in England. However, the pace of policy implementation in one particular area had far exceeded other Scottish authorities.

Given this exemplary progress it was felt that this area must be included in the sample. The second Scottish area was chosen primarily through its non-implementation of policy, but also relative ease of access became an important consideration. In these terms, geographical and financial restraints removed any opportunities for making additional comparisons between the areas - for example on an urban-rural basis. Clearly, any research carried out in England from Scotland was going to be more costly and time consuming. However local connections and the availability of travel expenses, allowed inclusion of a more southern and politically contrasting area in the study. An additional benefit of using theoretical sampling is that it allows flexibility in the sampling *during* the research process (Silverman, 2000, p. 107). This flexibility became necessary at several stages. Initially, it was decided that four areas should be used within the research – two in Scotland and two in England. However as the process of exploratory interviews with key informants developed, it became apparent that the time required to research a fourth area would necessitate a less rigorous interview schedule. Pilot interviewing with users and planners (see below) indicated that this was not a realistic compromise, so the fieldwork was organised around three areas. To summarise, the following three areas were approached to participate in the research[i]:

- **Area I: 'East Anglia'** Traditionally Conservative authority, with a majority at the time of policy planning for direct payments, now Labour are the largest party but with no overall control. Implementation of direct payments from April 1997.

- **Area II: 'East Scotland'** Traditionally Labour as the largest political party, increasing to majority control in recent years. Implementation of direct payments from April 1997.

- **Area III: 'West Scotland'** Traditional Labour stronghold. Non-implementation of direct payments at the time of fieldwork and up until the time of thesis submission (November 1998 – November 2000) but indirect payments operating since the mid-1990s[ii].

Seeking access and establishing a research dialogue

Having chosen three areas, access and interest from both direct payments users and planners was required – inviting both groups to participate in the research. Underpinning this process was the need to establish what was referred to earlier as a 'workable dialogue' (C. Barnes, 1992, p. 122) between myself as an academic researcher and those involved in local direct or indirect payment schemes.

Each of the areas provisionally chosen for the study all had established centres for independent living (CIL). Likewise at the local authority level, planning for direct payments had been designated as a specific role in the remit of key staff. From conversations with the National Centre for Independent Living, it was suggested that an initial request for participation in the study should be made through both local authority and CIL levels. In turn personnel in each area were contacted by letter (see appendix I), outlining my interest in direct payments and wish to explore the user and planning response in the area. Rather than detailing a list of specific requirements, an initial meeting was suggested to discuss the background of direct payments and independent living in the area. Perhaps surprisingly, personnel in all three areas showed immediate interest in meeting and in assisting in the research. This established a level of co-operation which continued throughout the research process from both local authority and CILs. When asked why they had agreed to participate in the study all said that they were genuinely interested in hearing the views of users and saw the research as a means to gauge the scheme's progress in the early stages of implementation. Given the heightened use of 'empowering' rhetoric in social service provision, M. Barnes (1993) argues that a basic challenge for managers is how to establish opportunities for dialogue with users of services from whom they have been largely separated. In this sense, from a local authority point of view the research was generally conceived as a useful way of facilitating this process.

Although an approach had been made to representatives at both local authority and CIL level, it became apparent from initial discussions in East Anglia and East Scotland that a dialogue in the planning and implementation of direct payments was already well established. The position differed slightly in West Scotland in that at the stage of these exploratory interviews whilst agreement had been made in theory to

develop policy, no coherent strategy had emerged on how to proceed with policy development. Although the CIL were involved in consultations, their role was far less integral than in East Anglia and East Scotland. Moreover, this blurred any pre-conception of a fixed boundary between 'planners' and the 'disability movement' as in each of the areas some of the planners working at local authority level were also active in the CILs and were direct/indirect payment users themselves.

These initial meetings took the form of unstructured interviews. As May (1997, p. 112) argues, one of the main uses for this type of approach is that it allows the interviewee to talk about the subject within their own terms of reference. At this early stage of the research, such an approach allowed interviewees to detail the policy background to direct payments. In these terms, it was important to engage in an understanding of the long-term interaction between the local authority and disability movement in each area as a basis for exploring the overall policy direction. Contact at this planning level initiated a process of 'snowballing' whereby through these conversations access to a much wider community of policy planners was gained. It became immediately apparent that direct payments was not a 'high profile' policy in any of the local authorities and so seeking those involved in policy development required co-operation from interviewees at this early stage. This involved an element of 'personal recommendation' from the original contact (Arber, 1993a). This technique was used in each of the three areas to a greater or lesser degree In East Anglia and West Scotland, the network of planners was far narrower – involving two representatives from the CIL and one from the local authority in East Anglia and two planners at local authority level in West Scotland. Conversely in East Scotland, a far wider body of interests was included – leading to interviews with all those involved in the 'Direct Payments Working Group' – a group of seven from planning, social work and user backgrounds. Access was also gained to the Head of Operations who had made recommendations on direct payments both in terms of local and national policy development.

Maintaining a research dialogue
Whilst an initial set of interviews with all those involved in direct payments planning was carried out, an on-going dialogue with CIL and key local authority planning

representatives was established. For Moore, Beazley and Maelzer (1998, p. 94), this type of *partnership* approach - bringing together non-disabled and disabled people together - in the research process is central. Clearly for such an individualised piece of work as a Ph.D thesis, the possibilities for developing a 'research team' of disabled and non-disabled personnel are limited. However in each of the areas, a mutually beneficial link developed. This involved individuals whose interest in direct payments spread across both their personal and employment lives and took the form of occasional phone calls and informal meetings every two or three months - allowing both parties to exchange information with regard to policy development and research findings. Indeed throughout the duration of the research contact with Scottish personnel overlapped into other areas of interest – for example on several occasions myself and CIL representatives presented ideas at the same seminars and taught consecutive classes on direct payments and independent living to Social Work students at Glasgow University. For C. Barnes (1992, p. 122), this type of regular interaction with the disability community is fundamental for emancipatory research. Moreover, using qualitative research techniques in this way removes some of the earlier problems of 'hierarchy' between the researcher and disabled community associated with the interpretist tradition.

Whilst some of the discussions were tape-recorded, because of the ad-hoc nature of many of the meetings it was not always possible (or appropriate) to do this with all discussions. Moreover by *not* taping all dialogue, a greater degree of confidence was gained from the planners – most were happy to give a personal view on the direction of policy but a more honest account seemed to be revealed in less formal conversations. For example in East Scotland, one of those involved in the direct payments working group and a user herself admitted that she thought that 'the policy consultation was lacking and that most users were unaware of developments'. This conflicted with earlier comments where it was stated that 'every effort had been made to consult widely with service users'. Therefore at this stage of the fieldwork, much of the dialogue was recorded through detailed hand written notes.

Policy documents

Although the dialogue between myself and planners became a vital link in understanding the way direct payments was being developed in each area, this process needed to be supported by examining how policy was being publicly presented in document form. On one level planners talked casually and 'off the record' about the rationale for policy development, yet explanations often conflicted with language employed in user policy guidance. Ball (1993, p. 11) highlights the contested nature of policy texts, arguing that they are rarely the work of single authors or a single process of production. Similarly, he describes them as 'the products of compromise' in the politics and micro-politics of interest group articulation. Likewise May (1997, p. 171) argues that documents do not stand on their own but need to be situated within a theoretical frame of reference in order that their content can be understood. In these terms, these two 'formal' and 'informal' processes of identifying the legitimising discourses in the policy documents complimented each other.

Stage II: Exploring the user experience of direct payments

Having developed a network of contacts involved in local planning and implementation of direct payments, these links were used to access a sample of service users. In East Anglia and East Scotland this involved actual direct payment users and in West Scotland – because implementation of direct payments had yet to take place – this included indirect payment users. Prior contact had been made with the Association of Directors of Social Services (ADSS) research group requesting support for the study. In response, they stated that participation was at the discretion of individual local authorities. Only East Scotland sought a formal application for access and this was granted through their research committee. Access was organised through the 'gate-keepers' for direct payments – in East and West Scotland - the Social Work Department and in East Anglia through the CIL – who sent out brief letters inviting users to participate in the study (see appendix I)[iii]. This was supplemented with a letter from the local authority supporting my involvement in the study.

Sampling and representing direct payment users

The process of sampling used to access users may be best described as 'opportunistic'. Attempts were made to integrate class, gender, age and employment variables into the sample by asking personnel in each area to distribute access letters to a range of users with regard to these. However, the small numbers of total user populations made it impossible to match these characteristics proportionately. Indeed, although the request for representation was accommodated in the distribution of access letters, the profile of those who agreed to participate in the study did not accurately mirror the total user population across the three authorities. In each area, social (work) service personnel were asked to comment on how representative the sample was in comparison to the overall profile of payment users. In East Anglia and East Scotland, a broad match of characteristics was made. However in West Scotland, as figure I indicates, the gender profile was clearly an area of imbalance as only one male user agreed to participate in the study. Although additional letters were sent out in an attempt to counter this, no other men volunteered an interest in the research. Whilst this imbalance was not ideal, given that recruitment to the study was voluntary it was not possible to counter this problem. This leaves a number of wider questions open to speculation - such as why most male users in West Scotland did not wish to participate in the study, yet in the other two areas the gender balance was more evenly maintained. This type of question would clearly benefit from future research into the user experience of direct payments.

Similarly in both East Anglia and West Scotland, by coincidence 15 users agreed to be interviewed, whilst in East Scotland 20 came forward. Rather than exclude the additional five respondents in this area for the sake of an even number, it was felt that their experiences would make for a richer and more diverse sample. This links into wider issues of representation – a key concern in small-scale qualitative research (Arber, 1993b, p. 73). Arber argues that many sociological studies focus on very specific sub-groups of the population, for whom sampling frames are not readily available. Given that a more rigorous sampling method may not generate an adequate number of users, Arber (1993b, p. 73) suggests that in this type of study the over-riding goal is to understand social processes rather than to obtain a representative sample.

A further problem arising in East and West Scotland was the absence of available data on the profiles of direct/indirect payment users. As stated, each of the areas was asked to provide basic details of total user populations – such as age, employment status etc. However in East and West Scotland, this information had not been collated. Figures relating to age, gender and ethnic origin were held by local divisional social work teams but in all areas additional information such as employment status had not been recorded, therefore accessing users in and out of work was reliant on individual practitioner knowledge. In East and West Scotland, providing this information was considered to be 'too time consuming' for staff, therefore as stated attempts to match the sample with the total user population profile could only be confirmed informally by planning personnel. Overall, it appeared that in East Anglia and East Scotland the sample broadly reflected the wider profile of service users. In West Scotland, the sample was skewed towards older women and therefore was not representative of all service users.

A total of 50 letters were sent out in each area from total user populations of 160 in East Anglia, 63 in East Scotland and 121 in West Scotland. From the 50 letters sent, 15 users[iv] agreed to be interviewed in East Anglia, 20 in East Scotland and 15 in West Scotland. As shown in figure I, ages ranged from 26 to 56 in East Anglia, 25 to 60 in East Scotland and 32 to 64 in West Scotland. Five users were in paid employment in East Anglia, six in East Scotland and two in West Scotland.[v]

All of the areas made policy accessible primarily to users with physical impairments and this imbalance was also represented in the sample with only two users (from a total of four) with learning difficulties interviewed in East Anglia and one (from a total of six) in East Scotland (specific issues related to these interviews are addressed later in this section and the concept of 'willing and able' in relation to users with learning difficulties is examined in chapter V). There were no users with learning difficulties in West Scotland. The under-representation of this group of users mirrors the wider pattern in both Scotland (see Witcher *et al*, 2000) and England and Wales (see Holman and Bewley, 1999). Similarly, although permissible by the legislation, none of the authorities had users with sensory impairments or mental health problems. Again, this would appear to match the overall pattern of users across the UK. In particular, accessing direct payments to persons with mental health problems has

proved to have been especially unsuccessful, with fewer than ten users in England and Wales (Maglajlic, Bryant, Brandon and Given, 1998) and none in Scotland (Witcher *et al*, 2000). Other characteristics shown in figure I relate to user's employment status. Like the other variables shown, this is explored in further detail in following chapters. In turn, differences between each area are evidently indicative of how payments are used and the type of user they are accessed by. An obvious gap in each of the samples is the absence of minority ethnic users – a trend typical of policy access to date throughout the UK (see Bignall and Butt, 2000). Despite framing direct payments in 'needs-led' rhetoric, no individuals from minority groups receive payments in East and West Scotland and only two in East Anglia, neither of whom agreed to participate in the study.

Figure I: Summary of key interview characteristics in each of the three areas

Demographics	East Anglia		East Scotland		West Scotland	
Gender	Male	Female	Male	Female	Male	Female
Age						
18-24	0	0	0	0	0	0
25-29	0	1	1	2	0	0
30-34	2*	1	0	3	0	2
35-39	2	0	2	0	0	2
40-44	4	1	0	1	0	1
45-49	1	0	3	1	0	1
50-54	1	0	0	0	0	1
55-59	0	2	1	0	1	4
60+	0	0	2	4	0	3
Employment	4	1	3	3	0	2
Physical impairments	8	5	7	12	1	14
Learning difficulties	*1	1	1	0	0	0

*This figure includes responses given by Valerie, mother of Jonathan

Exploring the user role: piloting ideas

Central to exploring how market and independent living discourses have been used in policy implementation related to how disabled people conceptualised these ideas. From an early stage in the research design, it was apparent that the method of data collection had to allow users maximum freedom to define this role. As suggested

through earlier discussion in this chapter, this linked directly with the need to explore the role of identity – both through the specific market and independent living ideas underpinning direct payments and wider issues operating in 'disability policies' as a whole.

At this stage, conversations with planners who also used direct/indirect payment schemes proved a vital resource in considering the best way to explore the user role. Consequently, their role was extended to a 'piloting process' for the user interviewing stage - where ideas and questions were openly examined. Initially, the possibility of using a focus group was discussed. For writers such as Wainwright (1994) focus groups allow a more implicit theoretical understanding of new social movements. In these terms they highlight the freedom permitted by this type of forum for users to express their views and the opportunity to study the individual not as a single entity but part of a collective. Indeed, it was mainly for this last reason – that understanding of the *individual* role of payment users was sought – that one-to-one semi-structured interviews with service users were chosen in favour of the focus group. As detailed earlier, policies need to be understood in the context of multi-dimensional identities. Hence, although contacts involved in CIL/planning and user roles stated that their disability also underpinned a more political involvement in the 'disability movement', it suggested that not all users wanted to be associated with the CILs or any broader involvement with 'disability activism'. Therefore even at this early stage, it was clear for some that access to a direct payment would perhaps represent a more transient user identity.

Extending use of the semi-structured interview to exploring the user role, therefore, permitted the flexibility required in understanding the role and significance of direct payments in individual lives. As Fielding (1993a, p. 136) describes, these types of interview are 'valuable as strategies for discovery'. In turn, an interview schedule was drawn up - with the assistance of one of the users involved at planning level. Questions were framed loosely around the user's day to day living experiences, which allowed the interviewee to define the significance of direct payments in their lives (see appendix II). A deliberate attempt was made not to ask interviewees about their impairments unless they volunteered the information; thus allowing a clearer understanding of the user conceptualisation of direct payments.

Although some writers suggest that pilot interviews are not always necessary with less structured interview techniques (Fielding, 1993a, p. 137), two preliminary interviews were carried out as an additional information-gathering exercise. Once again, contacts through the planning stage were used to gain access. This involved two users with physical impairments: Derek, who was on the waiting list for indirect payments in West Scotland; and Margaret, who had already accessed the scheme. The interviews provided two very different experiences of independent living and ultimately proved most useful as a means of familiarising myself with some of the issues surrounding the differences and restrictions relating to the role of service provision in individual lives. For example, Derek described himself as a 'disability activist' and assumed an overtly political identity. In turn, he construed the delay in receiving an indirect payment as part of a wider oppression of disabled people by the local authority. Freda, on the other hand, described her experience of indirect payments solely in terms of improvements to her personal care arrangements. Taken together, these interviews underlined the need for a more open-ended and reflexive interview schedule.

Representing the user's views?: issues and conflicts

The relative ease in accessing users appeared to be linked to two main – and often conflicting - reasons. Primarily, across all of the areas many saw the interview as a means of expressing satisfaction with cash payments – both direct and indirect. Therefore whilst it was made clear that the research was unlikely to affect them as individual users, all participants were happy to describe their own experiences with the view to benefiting future users. For Butt (1994) this type of honesty about the power researchers are able to exercise is fundamental. As Helen in East Anglia said 'it's [the direct payment] just been such a liberation…I just want other people to know about it'. However for Jean - also in East Anglia - whilst she had welcomed the transition to direct payments, the proposed introduction of charges by the local authority had greatly angered her and so she saw the interview as a means of venting her displeasure. In fact when arranging the interview with her, she told me 'not to bother coming if I was expecting nice things to be said about them [the local authority in East Anglia]'. For some of the older interviewees, this type of reaction was often indicative of initial confusion over my role and interest in direct payments. Attempts were made at the point of initial contact with users to create a relaxed and informal

basis for discussion, although ultimately the dynamics of the meeting were controlled by the interviewees. As Coffey (1999, p. 39) argues 'fieldwork relationships are at once professional and personal, yet not necessarily readily characterised as either'. In many cases, user views of my role as a researcher replicated their own construction of direct payments. This ranged from semi-formal conversations in the user's employment setting – where discussion focused on a 'consumerist' approach to 'buying in' personal assistance and whose role was defined exclusively through a 'employer-employee' relationship - to very informal conversation in the user's home, where interaction was based more on 'friendship' dynamics. However, in all the user interviews, participants welcomed the opportunity to discuss their feelings about direct payments – and where interest was shown discussion papers and findings were shared after the initial meetings.

This part of fieldwork would suggest that being a non-disabled researcher working in a disability field was ultimately unproblematic to users or the representation of their experiences. This is perhaps an over-simplification, although where relationships with interviewees were more relaxed, this related more to other social divisions such as age and class than to disability.

More distressing was an interview with a woman of a similar age, who had given up a career in research after an accident which had left her with significant memory loss and physical impairments. For her, similarities in interests and life experiences between us appeared to accentuate her distress. From my point of view it would have been perhaps more comfortable to end the interview early, however she was keen to discuss not only her own experiences but my views on research and other issues.

Representing the user view: interviewing users with learning difficulties
Issues of user representation and control became more difficult to negotiate during interviews with users with learning difficulties. Previous discussion has outlined that although direct payments are overwhelmingly accessed by persons with physical impairments, there is scope within the legislation for those with learning difficulties to organise their support through this route. Therefore, it was important to include the views of these users at this stage of interviewing.

Clearly people with learning difficulties can be particularly vulnerable to manipulation and exploitation by researchers (Booth and Booth, 1994). This relates to a number of issues. For example, Stalker (1998, p. 6) asks whether researchers really know if this group of people understand what is being asked of them and if they then really want to participate. In this sense, the issue of 'informed consent' has been a consistent theme in discussions of social research ethics Swain, Heyman and Gillman, 1998, p. 28). Similarly, research in this area draws into wider theoretical debates in disability studies. As Walmsley (1994) notes, the social model of disability implies that all that is needed before people with learning difficulties are able to take control of the research process, is for certain disabling barriers to be overcome. This type of appraisal of the social model links in with a number of problems experienced at this stage of interviewing direct payments users. Attempts were made to integrate the views of people with learning difficulties to inform the research design and fieldwork process, although the level of involvement was considerably less than consultations with users with physical impairments. However, several approaches were used. The organisation 'Values into Action' has been particularly active in campaigning for direct payments for this group and have presented these issues with users at conferences in Scotland and England. In turn, attendance at these events provided a useful forum to explore some of the main issues. Meetings were also held with a researcher working for the organisation who was examining the development of policy in Scotland. Although she was non-disabled, the discussions were important in sharing knowledge of this area of policy development. Further conversations took place with planning representatives for this group, including personnel in East Scotland who had had long term involvement in securing payments for two day care users as part of the authority's piloting process.

In terms of interviewing direct payments users with leaning difficulties, access through letter distribution had resulted in interest from one user in East Anglia – Anne - in participating in the study. Anne had very limited speech and severe learning difficulties and so her responses were communicated through her personal assistant. Corbett (1998, p. 59) explores this third party role through her analysis of 'voice' in emancipatory research. She argues that the 'support professional' may be used as what she terms an 'active accommodator' 'to link the person they are concerned to listen to into a dominant discourse which they can make *actively receptive* [author's

emphasis] to what they have to say'. On one level this proved successful – the interview was conducted *to* Anne but communicated *through* the personal assistant. However, the content and style of interviewing was very different from previous experiences. This drew on an approach which Stalker (1998, p. 11) terms a 'guided conversation'. We discussed issues and relationships around her daily life pattern. For example, the interview began by asking Anne what she liked doing and how activities had changed. In these terms, an understanding of how the direct payment was used was gained by exploring these roles and through additional information given by the personal assistant. Every attempt was made to explain my role and maintain an informal and comfortable dialogue but it was clear that Anne did not fully understand who I was. Similarly, an interview with Paul in East Scotland raised similar issues. In this instance, Paul had been approached by one of his support workers (also a planner) and asked if he would talk to me. I had also briefly met Paul at a 'Values into Action' seminar, although he had no recollection of this. This time I conducted the interview without any one else present – although I did meet with Paul's personal assistant on a separate occasion. In terms of interview content, the conversation allowed Paul to talk freely about recent changes in his life (which had been initiated by access to a direct payment) and his control over use of the direct payment. However, again it was clear that my role was confusing. In retrospect, there are some important methodological issues which need to be addressed at this stage. Whilst I felt that the conversations allowed user views to be expressed, the value of a 'one-off' meeting could be questioned. Much of the recent research carried out with people with learning difficulties has been designed around a longer-term relationship with participants – often meeting on a number of occasions (see for example, Holman and Bewley, 1999; Stalker, 1998). For example, Stalker (1998, p. 9) met with interviewees every fortnight over a four month period. Whether this type of approach would have allowed interviewees more control and involvement in the research process or understanding of my role is debatable. However, at no stage of the interviews did I feel that participants were uncomfortable with my presence. Similarly, whether it would have been more beneficial to establish a longer-term relationship with users is also unclear. Given that most people experience transient social relations throughout their lives, it can be asked whether different 'norms' should be applied to people with learning difficulties (Stalker, 1998, p. 10). Therefore from this position use of a one-off meeting was maintained.

Representing the wrong voice?

Although every attempt was made to allow users to freely discuss their views on direct payments, in three cases the interview was dominated by other parties present. Where appropriate, I expressed a preference for interviews to be carried out on a one-to-one basis, but in some circumstances interviewees wanted their personal assistants, partners or a friend present. In these cases this raised the question of whose 'voice' was being represented. During one interview in West Scotland, although questions were directed at the interviewee, responses were continually given by the interviewee's husband. A similar problem was experienced in two other cases in East Anglia and West Scotland with domineering personal assistants. In all cases, the user did not seem bothered by the interventions but equally content to give their own views when I persevered with more direct questioning. These interventions were noted in field notes and integrated into the transcripts. In turn, responses were framed as an additional dimension within the analysis from which to explore relationships underpinning individual use of direct payments.

Perhaps the most problematic issue of user representation emerged through an interview with a mother of a direct payments user in East Anglia – Jonathan – who had severe learning difficulties and no speech. Although through my access letters I had requested interviews with direct payment users, in this case the response came through the mother. When arranging the interview, I had asked if Jonathan could be present. A mutually convenient time could not be found so the meeting was conducted without him. Indeed, whether communication of Jonathan's views could have been integrated into the research had he been present is unclear – and according to his mother this is unlikely. As writers such as French (1993, p. 17) have commented 'some of the most profound problems experienced by people with certain impairments are difficult, if not impossible, to solve by social manipulation'.

Therefore although the interview raised some important issues relating to accessing direct payments for users with learning difficulties, the views given were obviously hers – those of someone in a 'caring' role and not a payment user – a perspective that differed from the focus of this research. Moreover, at times Valerie used language which would be uncomfortable for the disability movement (see for example, Morris,

1991 and commentary in chapter II). This centred on her son's dependency and her own 'burden of care'. However, her perception of care may be linked to ideas put forward by Shakespeare (2000, p.64) and referred to in chapter II. As indicated, Shakespeare highlighted the importance of inter-dependence and mutual support in *all* human relationships, suggesting that this becomes problematic when disabled people become reliant on unresponsive services or demeaning charity. In these terms, the flexibility and choice offered to both Jonathan and Valerie through the shift to direct payments could be understood as a positive shift for *both* parties. Furthermore, the interview addresses some critical issues in relation to learning difficulties and direct payments. In this sense, the limited number of users in this group necessitates a need to provide more information of current experiences through research. Hence, Valerie's comments also contributed to this body of knowledge.

Recording the user view

As detailed, the style of interview with direct payments users varied considerably. In turn this was reflected in the interview duration This varied from a very focused discussion of direct payments, lasting only around 25 minutes to longer conversations continuing for well over an hour. All participants agreed to allow the interview to be tape-recorded and their comments to be used both in the thesis and publications resulting from the research (although all names have been changed to maintain confidentiality). Additional field notes were also made. As Silverman (2000, p. 126) suggests, this allows inclusion of other issues relating to general environment and the behaviour of those present to be recorded. In this case, notes focused on issues such as the role and interaction of personal assistants, visual perceptions of my presence and general background information concerning location. Further notes recorded comments made after the interview had finished – often interesting points were raised after the tape recorder was switched off and so these were recorded manually.

Transcription

As Fielding (1993b, p. 146) notes, the first decision to make when transcribing interviews is whether to do them verbatim or selectively. Whilst maintaining that the former process means that you have not lost any data that may become significant in the wider analysis, it is laborious and time consuming. Given that some of the longer interviews had extended into other conversational areas - which were completely

unrelated to the research – it was decided that a degree of selectivity could be used. However, as suggested by Fielding, the first few were transcribed in full in order to guide the analysis and ensure that all levels of enquiry were explored. Verbatim transcription was also used by my mother - who kindly agreed to help at this stage – therefore any selection of interview dialogue was made only in the ones I processed.

Reflecting on the interview process

This section concludes by providing a brief reflective summary of this part of the research by focusing more specifically on some of the key issues surrounding the interview stage. For many writers (see for example, Stevenson and Cooper, 1997; Moore *et al*, 1998; Alvesson and Sköldberg, 2000) reflexivity forms an essential part of the research process. This allows the researcher to develop a more thorough basis for the stages of coding, analysing and interpreting findings – areas which will be outlined in the next section. Commentary begins by looking at some of the issues surrounding the user interviews and then shifts to those raised with the planners.

Earlier discussion has already acknowledged the relative ease of accessing a sample of users willing to participate in the study in each of the three areas. Similarly, ease of access was replicated by user's overall enthusiasm to discuss their experiences and issues surrounding indirect/direct payments. As shown earlier, user interviews were semi-structured and framed largely around an interview schedule (see appendix II). However, although they drew on the same format, the direction of discussion often covered differing issues. This was generally initiated from the first part of the interview, where users were asked to provide some background information by asking them to tell me about themselves. Several users in each of the areas sought more clarity over the type of issues to raise and seemed at first to be uneasy. For example Jean in East Anglia, stated 'you'll have to ask the questions and I'll answer them' – therefore specific prompts were given (again these are listed in appendix II). In this instance, sensing that the interviewee was likely to be uncomfortable discussing personnel details immediately, questioning began with broader issues surrounding direct payments and support services. As she became more comfortable with my presence, Jean openly volunteered more information about herself later in the interview.

However, most seemed content to provide a brief biography – drawing on what they considered to be the most relevant aspects of their life. Consequently, this first line of questioning provided an interesting insight into the relationship between structural and identity issues in individual lives. Whilst this forms a substantive part of the analysis developed in subsequent chapters, reflection on the variation in user responses at this stage highlights some of the issues surrounding how users themselves responded to the interview process. For example, in East Anglia and East Scotland, a third of users described their background only through issues such as current or former employment or education status. This contrasted with West Scotland where only one user made any immediate reference to work and around two-thirds of respondents defined themselves solely through their 'illness' or impairment. The remainder of users across the areas drew on both wider structural and identity issues – such as work, family, friends, housing – and those more specific to their impairments – e.g. transitions over the life course and changes in support services. With the interview dialogue beginning in this way, most users seemed content to lead the discussion and introduce issues of their own as they became more used to my presence. Indeed, whilst more specific issues have been outlined earlier with regards to interviewing users with learning difficulties, this type of flexibility in the questioning appeared to provide an empowering forum to represent the views of the users interviewed.

One main problem occurred in several cases. Having formally completed the interview and switched off the tape recorder, additional information would be volunteered. Clearly in these cases it would have been inappropriate to switch the tape recorder on again, so any relevant information was written up as field notes soon after leaving the interview. Although no-one expressed particular discomfort in having the interview taped, clearly for some it represented a barrier to a more relaxed conversation. All respondents appeared to find the interviews useful as a means of representing opinions both in terms of their support and day to day living. Moreover, many from each area were keen to hear the outcome of the research findings. In these instances, papers have been exchanged throughout the development of the thesis.

The series of interviews and informal conversations with policy planners and key informants also raised a number of issues. This centred on my position as a

'researcher' and the interpretation of this role by planning personnel in each of the localities. As suggested earlier in this section, sustaining a research dialogue throughout the duration of the study became fundamentally important both in terms of exchanging ideas and to gauge policy development. In East Anglia and East Scotland, because of the co-operation of key individuals in the CIL and local authority, informal and regular exchanges took place by telephone or e-mail. This provided a particularly valuable means of gauging the opinions of policy planners and further insight into the ideas informing policy development. However given the sensitivity of some of the exchanges, where necessary personnel have been suitably anonymised in the context of the discussion of the findings. In West Scotland, a similar process of information exchange began but became less fluid as the main contact in the local authority left two years into the study. His departure did not ultimately prevent information being gathered but meetings were more formal and sporadic as personnel had not been involved in the research from the outset. Again as stated, papers and ideas were exchanged with interested parties as the study developed.

Exploring data, identifying the legitimising discourses: *coding, analysing and interpreting findings*

This final section outlines some of the issues related to data analysis and the framework used to explore the research findings in the following chapters. Discussion begins by focusing on some of the wider commentary associated with theory development through empirical research and the role of computer software packages in this process. By rejecting grounded theory as a means of processing ideas, the roles of discourse and identity are explored by returning to the themes of diversity and difference outlined in chapters I and III. This reiterates the need to examine data at a number of levels. In turn, discussion shifts to outline some of the key issues and difficulties emerging from the data analysis through NUD*IST and how themes were developed for dissemination in following chapters.

Coding data, grounding theory?

An integral part of much qualitative data analysis is to begin with the identification of key themes and patterns and then organise the discussion around theme generalisations, interspersed with illustrative examples (Critcher, Waddington and

Dicks, 1999, p. 77). This process is usually associated with coding (Coffey and Atkinson, 1996, p. 26). The importance of coding as a part of the analytical process has traditionally formed a key role in grounded theory. This draws on the method of analytic induction, whereby hypotheses are generated based on a few cases (Critcher *et al*, 1999, p. 80). From Charmaz's (1993) characterisation of grounded theory methods, the approaches used to develop the research themes in this study link into a number of similar areas. For example, throughout the fieldwork analytical themes were noted and developed as the data was collected. Likewise, areas were chosen through theoretical sampling – thereby generating sampling for theory construction rather than attempting to represent a given population. However, there remain important differences which link into wider critiques of the grounded theory approach. Notably, whilst the development of analytic codes formed part of an on-going process throughout the data collection stages, the structure and ideas informing this stage drew at least in part from pre-conceived hypotheses. Primarily, this returned to the rationale underpinning use of a comparative framework for this research – that there *would* be differences in the user and planning experience of direct payments between areas. To reiterate earlier commentary, this was informed by a preliminary examination of the research into independent living indicating differences in local schemes (see for example, Zarb *et al*, 1997; Zarb and Nadash, 1994), knowledge of developing 'care markets' in social policy, conversations with personnel at the National Centre for Independent Living and an awareness of the importance of direct payments as a key policy demand from the disability movement. Therefore, a clear understanding of the market and independent living discourses informing the development of policy was apparent prior to the more formal stage of coding and data analysis.

Indeed for Coffey and Atkinson (1996), one of their objections to grounded theory relates more specifically to its heavy reliance on coding as the main focus of qualitative data analysis – a procedure particularly encouraged by the use of qualitative computer software packages. In turn, they suggest this mode of analysis can often lead to the application of 'standardized [sic], often mechanistic procedures' (Coffey, Holbrook and Atkinson, 1996, 7.6), leading to the imposition of a single exclusive interpretation of the data. Hence they emphasise the need to examine data more widely – by looking at whole structures that may otherwise become fragmented

and decontextualised if discrete segments are coded and grouped with others under invented categories (Seale, 1999, p. 103).

Developing an analytical framework to examine policy implementation

Coffey *et al*'s (1996) and Coffey and Atkinson's (1996) critiques of grounded theory link into a broader discussion of the role of computer packages for qualitative analysis and their function in this study. As outlined, this thesis explores the legitimising discourses used by planners and users to justify the adoption of direct payments in two authorities. A third authority – where direct payments have not been implemented but an indirect payment scheme is in place – is also examined. This approach draws on the post-structuralist tradition of examining the relationship between ideology, structure and human action. This returns to Williams' (1994; 1996) focus on policy analysis through multi-faceted meanings of diversity and difference. Therefore to address the research questions, this study includes:

- An examination of some of the identities surrounding the user role.

- Analysis of the collective and individual roles of policy planners.

- Identification of the legitimising discourses influencing the direction of policy.

- Consideration of the legitimising discourses influencing user's experiences of direct payments.

- Analysis of differences in the above between the three areas.

This framework draws loosely on conceptual dimensions set out by Williams and Popay (1999, p. 179). They argue that this type of multi-dimensional appraisal of policy is central to developing a 'new paradigm for welfare research'. The following section details how this framework has been organised.

Using NUDIST: roles and restrictions

Previous commentary has focused on how software packages such as NUD*IST have been developed as a means to ground theory. Despite rejecting this theoretical stance, NUD*IST was still used as the main tool to organise data analysis. However, this section details the boundaries from which this process was developed and the methods used to supplement these limitations.

From the fieldwork process, three main types of data had been collected. In each of the three areas these included:

- Transcripts and field notes from semi-structured interviews and conversations with key informants involved in local planning of direct payments.

- Policy documents for direct payments.

- Transcripts and field notes from semi-structured interviews with direct payment users.

Each of these files was imported into NUD*IST for coding and working through ideas for preliminary analysis. Although data were processed into the same framework, initial coding through headers clarified the type of data (e.g. policy document, planning interviews and discussions and user interviews) and the area it originated from. Prior to this stage, some analytical categories had already been developed since the outset of data collection underpinned by the broad framework of analytic relationships detailed earlier. These linked both directly and indirectly to the over-riding market and independent living themes initiated by users and planners in earlier discussions. In turn, these categories were established initially as a basis to develop related identities highlighted in each of the area's data sets (see figures I and II for examples of this process). From the interview schedule (see appendix II) and similar sections in policy guidance, it was possible to broadly group themes together, but the coding frame needed to reflect the interaction between themes. For example, figures II and III focus on some of the issues surrounding 'transitions to direct payments'. This initiates discussion at a number of levels. Structurally, it can link on changes in local

policy planning and the integration of disability groups into the planning process. This brings in both market and independent living interests as alternative providers to local authority services are sought, and the resulting change looks to offer users more flexibility and control in their day to day living. From this example, very quickly the 'structural' role becomes linked to user identities and experiences. Similarly, the demarcation between 'market' and 'independent living' discourses is removed as decisions to proceed (or not) with direct payments reflect both interests. Therefore, coding needed to accommodate these diversities and highlight the interaction between ideas.

The utility of NUD*IST in developing these ideas centred mainly on the basic organisational capacity offered by the program – thereby allowing a more systematic approach to data analysis than manual processing. In turn, transcript sections could be coded and linked to the wider discourse themes. Whilst this proved helpful in terms of a 'filing cabinet' approach, the use of hierarchically ordered trees or 'free nodes' made the forementioned links between main themes difficult to develop without further analysis. Initially, this resulted in the type of one-dimensional analysis shown in figures II and III. To overcome this, coded sections were often replicated into a number of categories, rather than rigidly placed in one. This clearly links in with some of the earlier criticisms of these type of programs developed by Coffey *et al* and Coffey and Atkinson, whereby program design can perhaps encourage a narrow appraisal of data and makes thematic links difficult to represent. Indeed, at face value, figures II and III would suggest that a rigid division between 'market' and 'independent living' identities exist – thereby rejecting an interaction between the two. But by developing theory and conceptual understanding of direct payments since the outset of data collection, ideas could evolve more fully through a process of replicating discourse sections into a number of categories. The main disadvantage of this process was the resulting expanse of nodes (figures II and III are shown only as examples because the final index tree was too large to duplicate in the thesis). However by replicating discourses in this way, data was more thoroughly examined – allowing analysis to incorporate a number of dimensions.

Figure II: *Example of developing themes through NUD*IST*

Market   **Transitions to DPs**

Changing organisational ——— **Locality policy**
structures   **planning**

Consumer identities—— Choice

Control
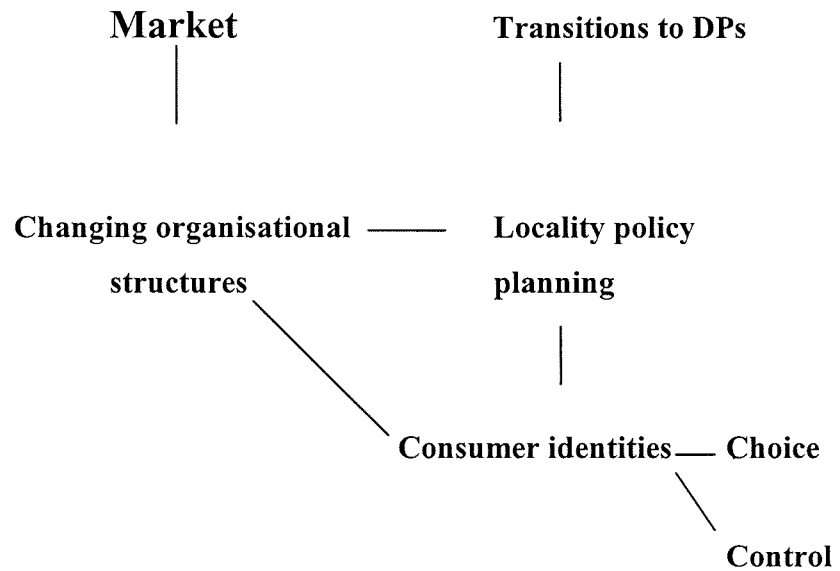
Figure III: *Example of developing themes through NUD*IST*

Independent living

Transitions to DPs

Changing organisational ——— **Involvement with**
structures   **disability groups**

Cash payment   ——— **Choice**

——— **Control**
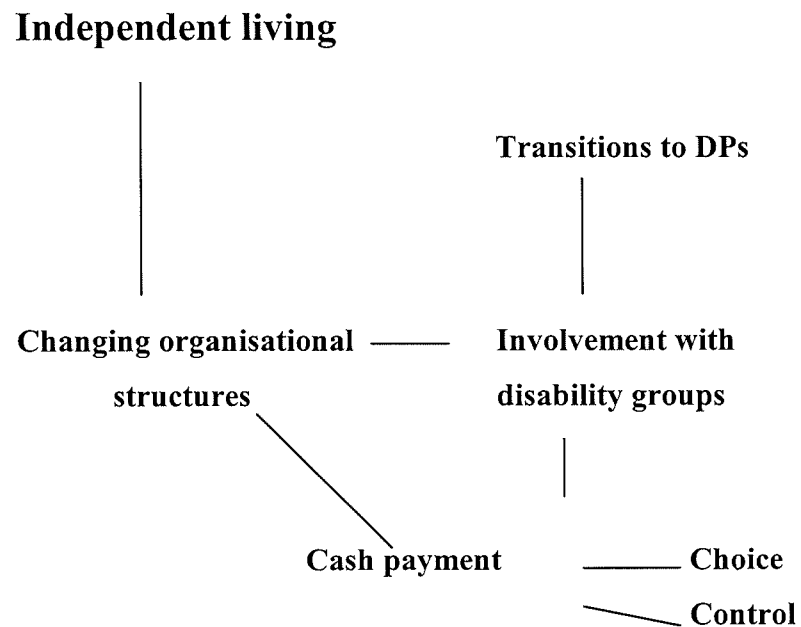
Comparability

By processing all the data through one NUD*IST index tree, themes in each coding category could be compared more clearly. In turn, this presented differences and similarities between planning and user perspectives in one frame as each file was opened up. These were recorded by attaching 'analytic memos' (see for example,

Strauss, 1987) to each file. Having grouped coded sections together in this way for analysis, the same approach was used to discuss findings. Therefore rather than examining each area separately, findings are disseminated thematically in the following chapters.

Conclusions

This chapter has addressed a number of themes, initially in examining the values underpinning contemporary research into 'disability issues' and then through a more specific focus on the framework designed for this study. Overall, this raises questions of how areas such as user identity and policy structure are examined in the research process. By focusing on how disability research has changed over the past decade, commentary has drawn on similar parallels with the formation of disability policies through medicalised appraisals of impairment addressed in chapter II. In research programmes, within both positivist and interpretist traditions a hierarchical relationship between academics casting themselves as 'experts', and disabled participants as 'research subjects' has been shown. Challenges to this framework introduced the notion of emancipatory research to disability studies. By exploring the values associated with this paradigm, discussion centred on the need to renegotiate the relationship between researchers and the subjects of research – disabled people. This has presented the emancipatory paradigm in more flexible forms – moving from a narrow approach which excludes non-disabled personnel from the research field, towards a focus on the values and goals held by individual researchers. Debate has also included issues surrounding ownership and accountability of disability research by academia and its relationship with the wider disability movement. By referring to some of the ideas surrounding post-structural analysis laid out in chapter III, this invites a less rigid labelling of research and encourages an understanding of direct payments not only as part of a wider contribution to 'disability studies', but also as part of a wider analysis of policy restructuring.

Debates surrounding the values underpinning disability research have also been shown to relate to a genre of 'empowerment research' emerging throughout the 1990s. This underlined gaps in understanding policy rhetoric like 'empowerment' through a body of research which has focused solely on individualised and consumerist

experiences. Therefore having determined the influence of the disability movement in the formation of direct payments legislation in chapter III, the need to explore empowerment as part of a dual process has been highlighted.

These values are transferred into the research design for this study of direct payments. Implicit within the research questions is an attempt to explore the legitimising discourses underpinning the policy structure and user interpretation of direct payments in three contrasting areas. Commentary has underlined a number of methodological issues and problems relating to how the research was carried out and the comparative framework from which it has been organised. This has presented a further opportunity to explore some of the issues surrounding the representation of identities addressed earlier in this chapter.

The chapter concludes by detailing the role of NUD*IST in the stages of data analysis. Although acknowledging some of the limitations of using this package as a sole means of theory development, its utility is shown in its organisational capacity. Having processed findings from the three data sources, themes are discussed in subsequent chapters.

Notes

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[i] In response to requests made by two of the local authorities, exact locations are not given.
[ii] A more thorough account of each area is given in chapter V.
[iii] This 'gate-keeping' role is explored in greater detail in chapter V.
[iv] This figure includes an interview with a mother of a direct payments user with learning difficulties. Issues relating to this interview are explored in the section entitled 'Representing the wrong voice?'
[v] These figures were accurate at the time fieldwork was completed (July 1999).

Chapter V: Planning for payments: *Developing policy in the local area.*

Introduction

ONE OF THE KEY IDEAS introduced into discussion of the restructuring of welfare in chapter III was the formation of more localised social policy provision. To re-cap, this has encouraged more diversity among local areas in their response to legislative change over the past decade. In terms of social service provision, this type of differentiation was accentuated through the 1990 NHS and Community Care Act which saw local authorities respond at varying speeds to calls to develop 'local care markets' for community support services and their management. Development of legislation for direct payments drew on this devolved framework, stating that 'The Act gives local authority social [work] service departments a power to make direct payments', emphasising that 'Each local authority may decide for itself whether to use direct payments to help meet the needs of its local population and, in each case, for which service or services to offer direct payments' (Department of Health, 1997, para. 6/Scottish Office, 1997, p. 5). In other words, local authority planners were given the options to decide whether direct payments should be implemented together with the framework from which this may proceed.

Indeed, local authority decisions to implement policy reflected in this chapter are shown to draw on broader trends within the UK. As detailed in chapter III, this has seen long-term suspicions in Scottish (and some northern English) authorities of direct payments. This has promoted an understanding of policy dominated by the market discourse, whereby planning conceptualisations tend to be led by their view of policy as a means to accentuate the mixed economy in the social care system.

Discussion in chapter III also focused on the growth of CILs and other collective disability action – a change which also contributed to a significant shift in the issues raised in the restructuring of welfare. Writers such as Oliver (1997, p. 245) highlighted the 1980s as an especially influential time for disability activism.

Campaigning integrated a wide range of issues extending beyond the national stage and sought to challenge local political structures, policies and service provision. Hence a process of change emerged in each of the three areas used in this study, promoting a long-term goal of transforming the pattern and culture of local authority service provision through the principles of independent living. However, it is the direction and influence of the collective action that varied between the areas as disability activists negotiated change with service planners. In these terms, developments surrounding this process become the focus of discussion in the first section of this chapter. This is supplemented with a brief outline of the organisational structure for cash payments in each area.

In detailing the influence of independent living and market discourses in developing cash payment policies in each of the three areas, the second section provides a more in-depth appraisal of how local policies have framed access for key user groups. As policy changes regarding the allocation of direct payments to persons with learning difficulties have been made since completion of this fieldwork, its inclusion at this stage provides the background for analysis of user experiences outlined in chapters VI and VII and future policy development in chapter VIII.

Data informing discussion in this chapter is derived primarily from semi-structured interviews with local authority planners and disability activists – including one-to-one meetings and telephone conversations – which took place from November 1999 until final submission of this thesis (Autumn 2000). Additional material is taken from a seminar presentation paper given by the Director of the CIL in West Scotland.

Action for change? Developing policy and establishing an agenda for cash payments

Discussion in this section gives an outline of how cash payment schemes have emerged in each area. It begins by reproducing the brief profiles of key socio-economic and political factors shown in chapter IV and then shifts to explore how the local authority and disability activism have worked together in developing policy. In East Anglia and East Scotland – where direct payments have now been formally implemented – commentary highlights the differences between a more marketised and

personal care oriented planning focus (East Anglia) and an approach more fully concerned with the principles of independent living but embedded within an anti-market framework (East Scotland). In contrast a focus on West Scotland shows lack lustre disability activism, a local authority cash starved from reorganisation, resistant to implementing direct payments, and instead reliant on an indirect payment policy focused on providing limited personal care in a home care setting.

East Anglia

This authority covers a county population of around 1,500,210 (Great Britain, 1991). Economic activity stands at approximately 90 per cent for males and 67 per cent for females. Owner occupation is at 75 per cent. Politically, the local authority has undergone change in recent years. A traditionally Conservative authority and with a majority at the time of policy planning for direct payments, Labour are now the largest party but with no overall control.

The development of cash payments in East Anglia draws on the promotion of independent living by users and planners over the past decade. However, service change was for the main part brought in alongside implementation of the 1990 Community Care reforms. Therefore from the outset, the concept of 'independent living' became intrinsically linked to planning centred on provision of personal care services with domestic and social activities given a much lower priority. Change has integrated both co-operation and conflict between user and planning levels as an impetus for this shift – culminating with the eventual implementation of the direct payments legislation in April 1997. According to local authority service planners and representatives from the CIL, central to policy development were two main factors: the timing of change and activism by a small group of disabled people dissatisfied with their service provision.

In terms of timing, the local authority's decision to develop independent living schemes (i.e. through indirect payments) emerged alongside the wider response to the 1990 Community Care Act. Around this time, a small group of disabled people were invited to join the *Joint Health and Social Services Strategic Planning Team* for *Persons with Physical and Sensory Impairments* in one of the five area teams in the

local authority. There was much concern about what the impending community care legislation would entail, but as the legislative focus on user-involvement (see chapter III) and care management (Department of Health, 1990) emerged, planners began to explore the idea of independent care management. This was described as an approach whereby disabled people become more involved in decisions relating to their service provision. Discussions culminated in a proposal to establish an *Independent Care Management and Advocacy Service*. Although the remit for this service was unspecified, it developed in line with providing support for users who were having difficulties with health or social care services. Management for this service was based on a tripartite arrangement with the local disabled person's association, social services and the NHS Trust all involved, and led by personnel who were themselves disabled and an existing social service user. Whilst developing this advocacy support service, local authority planners began to explore indirect payment schemes which were beginning to emerge in other English local authorities at the same time. These included schemes in Hampshire and Derbyshire (see chapter III for brief details on these early approaches).

Planners in East Anglia were keen to emphasise their enthusiasm to develop a more user-led focus to care management as an impetus to independent living in the early 1990s. However according to CIL representatives, the introduction of indirect payments was ultimately secured through activism by a group of five disabled young adults who continually pressurised the local authority into allowing them to receive cash to buy in their own services. Prior to this time, the five had lived independently on university campus. Having completed their courses, they were not prepared to use mainstream social service provision and asked that funding be paid directly to them in order that they could buy-in and make their own service arrangements. As the Chair of the CIL stated, 'the main thing that the Independent Care Management and Advocacy Service had to deal with was the 'difficult people' who just weren't accepting the way in which services were run'. After a few months of confrontation, the local authority relented and the group were given cash directly to purchase their support. When asking the CIL representative why he thought the local authority gave in to their demands he stated:

> Because the individuals had a good idea of their rights and were persistently
> causing problems...Once they realised [the local authority] that it was cheaper
> for them [the users] to sort it [their support] out for themselves and basically
> said 'here's the money, go and do it'.

At this time (the early 1990s), the payment of cash directly to service users in England and Wales was illegal. Whilst social service personnel were aware of this, they relied on not being challenged in the courts. Hence the experience of this group of five users became the basis for developing a more substantive indirect payment scheme. This was set up using the local disabled persons association to transfer cash from the local authority to individual users.

As the take-up for indirect payments grew throughout the early 1990s, the work load of the Independent Care Management and Advocacy Service also escalated. By 1996 there were approximately 90 service users and in anticipation of the direct payments legislation, local authority planners established an 'in-care advocacy project'. This was drawn from a team of service users, carers, organisations run by disabled people and representatives from Social Service and Health Departments and led to funding being set aside for the development of the CIL in East Anglia. With these structures in place, a policy proposal to formally adopt direct payments was put forward to the social services committee. It was emphasised by the Physical and Sensory Disabilities Service Manager in the local authority that the inclusion and presentation of ideas by users was crucial in gaining acceptance for the policy. The subsequent scheme developed for direct payments in East Anglia draws on two routes: firstly those transferred from the indirect payment scheme, whereby the third party role was removed; and secondly new service users entering the scheme for the first time. By July 1997, the first users transferred from the indirect to the direct payment scheme – approximately 90 users. This figure had risen to around 160 at the outset of this research (September 1998). In line with the requirements of the 1996 Act, direct payments are now offered as a mainstream option to all those receiving a community care assessment.

Whilst the local authority has been generally sympathetic to the ethos of user control and did work with disability activists throughout the development of cash payment

schemes in East Anglia, 'cost effectiveness' and 'user choice' have been continually presented as the main outcomes of policy change ([East Anglia] Policy Guidance, 1998, p. 15). Both planners and disability activists acknowledged the importance of these factors in securing the transition. As the Chair of the CIL remarked, 'I don't think they're [the local authority] doing it [implementing direct payments] just because its going to save them money, but I think they'll be disappointed when it doesn't save them as much as they think it will'. Indeed, market discourse is strongly reflected throughout the policy guidance. This focuses on the rhetoric of individual 'choice', 'flexibility' and 'control' in service provision, but is matched with an equal emphasis on 'cost efficiency' and 'service accountability' ([East Anglia], Policy Guidance, 1998).

The experience of policy development in East Anglia offers a useful example of how traditionally opposing political standpoints can work together and initiate a framework for service change. However as discussion in the remaining chapters will show, the interaction between market and independent living discourses in this area fails to represent an equal balance. This point was acknowledged by the Chair of the CIL:

> The worrying thing for anything like this – when 'left' and 'right' agree on something – there's real cause for concern. But when it comes down to how it operates in practice, the fact is they [the local authority] hold the purse strings.

A further issue affecting the impact of market and independent living discourses in policy implementation is that of charging for social services. At the time of interviewing for this study, East Anglia had in place a flat-rate charge levied at all local authority service users, so direct payment users paid a set fee towards the costs of their payments irrespective of income. However from May 1999, it was replaced by a means test to be applied retrospectively. As this had yet to be implemented within the time frame of the fieldwork, changes are discussed in the context of chapter VIII in the context of issues surrounding future policy development.

Payments in place: the organisational framework for direct payments in East Anglia

Having detailed the main issues surrounding policy development in East Anglia, the key features of the organisational framework for direct payments are laid out. In line with national guidance (Department of Health, 1997), initial access to a direct payment is made through a community care assessment and is available to 'any disabled person (i.e. someone with a physical and/or a sensory disability [sic], a learning disability, HIV/AIDS or an enduring mental health problem) who is over the age of 18 and under the age of 65'[i] ([East Anglia] Users Guide to Direct Payments, 1998, p. 2). National policy guidance states that, 'experience with independent living projects suggests that direct payments will work best where people who receive the payments have access to support'. In turn, guidance encourages the use of support services, suggesting that 'this might be by providing a service directly, in partnership with a local authority, or by some other means' (Department of Health, 1997, para. 32). In East Anglia, a strong support network has been developed, incorporating both independent advocacy through the CIL and payroll support. Prior to assessment, users are put into contact with an advocate worker at the CIL whose role is to 'provide…support and advice to assist them through the community care assessment process' ([East Anglia] Users Guide to Direct Payments, 1998, p. 5). Therefore if the user decides to proceed with a direct payment, the advocate works through the arrangements and offers independent advice on aspects of employing personal assistants. Job descriptions, advertising and recruitment may be included ([East Anglia] Users Guide to Direct Payments, 1998, p. 5). If users require support with day to day administration of their payments, a payroll service is offered by a local disability organisation.

Once the annual cost of the direct payment package is worked out, instalments are paid every four weeks in advance. Users are required to set up an exclusive bank account through which monies are paid ([East Anglia], Policy and Practice Guidance, 1997, p. 12).

East Scotland

East Scotland covers one of the major east coast cities in Scotland. An area of rapid economic growth, the population of around 441,620 (GRO Scotland, 1993) represents a mainly urban population. According to the 1991 census, levels of economic activity

are 85.4 per cent for males and 72.3 per cent for females and owner occupation stands at 66.4 per cent. The Labour Party has traditionally been the largest political force in local government, increasing to majority control in recent years.

A number of parallels may be drawn between the development of policy in East Anglia and in East Scotland. Notably as in East Anglia, indirect payments developed in the late 1980s primarily in response to individual demands from disabled people, dissatisfied with their existing provision. More specifically, three disabled people pushed for change having heard about Hampshire's scheme. In response, planning service personnel looked initially at the provisions of the 1968 Social Work (Scotland) Act - which as shown in chapter III — gave Scottish local authorities powers to make direct payments in 'exceptional circumstances constituting an emergency' (Section 12, 1968 Social Work (Scotland) Act). However, because the user's need for support did not meet these requirements, it was decided that payments could not be made through this route. To overcome these checks, under section 10 of the 1968 Act it was found that money could be paid if facilitated through a third party. In turn, funding was organised and paid through a local voluntary organisation.

As detailed in chapter IV, this arrangement remained in place during the early 1990s but became increasingly problematic because of the precarious legal position in the UK as a whole. Indeed, the planner directly involved in organising these payments acknowledged that these concerns were heightened when the community care legislation was passing through parliament:

> At this time, the then Secretary of State for Health, Virginia Bottomley was reminded of the illegality of making cash payments. This was evidently problematic because by then quite a few local authorities in England and us [East Scotland] in Scotland were using this type of approach.

Concern reached a climax in 1995-96, when the DSS became alerted to one of the payment recipients in East Scotland and suspended his Income Support. A challenge to this decision was made and won by the local authority, but the case had raised the profile of cash payments thereby instigating the need for a formal legislative path to be developed (see chapter III). Although the DSS case caused concern over the

legality of this type of arrangement amongst other local authorities and, indeed, prevented many from developing schemes at this time, planners in East Scotland continued making payments to specific individuals. As the Commissioning Officer for Disability Services explained, 'at the time disability activism had gained a much higher profile – through the Disability Discrimination Act [legislation was passing through parliament at this time]. I think it just pushed the DSS to turning a blind eye until the direct payments legislation was in place'.

Adoption of the 1996 direct payments legislation in East Scotland highlights a more incremental approach to policy development than in East Anglia. Although as shown, planners had been keen to innovate change in rigid policy boundaries, individual action has been supported through and linked into the wider goals of a pro-active disability movement. This began in the late 1980s when the work of the local Independent Living Group – a consumer group of disabled people and Coalition of Disabled People – the main campaigning force for disabled people in the area - led to the establishment of the first CIL in Scotland in 1991. With this support network in place, adoption of direct payment policy - developing from the indirect payment scheme already in place - was described by several of the planners as 'a logical conclusion'.

Development of a formal route for the implementation of direct payments centred mainly on the input from a working group. As in East Anglia, this included a range of user and planning representatives from community care and social work backgrounds. However, it differed in that project workers from independent living schemes around the area were more strongly represented and health personnel were not included. From the group's work, three routes to direct payments were established. Firstly, as in East Anglia the transference of the existing indirect payment scheme users formed the mainstream route, accounting for 50 users (and the majority of those interviewed for this research). Secondly, the working group secured £100,000 to fund 'demonstration projects'. These were developed with funding set aside to examine how policy could be used at its most innovative level. In the words of the Purchasing, Planning and Commissioning Officer for Learning Difficulties in the local authority, the purpose of the projects was to 'test out' the legislation and see 'how far policy could be taken'. Hence planners moved the focus of direct payments away from just users with

physical impairments to look at how payments can be used in the areas of learning difficulties, physical and cognitive impairments and, since completing field work, sensory impairments. At the time of writing, eight users are funded through the demonstration projects (one of whom agreed to be interviewed in this study). Issues surrounding direct payments for users with learning difficulties are explored more thoroughly later in this section. Thirdly, direct payment were set up to be offered as a mainstream service option in line with other modes of community care service provision. As stated in chapter IV, given that this route has only been in place since May 1999 and currently includes seven users[ii], the time scale for this fieldwork did not allow any of this group to be represented in this study. As in East Anglia, planners were keen to emphasise the ethos of user control as the main impetus to policy development. Certainly the commitment of all those involved on the working group would suggest that policy is underpinned primarily by a strong commitment to the principles of independent living. Similarly, guidance makes clear statements concerning independence and control, emphasising that 'the disabled person must maintain the role of the major decision-maker' ([East Scotland], Policy Guidance, 1998, p. 2). In contrast with East Anglia, market discourse is limited. No mention is made of it beyond central government guidelines on 'cost efficiency', whereby payments cannot be made unless they are at least as cost-effective as existing services (Department of Health, 1997, p. 16). However, the position on 'market development' is clarified in light of conditions placed on offering direct payments as a mainstream option to *all* community care users. In this sense, access has been restricted by wider ideological concerns in the authority. Planners found that to offer payments to users already in receipt of a local authority service would amount to either double funding – in other words, covering the service cost *and* the direct payment - or loss of the service. In keeping with central government rulings on cost efficiency, the funding of double costs in these instances could not be accommodated, but likewise the alternative was equally unacceptable – as indicated during an interview with the Head of Operations:

> Ideologically 'choice' is not a problem, but it becomes untenable if it leads to redundancies for local authority service providers.

As a result, resistance to market development leads to the exclusion of this group of potential users from the direct payment scheme. This clearly raises a number of issues with regards to allowing equal access to direct payments to *all* those receiving a community care assessment. Moreover, restriction of access in this way may contradict national guidelines which state that, 'People who are already receiving services may wish to switch to direct payments. They may raise this possibility themselves, or the local authority may wish to suggest it, and the issue might arise at, or between a person's review' (Department of Health, 1997, para. 20/1999, para. 16) Indeed, the ruling will clearly limit wider use of direct payments across all groups but particularly for persons with learning difficulties who make greater overall use of local authority services such as day care centres. Again, this is an issue that will be returned to later in this chapter.

Payments in place: the organisational framework for direct payments in East Scotland

As in East Anglia, assessment for a direct payment conforms with national guidelines. However, as stated previously eligibility differs in that payments can *not* be made to anyone who is 'provided with a service by the [East Scotland Social Work Service} Department or any provider the Department funds through a grant or block purchase' ([East Scotland], Direct Payments Procedure and Guidance, para. 2). Furthermore the support structure offered by the local authority includes important differences. In contrast to East Anglia, a referral to advocates at the CIL does *not* form an automatic part of the assessment procedure. Whilst the CIL in East Scotland offers users similar advocacy support and training, users have to make the initial contact themselves to access these services is required from the user. Therefore users are reliant upon social workers to pass on relevant information. Guidance makes only a vague reference to the services on offer, stating that 'people find it useful to talk to other disabled people about these [direct payment] experiences and user organisations are helpful, e.g. [East Scotland] CIL' ([East Scotland], Practice Guidance, 1998, p. 10). However, both areas offer a payroll service run through a local disability group and users are also required to set up a separate bank account into which payments are placed on a monthly basis.

West Scotland

West Scotland covers the largest urban area in the study – representing a total population of approximately 653,618. Levels of economic activity are notably lower, standing at around 80 per cent for men and 61 per cent for women. Similarly, owner occupation is much lower at 37 per cent. Politically, the authority is a traditional Labour stronghold.

As discussed in chapter IV, the main difference in detailing policy planning and key influences in West Scotland, is that during the time period covering this research (November 1998 – Autumn 2000), the local authority had yet to formally adopt *direct* payments. Whilst piloting eventually began in July 2000 (see chapter VIII for more details), a final decision as to whether the area should proceed with implementation of legislation has yet to emerge. However, the debates surrounding the development of *indirect* payments highlight some of the key conflicts, which in turn has led to resistance to the 1996 Act.

As with East Anglia and East Scotland, central to understanding the discourses and influences surrounding resistance to direct payments is to outline the climate through which policy entered. In these terms the focus on policy *under* development in West Scotland came largely from the emphasis put on it by planners and disability activists during interviews. Firstly, attention was brought to the enormous problems created by local government reorganisation, which restricted the impetus to develop new policies. One planner in particular described the culture in the authority as 'a council under siege'. This centred on the shift to unitary status in 1996 which was far more chaotic than in surrounding areas. In this part of Scotland, the formerly monolithic regional authority was disbanded into much smaller units, leaving many of the new authorities in turmoil as they adapted to their changing roles. For West Scotland Social Work Services in particular, substantial budget cuts ensued (d'Aboville, 1999, p. 16). Secondly, reorganisation also signalled the end of what had been the main regional campaigning organisation of disabled people. Whilst disability activism in the area has been historically fragmented and low key, this shift seemed to accentuate the problems faced in sustaining interest and representation of disability issues and - as one planner suggested – 'made services particularly susceptible to budget cuts'.

Although a new area wide campaigning group had been formed, activity has been limited, leaving all lobbying for direct payments to the CIL. As one activist and CIL worker commented, 'Its [the new campaigning group] been so slow getting off the ground – but that seems to happen in [West Scotland] – I'm not quite sure why but we just don't seem to be politically active here. Disabled people just need to get their act together here'. Thirdly, several people – from both planning and CIL backgrounds – voiced the concern that direct payments were seen by some in the local authority as 'backdoor privatisation'. This, according to a CIL representative, was a sentiment prominent amongst many of the elected council officials and acted as an additional delaying factor.

As stated, provision for cash payments in West Scotland centres on the development of an indirect payment scheme in the mid-1990s. In contrast to East Anglia and East Scotland, the emergence of indirect payments in West Scotland has been led by changes in national policy rather than direct activism of individuals in the locality. Indeed whilst efforts had been made to facilitate independent living services prior to this time, these had been met with resistance from senior planning personnel within the local authority. A key example of this was given by the Senior Officer for Physical Disabilities when in 1993 he put forward a proposal to introduce the ethos of independent living in service provision by targeting funds at specific advocacy projects. In rejecting the proposal, senior management argued that disabled people in the area 'were not ready for control'. This type of attitude – although not universal – was said to be prominent amongst a number of key senior planning personnel and elected officials.

Hence policy developed largely in response to changes made to the ILF in 1993[iii] (see also chapter II for more details), where through the Independent Living Transfer (ILT) over nine million pounds was allocated to the former regional authority to compensate for the loss of additional payments for disabled people contained in social security reform (this should be distinguished from the more general transfer to cover community care services). From 1995, this funding was used to develop a three-fold independent living strategy comprising the establishment of a CIL, funding for six Personal Assistance Advisors (employed through Social Work Services) and an

indirect payment scheme for individuals together with a payroll service organised through the local Council for Voluntary Services.

Despite the importance of indirect payments as the basis of independent living services in the locality, the effectiveness of the scheme has been gradually reduced over the past few years following budget cuts made in light of local authority reorganisation. As ILT funding was not ring-fenced, the indirect payment scheme budget of £1.8 million became effectively halved over a period of three years up until 1997/98 (d'Aboville, 1999, p. 16). As d'Aboville argues, 'even within the context of severe reductions in service budgets this was a disproportionately large reduction for a new and innovative service at the cutting edge of national and local policy'. To place these budget cuts in context, when indirect payments were first set up there were just over 100 users. The figure now stands at around 90. Moreover at the time of fieldwork, the indirect payment budget had been frozen for 18 months – leaving a waiting list of over fifty individuals assessed as requiring a payment package. Therefore in West Scotland, a paradox has emerged whereby indirect payments were developed as one of the few such schemes in Scotland, but have clearly been marginalised by wider financial controls which have drastically reduced spending on disability services and accentuated already limited disability activism. From the outset, indirect payments have not been framed as mainstream alternative to services in kind for all potential community care users. In turn, funding cuts weakened the base from which direct payments could be developed. However, securing this shift remains a key campaigning issue for the CIL - although given the severe financial restraints on their own budget the momentum has often been difficult to sustain (more details are give in chapter VIII). Indeed, whilst West Scotland does have examples of advocacy and independent living projects across user groups, interaction between such groups and the local authority appeared to be limited and, again, out-with the framework of mainstream services. In contrast to East Scotland - where project staff from a range of independent living backgrounds were integrated into the working group for direct payments - any input or discussion of how direct payments might be adopted in the area seemed to be limited to a very broad based consultation. For example, staff at a local project focused on developing person centred planning and cash payment approaches for people with learning difficulties, explained that they had felt that they had not been encouraged to develop a more involved role in either local

disability politics or collaboratively in service provision. This was emphasised by the project director, who stated that 'there is a perception that the Social Work Department don't want to plan for services and certainly not in a joint way'.

In returning to the indirect payments scheme in place, rhetoric contained within the policy guidance provides an initial insight into how policy has been positioned. However, given that the remit for the scheme falls outside the 1996 direct payments legislation, guidance in West Scotland cannot be directly contrasted with East Anglia and East Scotland. In these terms, the positioning of indirect payments is *not* made in the context of the wider 'care market', and is instead placed alongside access details for the ILF for disabled people in the area. At face value this might imply a stronger focus on independent living values. Yet whilst guidance emphasises that its primary goal is 'to empower disabled people directly by giving them the resources to take control of their own support systems' ([West Scotland], Independent Living Service Guidance Notes, p. 3), the focus on the possible use of payments, draws more narrowly on the provision of personal care in a home setting. In turn, this gives a far more limited framework, stating only that monies received should be used 'to provide more flexible home care provision' ([West Scotland], Independent Living Service Guidance Notes, p. 4). This is a theme explored in more depth in chapter VII, but reference at this stage serves to reiterate the boundaries within which policy has been framed.

Payments in place: the organisational framework for indirect payments in West Scotland

In detailing the structure in place for indirect payments in West Scotland, guidelines are framed only by local policy and are not related to national guidance for direct payments as determined by the 1996 Act. Whilst indirect payment users still receive a cash sum to buy in their support, there are key differences between the direct and indirect payment modes. This centres on the availability of contingency monies for *direct* payment users – covering payroll and insurance costs. For direct payment users, access to these additional sums give users more flexibility and control in purchasing their services. For example, this might be achieved by opting out of the payroll service or by negotiating their own insurance cover, rather than using a block deal secured by the local authority (as organised through the indirect payment scheme).

Consequently, cash savings may be used to buy in additional support and/or pay PAs a high rate. Therefore, users gain both more funding and overall control over their support budgets.

Securing an indirect payment in West Scotland is less straightforward - mainly because funding is not generated from the general community care budget (as in the case of direct payments) but comes from a separate source. As indicated, this has been substantially cut in recent years, and this has prevented new users from entering the scheme. Policy guidance remains limited, stating that cash payments are available for those requiring less than £200 per week in services and 'for those wishing to purchase their own support systems'. However, in abstract, access to an indirect payment follows the same route as direct payments – via a community care assessment. If an indirect payment is considered as an option, the user is referred to a personal assistant advisor. Whilst this is clearly a specialised post – with personnel trained to understand the principles of independent living - staff are based in the social work service department and assume a number of roles. These include advocacy support, gate-keepers to funding and providing advice to other social work staff. This may be contrasted with East Anglia, where the advocacy and support role in organising payment support is independent of the local authority – with workers based at the CIL. Therefore, although West Scotland's CIL also offers services such as personal assistance training and employer support, as in East Scotland they are dependent on social work and personal assistant advisors informing users of these.

Once users are accepted onto the indirect payment scheme, they are asked to set up a separate bank account and pass on monthly invoices to the local centre for voluntary services, which assumes the third party role in administering the payment. The service performs two main functions – payment of monies into the user's bank account each month and organisation of payroll details, including tax and national insurance contributions.

Whose payments?: user groups and access to cash payments

So far discussion has focused on how policy for cash payments has developed in each of the areas by highlighting how the key discourses are reflected in each framework.

Commentary now shifts to look more specifically at how local policies have been organised to access key user groups. More specifically, this underlines a policy differential between users with physical impairments and those with learning difficulties.

As Holman and Bewley (1999, p. 1) note, many social service managers and social workers continue to have difficulty in visualising how people with learning difficulties could use a direct payment. The ambiguity surrounding payment access is underpinned by vague policy criteria set out in the original guidance (Department of Health, 1997, para. 22). In these terms, local authorities could access direct payments to users who it considers 'will be able to manage them (alone or with assistance)'. The interpretation of who exactly is to be regarded as 'willing and able' is open to variation – both between local authorities and individual care managers carrying out assessments within the same authority. This has resulted in only marginal use of policy for this group. Indeed Holman and Bewley's assertion was reflected in the coverage of user groups in each of the three areas. However, whilst all had a majority of users with physical impairments, the emphasis and potential access for users with learning difficulties differed between localities. East Anglia had the most users with learning difficulties, but they still only numbered six out of the total user population of 160. In addressing this imbalance with planners, the Physical and Sensory Disabilities Service Manager - who had led the shift to cash payments - explained that the 'whole wealth of knowledge and experience in understanding [cash] payments in the authority was with physical and sensory impairments and so other groups tended to get left behind'. Whilst he was content to make direct payments accessible to users with learning difficulties, he emphasised that giving these users payments would raise 'a question of mental capacity'. A more positive and informed appraisal was given by the Director of the CIL, who was keen to develop policy more widely to include learning difficulties, but on the lines of a service brokerage model[iv]. At the time of interviewing (March 1999) he suggested that this type of approach would require changes in policy definitions from central government to move direct payments away from its limited focus on 'user control' (see for example, Department of Health, 1997, para. 10). Since conducting the interview, national guidance has altered slightly, offering wider policy definitions. The implications of these changes are explored in more detail in chapter VIII.

In East Scotland although users with learning difficulties only accounted for four out of the total of 63, policy development for this group seemed to be more inclusive. Unlike in the other two areas, the planner with specific responsibilities for learning difficulties assumed a far more pro-active role in the direct payment's working group and had instigated much of the work around the demonstration projects. Indeed his approach to developing policy for this group mirrored the rhetoric used by the Director of the CIL in East Anglia, by emphasising the need to 'build support around the person in order to facilitate control'. This had led him to examine how services could be delivered in a more flexible way, again moving away from more rigid notions of *user* control.

However as stated earlier in this chapter, the 'anti-market' discourse limiting access to direct payments to existing local authority service users looked set to be the main check on access for a wider population of users with learning difficulties in East Scotland. Although discussion in chapters VI and VII illustrates some of the benefits achieved by providing a direct payment to users formerly attending a local authority day care centre, under the present rules this type of service transition would not be permitted as a mainstream option. This was an issue raised during interviews with planners involved with the working group. Indeed although as suggested, all those involved in developing the area's strategy were committed to the independent living principles underpinning direct payments, there were important differences in application. For the Planning, Purchasing and Commissioning Officer for Physical and Sensory Impairments, sensitivity to user choice was a primary aim and she was clearly concerned at how the ruling on double funding would affect access. However she stressed the need to maintain local authority service provision – notably day care centres - as a means of sustaining a truly mixed economy of provision. As she explained, 'there has been a clear resistance to the privatisation of services in the area, but there is a definite wish to use staff more innovatively'. In these terms, she stated that opposition to direct payments had not focused entirely on an anti-market rationale, emphasising the need for local authority provision to 'fill the gap' in services like day care for persons with learning difficulties where alternative providers had failed to emerge:

If a wider use of direct payments is going to take place then service provision must offer real choice across *all* services. This isn't the case at the moment so the local authority provider role remains an essential component to care packages.

On one level, support for this type of mixed approach was reiterated by one of the project workers at a local day care centre who had been involved in securing direct payments for two people there through the demonstration projects. Although keen to see a reduced role for day centres by promoting at least part use of direct payments, she maintained the importance of continuing with these types of services:

> Some people want to come here because they're been doing so for so long. Its important for them to come here as part of their daily routine – I know its sounds segregated - but people seem to want it.

Hence, although both the service manager and project worker appeared to be advocating a more mixed approach to service provision – through cash payments and existing services – as the direct payments framework in East Scotland stands this could not develop. Again, this is an issue explored more thoroughly through individual user experience in chapters VI and VII. This line clearly contrasted with the views of representatives from a local project involved in developing inclusion and person-centred planning strategies for persons with learning difficulties. In these terms any opportunity to close day care centres was welcomed, thereby reducing local authority service provision which was more generally seen as 'rigid and stigmatising'. In West Scotland, the division between cash payments and strategies for independent living for those with physical and sensory impairments and learning difficulties appeared to be most rigid. Although the 1997 policy guidance for direct payments does not cover indirect schemes, it is important to note that no persons with learning difficulties were included in West Scotland's scheme. It was, however, stated by the key planner involved in this area added that 'they [indirect payments] were beginning to be considered as a service option'. Indeed on several occasions, references were made from local authority and other service personnel to the CIL as being 'more involved with physical impairments'. This imbalance was reflected in the initial planning group for direct payments where no representatives from the field of

learning difficulties had been included. In directly addressing this issue during an interview with the Senior Officer for Learning Difficulties, she conceded that 'very little work has been done in terms of developing direct payments [for persons with learning difficulties]' and that any involvement in the local authority's strategy 'would come after decisions had been made by the Social Work Department'. The lead planner involved in the development of direct payments reiterated this and suggested the focus on physical impairments represented a 'pragmatic decision'. In turn, although an 'inclusive model' for direct payments was described as a policy objective, it was stated that no pressure was felt to include representatives in the planning team. Clearly although across each of the areas, learning difficulties have been marginalised, the political will to represent these needs have been much weaker in West Scotland. As suggested earlier in this chapter, there remains in place a number of projects dedicated to providing independent living services for persons with learning difficulties, but their exclusion from strategic planning for direct payments evidently negates their influence. Since completing fieldwork for this study, pilot projects for direct payments have been funded and developed and these include two people (out of a total of 18) with learning difficulties. A more in-depth appraisal of this change is given in chapter VIII.

As discussion demonstrates, the marginal use of cash payments for users with learning difficulties is indicative of both a local and national policy focus on securing change for users with physical impairments. Moreover, it perhaps reiterates the importance of disability activism in gaining policy change, as both national and local lobbying has been more generally led by this group. However as groups of persons with learning difficulties and national organisations such as Values into Action have become more active in lobbying for change, there appears to be some evidence from this research that policy will develop to allow for a more inclusive framework (see chapter VIII). Similarly for other user groups permitted to use direct payments in the context of the 1996 Act - those with sensory impairments, mental health problems and HIV/AIDS - limited representation of their needs has also resulted in minimal policy use. As stated in chapter IV, at the time of interviewing no users in either of these groups were in receipt of a cash payment in any of the areas – although more recently East Anglia has included three sensory impaired users in their demonstration projects.

Three areas, three payment policies: summary

This chapter has laid out how key discourses and issues have influenced policy implementation of cash payments and access to key user groups in the three areas. This informs discussion and analysis in the forthcoming chapters. In East Anglia and East Scotland, this has culminated in implementation of the 1996 Community Care (Direct Payments) Act, whereas in West Scotland policy remains lodged with an indirect payment scheme as direct payments have yet to be formally adopted. Whilst each area shows different approaches to policy implementation, the impact of market and independent living discourses alongside wider issues of care are not always straight forward. Hence at this stage, statements about local policies may appear to contradict some of the broader arguments about the development of marketised and consumer-responsive services detailed in chapter III. However, these apparent anomalies will be clarified as analysis is developed.

Therefore to re-cap, planning in East Anglia has been led by a traditionally Conservative local authority alongside considerable input from individual and collective disability activists. Hence, implementation of direct payments derived from both the local authority's response to the 1990 NHS and Community Care Act and calls for independent living from an increasingly influential disability movement. In turn, the interaction of these positions exemplifies the market and independent living discourses informing the legislative background to direct payments (see chapter III) – whereby the political will to accommodate the demands of disability activists drew strongly on New Right notions of cost efficiency and the promotion of user choice. Thus whilst pressure from individuals discontent with their service provision formed a catalyst for developing independent living services, the local authority has remained strongly committed to a strategy of marketising 'care' services. This has resulted in a much faster growing user population and a higher number of *new* users than East Scotland (or indirect payment users in West Scotland), as all those receiving a community care assessment have been offered the option of a direct payment since the outset of policy implementation. However, the emphasis on developing an independent living strategy in line with the overall planning for a 'community care market', strongly suggests that the framework offered may be less conducive to fully promoting independent living.

In East Scotland, whilst policy development for direct payments also derived from disability activism, change represents a more gradual process of co-operation between planners and disabled people. Over the past decade, this has seen the growth of an increasingly vocal independent living movement - which, in turn, secured on-going input to the direct payment's working group. Although implementation of policy has been much slower than in East Anglia - with access to direct payments as a mainstream option only available from May 1999 - funds set aside for demonstration projects have shown a political will to use policy more innovatively. However, this partnership between planning and user levels has been challenged by an 'anti-market' discourse informing policy development. In turn, the refusal to allow existing users of local authority services the option of a direct payment, clearly limits choices for key user groups. Therefore whilst CILs in East Anglia and East Scotland had a similar level of level of input in policy planning for direct payments, the impact of this activism varies according to each local authority's relationship to the market.

Discussion of cash payments in West Scotland showed a local authority still undecided whether to formally implement direct payments or not. Wider issues of council reorganisation, ineffectual disability activism and fears of service privatisation were highlighted as the main reasons for this delay. Whilst the shift to unitary status has evidently limited impetus for policy planning, the contrast between the roles of disability groups in West Scotland – where campaigning has been limited - and those in East Anglia and East Scotland – where more vigorous independent living movements have emerged - demonstrates the importance of their role in gaining policy change. Indeed when placing this limited role alongside a local authority fearful of service privatisation, the importance of interaction between market and independent living discourses in securing a momentum for change is reiterated. Therefore in documenting the development of indirect payments in West Scotland, its emergence shows implementation led by *national* rather than *local* policy change. In these terms, changes to the ILF led to a transfer of cash being made available in West Scotland to develop key independent living services. Again, in line with the broader pattern of limited service support for disabled people in the locality, the coverage of the scheme has been hampered by budget cuts stemming from local authority reorganisation. Many of the themes surrounding the policy influences operating in each area are revisited in the second section of this chapter, as discussion shifted to

detail how local direct and indirect payment policies have been framed around access for key user groups. This has introduced a policy differential between users with physical impairments and those with learning difficulties – a trend underpinned by the vague criteria of 'willing and able' laid out in the 1997 guidance. Although planning personnel in East Anglia and East Scotland indicated an interest in developing wider use of direct payments for users with learning difficulties, both policy frameworks remain more appropriate to the needs of those with physical impairments. In East Anglia, recognition of this divide has been indicated as a stronger emphasis on the inclusion of other user groups looks set to emerge in line with changes in national policy definitions (see Department of Health, 1999). However in East Scotland, the will of planners to develop more inclusive access is constrained by anti-market checks emanating from senior management. Consequently within the current political climate in East Scotland, the opportunity to offer persons with learning difficulties already in receipt of a local authority service a direct payment remains strictly limited.

The structure for indirect payments in West Scotland provided the most acute divide between these user groups. This had resulted in *no* users with learning difficulties receiving an indirect payment and limited inclusion of individual or group representation in the planning strategy for direct payments. In turn, this reiterated the importance of activism as an impetus for policy change.

Having outlined the impact of market and independent living discourses framing cash payment policies in each of the three areas, discussion shifts in the next chapter to focus on user's accounts of structural and identity change as a shift to cash payments is made.

Notes

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[i] This information regarding direct payment access for older people remained accurate at the time of interviewing (May 1999). Older people have subsequently been included in revised policy guidance (see chapter VIII).

[ii] Figure correct at time of writing (July 2000).

[iii] In 1993 the then Conservative Government changed the criteria for applicants to the ILF, requiring disabled people to receive £200 of services per week from the local authority before they could apply for money from the fund. The ceiling of £500 per week still remained, but the first £200 per week had to come from the local authority.

[iv] This approach has been developed to assist persons with learning difficulties to receive an individualised cash payment by organising a network of support to facilitate the arrangement, but still allowing the user maximum control over its use. See Dowson (1995) for a wider discussion.

Chapter VI: Delivering independence?: *changing structures and changing identities.*

Introduction

THIS CHAPTER DRAWS largely on user accounts of changes experienced through the shift to cash payment schemes in each of the three areas. In examining these views, attention centres both on change in the delivery of services through the introduction of policy and the effects of this shift on individuals. Together, these themes reiterate earlier ideas which emphasise the importance of direct payments as a means of restructuring service delivery *and* user roles and identities.

At this stage, focus on *direct* payments in East Anglia and East Scotland and *indirect* payments in West Scotland shows similarities in the overall experience of receiving cash to buy-in support. Whilst there are some important differences between direct and indirect payments, in this and subsequent chapters these are highlighted specifically in the context of discussion. This chapter is organised within two main sections. The first, *Changing services – changing structures*, looks at issues surrounding access to policy and contrasts experiences of provision organised by or through the local authority with those of receipt of a cash payment. The second, *Changing services – changing identities*, focuses more specifically on the changing roles assumed by the service user through the policy transition.

The first section begins by exploring *why* users shifted service provision. In doing this, across each of the areas the rigidities of other support services are exposed not only in terms of organisational rulings on the type of service that can be offered, but also through views on disability held by service employees. User fears of dependency – either through entry into residential care (all areas) or by requiring long-term support from family (East Scotland and West Scotland) - are shown to be allayed by service change.

In addressing the changes in service delivery facilitated through cash payments, focus on structural transitions shows local authorities and CILs in a 'market facilitator' role. In turn, positive user perceptions and experiences of access to service information and support are shown as pre-requisites to securing an effective shift to cash payments. Whilst this requires social workers to be informed and to fully understand the principles surrounding policy, findings highlight major gaps in their knowledge. In each of the areas, user views and commentary from other personnel suggest that professional understanding of the concept of independent living varies considerably. Discussion then moves to examine the role of support structures used in each area to aid the shift to independent living. This begins by comparing user experiences of CILs – examining the type of input offered as service transitions are made - and exploring their role more specifically through users' own conceptualisations of support. Whilst knowledge of and involvement in CIL services varies between localities, generally positive user feedback is contrasted with views on local authority roles, particularly between East Anglia and West Scotland.

For many users in East Anglia and East Scotland, transitions to direct payments came via indirect payments. Although, as suggested, a re-routeing of payments directly to the user should imply minimal change, in East Anglia a number of issues are raised. In particular, discussion focuses on the increased bureaucracy now required by the local authority. By returning to the market discourse underpinning direct payments, this introduces a more sceptical view of the user role as 'user abuse' is shown to be an implicit concern in East Anglia's policy framework.

The second half of the chapter – *Changing services – changing identities* – gives a more in-depth appraisal of the user role through cash payments. Whilst both direct and indirect payment schemes highlight a dominant consumerist discourse through the importance of 'being an employer', it is the framework for direct payments developed in East Anglia and East Scotland which allows users more overall control. The freedom to offer PAs reasonable pay and conditions in East Anglia and East Scotland is contrasted with a more cash restricted indirect payment scheme in West Scotland. For users, being able to offer good pay and conditions for their PAs provides not only more individual satisfaction in working relationships but removes any feelings of dependency on either PAs or family members.

However across all areas, establishing successful working relationships with PAs underlines the importance of *who* is employed. In these terms, discussion gives examples of both successful and problematic relations and links this to a wider theme of 'market development' for personal assistance later in the chapter. Similarly, this transition to being an employer introduces key issues surrounding the management of this role which are revisited in chapter VII.

The next section introduces a more specific focus on user language – a theme which will be revisited in the remaining chapters. At this stage discussion highlights difference in user descriptions of those employed to carry out personal assistance. In particular, commentary shows a contrast between a more individualistic and 'consumerist' user population in East Anglia and those involved in a more collective disability identity in East Scotland. Whilst acknowledging the associations of dependency with personal care limited to a home setting, a paradox is shown whereby a majority of users in East Anglia demonstrate high expectations of control and independence, but discuss this support through a dialogue of 'caring'. However the same group reject a more politicised and collective disability identity. In contrast most users in East Scotland show more interest in disability politics and in turn define support through the more empowering term of 'personal assistance'. For indirect payment users in West Scotland, no discernible pattern could be identified at this stage, the terms 'caring' and 'personal assistance' were used inter-changeably and reflected a number of user conceptualisations of service provision.

The final section of this chapter brings together discussion surrounding user transitions by drawing out key themes emerging at this stage.

Changing services – changing structures

Attacking an 'agency culture'

One of the main successes of the cash payment schemes operating in each of the three areas was the control, flexibility and choice offered to users. This theme emerged throughout the interviews, but first became apparent when users discussed their previous service arrangements and were asked why direct/indirect payments seemed

appropriate to their needs. Change led not only to different organisational roles but also opened up a more in-depth attack on the views and conceptions of disability held by service personnel and the rigidity of previous service provision[i]. This was underlined by Carol[ii] in East Scotland, through her experience with district nurses who came to the house over a number of months:

> She [the nurse] made me feel that because I had a disability I had no rights. She just rushed me all the time and I felt completely disempowered.

Similarly in East Anglia almost all users who had received home care services expressed a level of dissatisfaction with the manner in which they were treated. As David explained, the presence of agency personnel made him 'feel more like a patient', as control over tasks remained with service staff. For most users in all areas, the views of some staff were reflected in their rigidity in the tasks they were allowed or prepared to do. Sometimes, it reflected organisational rulings from home care agencies or social service departments who prevented them from carrying out tasks beyond personal care. In this sense, categorisations of tasks led to increasing frustration. However, in other cases, for Tony, *some* agency staff were willing to carry out tasks like ironing. The arbitrary nature of this arrangement had left him greatly angered and encouraged a self-perception of dependency:

> They [the home care agency staff] provide a certain level of home care for one person and then different for another…I know it sounds petty but it makes you feel like a second class citizen just because you can't iron your own shirts.

Moreover, the lack of continuity in terms of who was entering the user's home left many in each area feeling uncomfortable. As Jean (East Anglia) explained:

> I would just get a phone call [from the home care agency] saying 'I'm sorry but I can't come till whenever, because I have to get somebody ready for the nurse or whatever'. I would just get tagged on at the end.

Similarly in East Scotland, Louise and Simon – a couple both now receiving direct payments had previously used community service volunteers for their support but

again felt restricted by the lack of choice and the high turnover of staff. In turn, they felt that 'it was more a case of you helping them'.

Attacking dependency: resistance to residential care

Whilst national guidance for direct payments allows users to purchase short-term respite care, they may not buy in residential care on a permanent basis (Department of Health, 1997, para. 14; Scottish Office, 1997, p. 13). In turn, for several users in each of the areas, access to a direct/indirect payment relieved their own fears of entering residential care. This was an on-going concern for Morag in East Scotland:

> I was always frightened of getting old and ending up in residential care – it was a big thing for me. But now with independent living [through a direct payment] I've managed to get rid of that fear.

Similarly for younger users such as David (East Anglia), after a spinal accident residential care was offered as the only alternative to a direct payment. Although he had been unsure about how the payment would work, he was clear that he did not want institutional support. Also for Valerie, mother of Jonathan a 33 year old user with severe learning difficulties, her own fears of residential care provoked a shift to direct payments:

> I would never let Jonathan go into residential care. I think it's just there for the carers and not the clients [sic]…They are just plonked there as long as the carers have a particular task to do.

Louise and Simon in East Scotland had both previously been living with their respective parents prior to meeting each other. When they decided to live together, direct payments provided them with the only alternative to residential care. As Louise explained, 'it just made a tremendous difference. It enabled me and my partner to live together, get married and have children'.

Attacking dependency: moving away from familial support

A consistent response from half the users in East Scotland and two-thirds in West Scotland when asked their view on the perceived appropriateness of direct/indirect payments drew on fears of being dependent on family members. This theme cut across all age groups, but presented similar patterns at different life stages. For younger users (those under 40), a direct payment had provided the first opportunity to leave their parental homes. As Lynn (East Scotland) explained, it gave her a freedom that she had never previously experienced:

> For some time [prior to receiving the direct payment] my activities outside work had been restricted to my mother's energy levels. I achieved as much as I needed to but it was becoming less comfortable.

In West Scotland, two-thirds of users had entered the indirect payment scheme having relied solely on family members for all their previous support. Many older users in particular expressed concern over the level of support previously required from their family. As Alison described, a deterioration in her health had resulted in her daughter taking a lot of time off from her studies to look after her. Similarly, for Elizabeth the transition to indirect payments removed much of her support needs from her husband.

Conversely whilst users in East Anglia often mentioned the effects of direct payments on their family, this tended to be more indirectly. For them, reasons for service transitions and the immediate appeal of direct payments centred mainly on dissatisfaction with existing service provision and a desire to secure more control over their arrangements. It should perhaps be noted at this stage that although in the context of this study a comparison of dependency on family members between direct/indirect payment users and disabled people using home care services cannot be made, it is clearly an area of interest that would merit future research.

In search of change – accessing policy information: roles and responsibilities

Access to policy information about direct payments integrates a number of different roles for service planners, CILs and social workers. In line with the quasi-market model (Le Grand, 1990) applied in community care and across other policy areas

since the early 1990s, local authorities are required to focus their support on making information available to users and enabling a diverse service provider base to emerge. This leaves service planners or social work managers in charge of overall strategic decisions with regards to the scope and expansion of direct payment schemes. Where organisations have been set up, local CILs have usually taken on support roles, offering users help with recruiting staff and management of payments. The 1996 Community Care (Direct Payments) Act determines that social workers making community care assessments should offer direct payments on an equal basis to other services in kind. Therefore, the social work role includes both information access and assessment. The national policy guidance for direct payments (Department of Health, 1997) gives only an outline as to how policy details may be made accessible to potential users (Department of Health, 1997, p. 8) by highlighting the need to make information 'readily available [and] providing information in all formats which are accessible to people with different forms of impairment and to people whose first language is not English'. No further suggestions are made as to how social workers might facilitate this through assessment procedures and ensure equal access to direct payments as a service option.

Guidelines for direct payment's assessment in East Anglia and East Scotland were laid out in local planning strategies. Policy in East Anglia clearly states that 'assessors and service users will complete the same process'. Perhaps given the more restrictive eligibility criteria in East Scotland (see chapter V for more details), guidance is more vague, stating that 'payments can be made to someone to allow them to buy the community care services that they are assessed as needing'. At the time of fieldwork, neither East Anglia or East Scotland had a specific monitoring system in place to ensure consistency from social workers in discussing service options with users. Whilst in both areas this was in the process of being developed, service planners in East Scotland and CIL representatives in East Anglia expressed concern that some social workers were not suitably informed themselves to offer direct payments as a service option. Whilst this was not experienced in all cases, examples were cited in both areas which showed significant short-comings in social worker's roles since policy implementation.

Observations from one social worker, himself directly involved in independent living and East Scotland's planning strategy, indicated 'slight indifference and concern over direct payments' from some colleagues. Others, he suggested 'can't see the point of them [direct payments]', viewing them just like 'a re-routeing of invoices, which expose the client [sic] to unnecessary risks'. Although planners had been involved in fairly extensive staff training, clearly many views on service provision were deep rooted. This is a theme that will be returned to shortly.

In East Anglia although the user population for direct payments appeared to be growing at a much faster rate, similar concerns over the social work role in promoting service change were expressed by CIL workers. However, user perceptions of social workers and their commitment to direct payments varied considerably. On one hand, users like Peter had found out about direct payments for himself and spent considerable time and energy trying to persuade his social worker that they would be appropriate to his needs. In his case, he found that 'they [his social worker] were more interested in what I couldn't do than what I got or should be able to do'. Yet where social workers had been informed and were committed to the role of independent living as an alternative to other forms of service provision, positive change occurred more quickly. Jean, Clare and Valerie – mother of Jonathan – all praised their social workers for encouraging them to shift to direct payments despite their own initial reservations.

However, for Tom information about independent living and/or direct payments in East Anglia had taken much longer to reach him. Initial contact with a social worker after a spinal accident in 1983 had left him with the belief that social services could not offer him any support. By the late 1980s, he had no contact with the social work department and said he was of the view 'stuff the state and social services, I'll just have to get on with this one myself'. Consequently, he funded his own personal assistance for over ten years from his salary. Only through chance contact with a district nurse did he become re-referred to the social work department and hear about direct payments:

> Why I didn't stop to ask why you can't give me the money to fund it myself, I don't know. I suppose I didn't think they had the ability.

At the time of interviewing in West Scotland, budget constraints in the local authority resulted in an eighteen-month freeze on indirect payments, meaning no new users are being offered indirect payment funding. However, for current users individual knowledge about policy proved to be important in determining their access to an indirect payment. Indeed despite already being in contact with a social worker, a third of those interviewed had initially found out about the local indirect payment scheme through their own enquiries. This varied from individual involvement with local disability groups or by simply 'coming across' information. Barbara, for example, had read about indirect payments and then contacted her social worker to find out more. Although the scheme was up and running in the area, her social worker had never heard of it and took around six weeks to get back to her with more information. A similar knowledge gap was identified by other users. As Fiona stated, 'I feel that I've informed *her* [the social worker] about the Independent Living Scheme [indirect payments]'. In turn, the social work role in West Scotland generally came across as an unreliable route of access to policy information for potential users.

More specifically, this was a major concern emphasised by a support worker at the CIL. In these terms, although social workers and the CIL were supposed to be assuming different roles in developing and supporting payment packages, an inadequate information base in the social work service department had resulted in an over-reliance by individual social workers on the CIL. As the support worker explained:

> Social workers are definitely not well informed...we get calls here all the time from them asking us things. Although we try and help, we end up saying to them 'our main focus is disabled people – you really should go to the PA advisors employed by your department [Social Work Services]' – because we're supposed to here working on behalf of disabled people so all of our time and money should go to them.

Hence she conceded that, 'the only reason I've been willing to meet with them is because if they don't understand [about independent living] people's packages are held up. So I have to give in because there's no-one at the department to advise them'.

Likewise as CIL workers had become aware of the gaps in social worker's understanding of independent living, as shown earlier in this section this had contributed to many users being unaware of the services offered by the CIL.

Utilising professional support: the example of access to direct payments for users with learning difficulties in East Scotland

A key example of the importance of professional support as an impetus to change emerged in East Scotland through the demonstration projects. As detailed in chapter V, these were set up to examine more innovative uses of direct payments. In particular, this allowed the local authority to focus on issues surrounding the allocation of direct payments for users with learning difficulties. Consequently, service change had been introduced for two people. Whilst the local authority had responded to the need to develop policy for this group, the main impetus came from the work of a local project committed to 'person-centred planning'. Having heard about the development of direct payments in the area, they became involved in the planning group and put forward a proposal to access a payment for two of their day care users. As the Project Worker explained:

> The two people we chose, we did so because they had become really fed up with the day centre and stopped coming. We never had enough time to give them individualised support.

Undoubtedly her role was pivotal in accessing the payments. However despite local authority agreement in taking the proposal forward and integrating the users into the demonstration project, the Project Worker admitted that 'they [the local authority] were pretty clueless and never really had much of an idea about what was going on'. Consequently, this lack of knowledge caused a considerable delay in accessing the payment and securing service change. One of the users, Paul, was interviewed for this study. His receipt of a direct payment had allowed him to give up his day care place and employ a personal assistant. By working with the Project Worker, Paul had put together a plan of the activities he wanted to do and this was translated into a care plan. This integrated change for him across a range of areas, including housing, employment and education.

The success of direct payments for users with learning difficulties such as Paul confirmed the Project Worker's and others (see Holman and Bewley, 1999) support for this type of service change. However, the narrow framework for policy used in East Scotland (see chapter V) would render Paul's use of a payment unlawful beyond the parameters of the piloting process. In turn, making direct payments available as partial or total alternative to day care for other users at the Project would not be permitted. Evidently, this has important implications for accessing choice to a wider user population. Indeed, this was confirmed by one of the planners, who in a conversation a year after policy implementation, stated that there was a definite concern that 'people will come forward to get a service who wouldn't have wanted one in the past'. In these terms, access to policy information and service choices may well be restricted to limit demand. This line clearly angered the Project Worker who had ensured that users at her day care centre were aware of direct payments:

> I've been telling users about the scheme because I think they have a right to know. I can see it happening when people will have to leave the centre to get a direct payment. We might have to say to people, 'Leave here because we can't provide what you want', but it's getting the [Social Work Service] Department to admit that.

Changing services — supporting structures: user perceptions of CIL, local authority and 'third party' organisation roles

Despite restrictions in making policy information accessible to future users, East Scotland demonstrated the most consistent information route to direct payments. All current users had received details, at least in part, through social work, health or housing personnel. Support and information also came from the local CIL although intervention tended to be more reliant on users making initial contact themselves. The position differed slightly in East Anglia, where the CIL was involved in user support from the outset. From the point of service professional referral, contact was automatically made with the CIL. Users were then put in touch with an Independent Living Advocate who assisted with application procedures and initial support. In turn, the local authority utilised CIL expertise as a more specialised information service for users. The importance of this role was outlined in East Anglia's policy guidance,

where it was stated that their role 'is to act as a guide for the disabled person promoting independence and maximising all potential possibilities for each individual disabled person'. Unlike in East and West Scotland, support from the CIL appeared to be more detached and did not rely on service knowledge or individual membership prior to receiving a payment as a means of gaining information and support. For East Anglia's users not involved in more political disability activity, the CIL was seen by them as being 'different' from other disability organisations. For example, when asked if he belonged to any disability groups Peter said no, describing them as 'a waste of time'. However, earlier in the interview he had praised the role of the CIL with whom he had maintained on-going contact. Tim expressed similar sentiments, stating 'I'm not a big shouter for causes'. In these terms, advocacy offered by the CIL was generally conceived as a more individualised consumer service rather than one based on a collective 'disability identity'. This perception is returned to in the context of user identity discussion later in this chapter. However at this stage, the emphasis is on the importance of the CIL in its informative capacity. As described in chapter V, East Anglia's organisational structure for direct payments differs considerably from the other two areas in that social workers make contact with the CIL as part of the initial assessment, and the organisation assumes an integral role from an early stage in supporting users[iii]. This type of partnership approach between local authority staff and the CIL has clearly been vital for users in their initial experiences of direct payments. In particular for users such as Helen, who had never been involved in any disability groups, meeting with CIL workers helped her organise her support and transformed her own perceptions of disability:

> My social worker suggested I go to the CIL to sort out my problems...I went to see [the group director] and in the first hour of talking to him he just turned my life around. Until I met him – although I had been to university and things – I was not aware that there was a social model and medical model of disability. He introduced me to the social model and it transformed my thinking.

Whilst all users in East Anglia talked positively about support and advice received from the CIL, some users often found it difficult to access *immediate* support as and when they required it. Indeed, workers at the CIL confirmed that the demand for their

services far outstretched staff availability. Consequently, one worker stated that 'we don't advertise [our services] too widely because we're over-run'.

As suggested, for users in East Scotland referrals to the local CIL were less direct than in East Anglia but all had had some contact with the organisation and the role was generally welcomed. Indeed, one of the CIL workers emphasised the need to work 'in partnership' with the local authority – although development of this arrangement appeared to be less cohesive than in East Anglia. As in East and West Scotland, support for services focused on a number of issues, including training offered on how to be an employer, the payroll service available for users requiring it (as explored in chapter V) also basic advice and discussion with users during their service transition. As Deborah, herself a user and also an employee at East Scotland's CIL, stated:

> I think places like these [CILs] are vital. Having worked here and with the scheme I can see this...You need to have someone there to take you through the whole process at your own pace. Its daunting for some people – just knowing that we've done it before with other people is helpful.

In West Scotland although similar services were offered by the CIL (e.g. through induction and training sessions for users employing PAs and a general PA support group) user involvement with the CIL seemed to require more individual input from them. Indeed, as stated earlier around a quarter of those interviewed knew very little about the services on offer. Whilst four users were in regular contact with the organisation, this usually occurred through individual membership – involving receipt of a newsletter and/or attendance at meetings and events. For them, contact with the CIL was generally seen positively. As Alison stated, the meetings allowed her to meet a wider range of people and talk through problems. However, younger users such as Sally whose contact was limited to a one-off PA training session, remained unimpressed, stating that 'there was a slight feeling of 'well you don't know as I have been doing this longer''. In this sense, she felt that the CIL was more appropriate for those wanting a more politicised role in disability issues rather than simply drawing on their service expertise.

Indeed for the majority of users in West Scotland, most basic support in payment management came from the local centre for voluntary services. This type of role matches with most other indirect payment schemes where social (work) service departments give a grant to a third party organisation to run payment schemes on their behalf (Means and Smith, 1998, p. 60). On the whole, very few comments were made about this role but when mentioned their input to payment organisation (through the payroll service – see chapter V) was welcomed and raised no issues of complaint.

User views of local authority roles

Support for the CIL in East Anglia contrasted with user views of the local authority social work department. In each of the areas, when mentioned, most users spoke about the local authority in generally unfavourable terms but this view appeared to link into wider expectations of service provision. This contrast was particularly noticeable between users in East Anglia and West Scotland. In West Scotland, many were aware of and referred to funding cuts in the local authority and the freeze on indirect payment funding which had prevented new users from entering the scheme. In this sense, whilst not being sympathetic to budget reductions, Barbara was fairly typical in describing her receipt of an indirect payment in terms of 'being one of the lucky ones'. However in East Anglia, users appeared to be far more confrontational and unwilling to accept any changes to service provision made by the local authority. Discontent centred on the introduction of charges (explored in chapter VII and VIII), organisational delays, a general perception of unreliability in providing basic information, increased bureaucracy and frustration over previous service arrangements. As Tony described '[East Anglia Social Services] are probably the most incompetent and disorganised organisation I've ever come across'. This replicates earlier themes, where for many users dissatisfaction with previous forms of service provision resulted in social workers suggesting a shift to direct payments. Likewise, Tony stated 'I think I was pushed towards the independent living scheme [now direct payments] because I was a pain in the arse for them'. In this sense, several users in East Anglia felt that direct payments had been offered by social workers as a 'last resort'. Whilst the transition had been welcomed, this type of approach, again, shifts direct payments away from being offered as a mode of service provision on an equal footing with other options.

Transitions from indirect payments – becoming a direct cash consumer

As stated in chapter IV, the majority of direct payment users interviewed in East Anglia and East Scotland had previously received a cash payment to buy in their support indirectly - with cash facilitated through the local voluntary services group. Discussion in chapter V indicated that the main difference for users in moving to a *direct* payment scheme was gaining access to a larger cash sum. This occurred through the inclusion of contingency monies in user's payments. Therefore in theory, implementation of direct payments simply meant removing the third party role and allocating the cash directly from the social (work) service department. Indeed this type of transition occurred in East Scotland and the only noticeable difference for users was the change of name on individual bank statements – from the local council of voluntary services to the local authority. However, in East Anglia the shift from indirect to direct payments resulted in substantial organisational change – and altered user perception of cash payments. It became clear throughout the user interviews that the shift to direct payments had led to an increased focus on 'service accountability' and this was being raised as a major irritant. Previously under indirect payments, users were simply required to collect receipts and pass them onto the CIL for administration purposes. However since transferring schemes, they had been required to provide substantially more 'proof' of payment for the local authority. Clearly a shift to direct payments should imply greater individual autonomy over the payment. However the increase in paperwork was continually voiced as a major limitation by users. Helen described the change:

> I used to either pay by cash or cheque – depending on what my carer wanted - and it wasn't a problem. But now I have to explain every detail of this and write everything down on a hundred forms…We have become accountants for them [East Anglia]…

This had left many users feeling mistrusted and ultimately *dis*empowered. As Natasha explained:

> I think the way [East Anglia] does direct payments is an infringement of your rights…You have to provide them with so much proof that you've spent the

money in a way that they say you can. You have to keep every receipt – like sending off your national insurance every quarter and you have to get a phot-copy of the cheque from the tax office to prove that you've spent the money properly...I find that quite offensive really...You really get the feeling that they don't trust you.

Similarly Valerie, mother of Jonathan, felt that the increased bureaucracy was a real deterrent for potential users and had become really frustrated with the local authority's new approach:

At one point I was sending my returns back [to the local authority] and I knew they were right but they sent them back to say that there was a payment short. There wasn't, it just wasn't set out exactly the way they wanted.

User anger at the increased bureaucracy in East Anglia had been raised as a concern both individually and within a research report commissioned by the local authority. Indeed, recommendations within the report suggested a simplification of the system (Morris, 1999). Less user input could be allowed whilst still remaining within national policy guidelines (Department of Health, 1997). However the local authority declined change, instead leaving the present system in place.

Accountability was *not* raised as an issue in East Scotland or by indirect payment users in West Scotland. Unlike East Anglia, the auditing process had not changed since the shift to direct payments as in East Scotland. This required users to set up a separate bank account for the payment – which the local authority may access – and submit a record of spending every three months. In addition, users are asked to keep all receipts, but are only asked to produce them if required. Planners emphasised that this would only occur if there was a discrepancy in the user's three monthly return. A similar approach to payment accountability was applied in West Scotland, but with the local centre for voluntary services administering payments instead of the local authority. Although in this context an equal comparison between direct payment accountability systems in East Anglia and East Scotland and indirect payments in West Scotland cannot be made, it is useful to note that users in West Scotland also made no mention of the approach used.

The introduction of a more rigid and bureaucratic system of accountability in East Anglia reflects a trade-off within the local authority between individual control and accountability. This centres on an increase in user control – by removing the third party role in distributing payments – and a perceived need to add in more 'checks' to compensate for this shift as support packages become more individualised. The fact that East Anglia required less accountability checks when indirect payments were offered suggests that local authority financiers were more comfortable using a voluntary organisation than an individual user to facilitate the payment. However, given that allocating cash through a third party appears to offer *less* control to the authority over potential abuse, the reasons for this are unclear. Two issues relating to this change in distribution may be considered at this stage. Inevitably, the shift to increased accountability needs to be understood in the context of the 'cash and care' divide between central and local governments in allocation of support to disabled people. As discussed in chapter II, traditionally central government has provided cash payments whereas local government has provided 'care' services in kind. Therefore, local authority unfamiliarity with giving individuals cash payments may have led finance officers to be particularly concerned about their accountability both to central government and local tax payers.

Secondly, the concept of 'abuse', as mentioned by many direct payment users in East Anglia raises some important issues in relation to the overall context of the policy framework. Returning to the dominant ideas underpinning direct payments, the notion of 'abuse' clearly reflects one of the wider themes of the market discourse of welfare emerging over the past decade. To re-iterate issues raised in chapter III, through its focus on enhanced 'accountability' and 'efficiency' in welfare spending and service provision, this variant of marketisation is underpinned by the notion of 'scroungerphobia' that dominated social security reform from the late 1980s onwards (see Cook, 1993; Finn, 1997). Whilst it is important to acknowledge that local authority planners themselves did not make this reference in our discussions, it was a perception regularly put forward by a number users. This is a theme that will be returned to as payment uses and routes to independent living are explored in more detail in the next chapter.

To recap, this first section has detailed changes and contrasts between each area as the control of who organises and delivers service provision has shifted *from* the local authority *to* the user. Across all areas, users welcomed the choices offered by negotiating their own support and leaving more rigid and prejudiced providers. Similarly concerns over entering residential care - or for many in East and West Scotland becoming dependent on family - were allayed by changes in service delivery. In turn, this change has accentuated the transformation in local authority responsibilities over the past decade, whereby both direct and indirect payments require more input at an organisational level and increasingly less through direct management and service provision. This has resulted in all areas drawing more strongly on the specialised services of CILs to assist users and in East Anglia, this role has become more formally integrated into practice. However, views from both users and professionals indicate that the local authority's transition has not been entirely successful. In East Anglia and East Scotland, social work knowledge of and commitment to direct payments remained inconsistent. Similarly in West Scotland, users indicated that information and access to indirect payments often came through their own persistence or the commitment of specific individuals rather than general support from the social work department and/or the CIL. In turn, in all areas it seems unlikely that cash payments are being offered on an equal footing with other modes of service provision.

The CIL role was more generally welcomed by users. As suggested in East Anglia, users not only praised the expertise offered but - for those rejecting a more politicised disability activity - the service appeared to look afters needs for 'consumer support'. This contrasted with many views expressed in East and West Scotland where access to the CIL required more individual input from the service user.

Whilst the overall similarities between direct and indirect payments have been highlighted so far, the issue of accountability marked a key difference in East Anglia as the authority formally implemented the direct payments legislation. Users complained of more stringent accountability demands from the local authority as the third party role was removed from the administration of their payments. Having drawn on some of the key issues relating to changing experiences in the delivery of

services, discussion now shifts to explore the implications of this change for user identities.

Changing services – changing identities

One of the main themes developed in this chapter so far concerns the issue of control and how overwhelmingly a shift to both direct and indirect payments has left users far more content with their structure of support. In turn, the transition to cash payments in each area allowed users to break from more rigid and welfarist modes of provision such as agency home care services or from reliance on familial or institutional support. Discussion now turns to focus on the effects of payments on user identities as control of employment shifts from the local authority to the user. For the majority of all users across each area, this drew strongly on an individualised consumer discourse and centred on the importance of 'being an employer'. This aspect of control is explored at two levels. Firstly, by examining the importance of *receiving* the cash payment and the role of 'being an employer' and secondly through an appraisal of relationships developed through the shift to personal assistance.

Changing roles and responsibilities – being an employer

The main change for users entering direct/indirect payment schemes was the notion that they were now the employer and had assumed both more individual control and responsibilities with this shift. As Lynn in East Scotland described, 'it's a lot clearer to have someone respond to your needs than it was when my mother was looking after me'. Similarly, Sally in West Scotland emphasised the increased flexibility in her day to day living, stating '*I* make the decisions when, how and why rather than pressing a button, waiting for hours and still not getting what you want'.

For a number of users in East Anglia and East Scotland, discontent with agency support services often centred on the rules imposed by the organisations rather than simply dissatisfaction with individual personal assistants. Consequently, when they shifted to direct payments some agency staff came to work directly for them. In turn, for many the importance of being an employer was intrinsically linked to being a *good* employer. As Jean in East Anglia explained:

> They [the home-care agency] just kept all the money and paid peanuts to the carers. Whereas when I hired them I paid them above the going rate which gave me a much better feeling in that it was not treating them like slaves, but treating them like people who were doing a really good job.

National guidance again allows individual local authorities discretion in calculating the amount of a direct payment, simply stating that 'it must be enough...to enable the recipient legally to secure the relevant service to a standard which the local authority considers is acceptable (Department of Health, 1997, p. 37; Scottish Office, 1997, p. 15). Although pay rates in each of the areas were set at approximately the same rate of £4.50p/hour (after subtractions for National Insurance, sickness cover and general insurance), users expressed contrasting views over the adequacy of this figure. This is an issue taken up in greater detail in other recent direct payments research (see Ungerson, 1999, p. 585). However, the flexibility of receiving a direct/indirect payment in theory allowed some scope for users to pay staff at a higher rate and receive less hours if they wanted. The notion of being able to provide better pay rates in East Anglia and East Scotland contrasted with West Scotland, where users expressed concern that their PAs were not being paid enough. Reductions in the local authority budget had resulted in many indirect payment users having their hours cut. Furthermore payment rates had not regularly been updated with inflation, with only one rise given since indirect payments had begun in the early 1990s. For Pauline, this was a major problem as she found herself reliant on her PAs staying for extra hours but without pay. Similarly Fiona was uncomfortable in having to rely on individual flexibility and good will from her PAs or family to cover any the gap in support.

Overall, users across the areas saw the transition to *being* the employer – either directly or indirectly - as an important shift. Fundamentally, this challenged the idea of being a *welfare client* and the associations of dependency with this role, to a more active and consumer based identity.

Hire purchase: finding the right staff

However, the employer-employee relationship established through cash payments was not always unproblematic for users. Whilst the role of being the employer generally

secured more individual control, clearly *who* was employed remained central to achieving an effective relationship. As Louise in East Scotland commented, 'it's a lot of hard work'. For Tony in East Anglia, despite being able to employ a PA directly, he still found that many staff had preconceived ideas both about disability and the type of work they would do, stating that 'many of the PAs I have had have had difficulty in understanding or remembering that they work for me', adding 'people can in very subtle ways manipulate you because they are physically able and in charge and therefore they dominate proceedings'. Similarly Karen in East Scotland had recently had problems with one of her PAs, explaining on one occasion that 'she tried to take over money issues like writing cheques. I told her that I liked doing that and I wanted to do it...she just flung the keys at the TV and walked out. That left me with only one PA'. Although these experiences were not universal, many users told of problems with individual PAs and had discovered that finding a suitable match often took time and patience.

Indeed, in each of the areas around a quarter of users recounted difficulties with PAs which had resulted in their dismissal. This centred mainly on issues like stealing and turning up for work drunk and general unwillingness to carry out tasks required. Although both direct and indirect payments gave users, as employers, the right to sack staff all admitted that they had found this particularly stressful. As Sally (West Scotland) explained, 'its like having a full time job. You're almost like personnel as well as being the boss but you get absolutely no rewards for it'.

Moreover, finding the right PA depended on the availability of staff in each locality. This had been particularly problematic for users living in more rural locations in East Anglia. Initially this was a difficulty encountered by Jean:

> People in towns don't want to come out for a couple of hours...Also coming at a time that *I* want to go to bed is difficult – there's no street lighting and people just don't want to come out here late at night.

Concerns over the availability of staff were also raised by one of the planners in East Scotland and reiterates wider research findings (see Ungerson, 1997). In these terms, the very low unemployment in the area's service sector seemed to have an adverse

effect on the supply of personal assistance. Hence, planners were looking at the possibility of raising the hourly rate for PAs in order to make the job more competitive with other local service sector industries.

Staff relations – negotiating boundaries between employment and friendship

In framing policy for direct payments, national guidance (Department of Health, 1997/Scottish Office, 1997) specifies that users may *not* in the majority of cases employ family – including partners or close relatives[iv] living in the same household or elsewhere (Department of Health, 1997, p. 14-15/Scottish Office, 1997, p. 14). This, according to guidance, is to ensure that the 'relationship between the two people is primarily contractual rather than personal' (Department of Health, 1997, p. 15). Overall the issue of employing relatives was not raised by users. However, Frank in East Scotland employed his son as his PA. As he explained, 'they did bend the rules for me – its really difficult it you don't get exactly the right person – but I knew things would be OK with my son'. Therefore, in line with national guidance Frank had been able to employ a member of his family as an 'exceptional circumstance' (Department of Health, 1997, p. 15/Scottish Office, 1997, p. 14). In contrast, Peter in East Anglia was not permitted the same discretion. He told of how he would have liked to have employed his sister but the local authority was unwilling to allow him to do so. For him, knowing the person outwith the personal assistance role was central to establishing a good working relationship. As he remarked, 'for me its just the fact that I actually know someone - either as family or a friend – I think you can relate to them better than someone who is a school girl or a silly kid and have no personality or nothing in common with them'.

Whilst policy encouraged user-employee relationships in this broadly consumerist mode, the reality of negotiating the boundaries between employment and friendship was far less clear cut. Indeed many users in each of the areas described positive relationships with their PAs which drew strongly on friendship dimensions. This returns to the importance of inter-dependency in caring relationships outlined by Shakespeare (2000) and others in chapter II. As Helen in East Anglia stated, 'they [her PAs] are both so important – they help with the physical stuff but the morale boost is enormous. Their personalities and the fact that there is somebody helping me

is so important'. Given the close proximity of personal assistance, users were asked to define the boundaries of this relationship. This centred on both employer/employee dynamics and friendship or a mixture of the two. In most cases the division was precarious – as Bill (East Scotland) remarked 'I don't see how it can be employer/employee when they're carrying out personal tasks for you'. But for Louise and Simon – a couple in their late twenties both in receipt of direct payments in East Scotland – the dividing point was clear. As Louise explained:

> You take on the role of employer. You have the responsibility for training them, dealing with wages, payments, conflicts, discipline etc. You really have to sit down and make sure you don't become too friendly with them and stay as the employer...You need to set boundaries – this person is being paid to be here – they're not a friend.

For Louise and Simon, framing their relationship with their PAs in these terms was the most acceptable way for them to manage their privacy and live as a family with their two-year old child. Conversely other users, again, such as Peter in East Anglia employed a friend and neighbour as his PA. In turn, support was organised around a much more flexible arrangement:

> Being as she's a friend of mine there's no set payment...She comes when I need help – in the morning when I need to get up and washed, when I need food preparing or the house cleaning. I'm lucky in that if I don't need help I tell her not to bother coming, but if I do she'll come straight away...On the receipts I just say I've paid so much, but really I just draw out the cash when she needs it.

However, as suggested for the majority of users in each area the division between employment and friendship was far less clear-cut. Sally (West Scotland) for example, had found the boundaries difficult to manage:

> I think the biggest problem is if we end up being very good friends and then I think its very hard to separate the friendship and the professionalism.

Others were content to allow friendships develop but still emphasised the employer-employee dynamics. As Deborah (East Scotland) explained:

> Friendship is important, but they definitely know that I'm the employer. I don't emphasise the employer role – its not apparent so I don't have to. I'm laid back about it and organised so I can be easy about it and people don't take advantage of that, I find.

For users over 55 in all areas, the development of friendship with PAs was seen as an additional benefit of cash payment schemes. In these terms, issues surrounding the negotiation of privacy were far less prominent than for younger users. However, although this often extended into being together out-with time allotted in payment packages, again users were still aware that certain boundaries had to be maintained. This was highlighted by Helen (East Anglia):

> You expect the person to turn up or at least let you know if they can't. With a friend you might have a more flexible arrangement. It has to be pretty rigid in that you're relying on their help on definite days.

Personal assistance and personal space

Individual relationships with PAs were explored more extensively through the issue of privacy. This is a theme also picked up in other research into personal assistance users (see Kestenbaum, 1999, p. 31). All users were asked how personal space was negotiated with PAs. For the majority this was done informally but was often only something that could be achieved through trial and error. As Sally (West Scotland) remarked 'its very hard having someone there who knows everything like what you eat and what paper you read'. Similarly Heather (West Scotland) organised her support specifically to accommodate some privacy, stating 'I like to have one day without anyone coming in because it's a big intrusion into family life'. For those receiving 24 hour packages, privacy was a particularly difficult issue to negotiate. As Louise and Simon (East Scotland) described:

> Having someone in the house 24 hours per day – just finding space to be a family – it's very difficult. We have time and the PAs have a room at the back, but if you argue or have a discussion you know they can hear – you're never totally alone in the house.

Discussions also highlighted some of the difficulties in establishing close friendships with PAs. An example of this was given by Fiona (West Scotland):

> A year ago I would have said that she [her PA] was my best pal but she left quite suddenly after I got into a real pickle with her. What happened was that she got to know a friend of mine when she visited and one day when the friend was leaving, she [the PA] told her that she should come more often. I thought that's wrong – that my PA invites my friends back. So next time I made sure that I established boundaries.

However, for Tom (East Anglia) whilst a close friendship with his PA had emerged this became difficult to manage when other more intimate relationships developed:

> If I ever have a girlfriend then there's instant confrontation between him [the PA] and whoever the person is...I wouldn't say that's the reason I don't have a girlfriend at the moment but it certainly has been very difficult to sort out.

Although Tom was not happy with this level of intrusion, for him the benefits of having one person who he liked and respected, responding to his needs largely out-weighed other issues.

A more formal negotiation of privacy was facilitated in East Scotland through an alternative to one-to-one personal assistance. This was used by four users – all in their early thirties - and organised through a housing project with a team of fifteen support workers based nearby and contacted by two-way radio. Unlike one-to-one personal assistance, contact is made only as and when support is required, thereby generating a more clear-cut private sphere for users. Although users conceded that spontaneity was often determined by staff availability, the more formal employer role achieved through the project was seen as a distinct advantage. For Emily this demarcation of

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space was vitally important as she explained that she 'wouldn't want a helper around all the time'. Likewise as Andy said 'I've got my sister staying with me at the moment and it would make a hell of a difference if I had a stranger staying in the next room'.

'Care' versus 'personal assistance': exploring the language of control

Throughout interviews with users, the language used to describe those employed to carry out personal assistance varied considerably. For most, the terms 'PA' or 'carer' were used, with occasional use of 'helper', 'support worker' or reference to individual names. At face value, a more individualised or consumer-based identity for direct payment users would perhaps suggest a shift towards the language of 'personal assistance'. Indeed this type of terminology fits in with calls from the disability movement to shift service provision away from the discourse of care and dependency and towards goals of social justice and independent living (see Morris, 1997). In these terms, Morris (1997, p. 54) has argued that 'people who are said to need caring for are assumed to be unable to exert choice and control'. However, to rigidly apply this type of understanding of 'care' to user terminologies would negate a more complex understanding of identities. As commentary in chapter II showed, the notion of 'care' integrates a number of positions. Therefore, discussion examines how language was used to describe roles but also introduces a focus on broader issues surrounding issues of consumerism, control, disability and 'caring' arising from user dialogues.

The most obvious contrast in the language used to described personal assistance emerged between users in East Anglia and East Scotland. In East Scotland, around two-thirds of users interviewed were directly involved with the local CIL, (through individual membership and/or management board level), demonstrated understanding of the values of the social model of disability and showed an active interest in disability politics. In turn, they presented a positive appraisal of the role of disability activism and drew on various aspects of a collective 'disabled identity'. During these interviews, almost all referred to their employees as 'PAs'. This directly contrasted with users in East Anglia where the same proportion referred to support by 'carers'. However, although the term 'carer' often implies a more dependent relationship, this group in East Anglia conceived their direct payments far beyond a limited provision of personal care in a home setting. Indeed as shown throughout this chapter, the most

fervent attack on the rigidities of services organised through the local authority emerged from users in East Anglia. At the same time it was this group that utilised CIL services through a more individualised and consumerised route and largely rejected a more collective role for a disability identity. Whilst in many areas of activity the CIL in East Anglia had assumed an overtly political and campaigning role focused on the social model, they also offered a more individualised system of service support for users. In this sense, it would appear that for many users, the CIL service could have been offered by any service broker. This type of support structure would perhaps suggest a shift towards a US model of CIL (see chapter III). Conversely, although East Anglia's users drew on a more paternalistic use of language, their expectations of control and independence extended far beyond a discourse of dependency. In these terms, Shakespeare's notion of inter-dependency (see chapter II) and the need for access to responsive services which enable independent living, becomes important.

For users in West Scotland a similar pattern could not be identified, with half users interviewed referring to 'PAs' and half 'carers'. However as will be shown in chapter VII, in these examples use of the term 'carer' drew more implicitly on a narrower use of indirect payments, with assistance restricted mainly to a limited number of hours for personal care tasks in a home setting. To a large extent, most users still reflected a home care service philosophy, instead of conceptualising their indirect payment in the wider framework of independent living. Whilst some of these users were involved in local disability groups, this tended to be limited to a more medicalised conception of peer support rather than the broader goal of independent living. As stated earlier in this chapter, contact with the CIL was limited in this area and tended to be associated with a more political role. With one exception, all users under the age of 50 used the term 'PA'. Unlike in East Anglia and East Scotland, although this included those such as Fiona and older users like George who were both involved with the CIL, it also reflected a number of other positions. For Heather – like many in East Anglia – a more individualised and consumerist route was described. This linked to the construction of her relationship with PAs which was organised strictly in employer-employee terms. However for the remainder of users, the term PA appeared to be used interchangeably with discussion of 'caring' roles.

Continuity and change – summarising contrasts in structure and identity transitions

This final section considers how the independent living and market discourses underpinning cash payments relate to individual transitions to direct or indirect payments in each of the three areas.

Summarising structural change

Discussion began by examining user's service arrangements prior to receiving direct payments in East Anglia and East Scotland and indirect payments in West Scotland. This opened up a focus on what may be termed as *structured dependencies through service provision* – through either formal or informal sectors. By centring on the rigidities of home care support services, a majority of users in East Anglia, half in East Scotland and a third in West Scotland highlighted a lack of choice and control in provision organised by the local authority. In these terms, their dependency had become institutionalised through rigid organisational rules and/or a medical conceptualisation of disability held by service personnel. For some, this extended into a fear of entering residential care either in the immediate future or as a long-term prospect. Similarly in East and West Scotland, users described long-term dependencies on family support – either from birth to adulthood or as individual circumstances changed later in life.

As users became aware of service alternatives, routes of access to policy information varied considerably between areas but highlighted a general inconsistency in professional knowledge of direct or indirect payments. Therefore in terms of shifting local authority responsibilities from service management and delivery to support the market for direct payments, a number of issues need to be addressed. Primarily in East Anglia and West Scotland, gaps in social workers' knowledge of direct/indirect payments were exposed by users. In West Scotland, this resulted in many users finding out about service change for themselves or social workers drawing on over-stretched CIL resources. However in East Anglia, any weaknesses in social work knowledge were often overcome by a more proactive CIL. Whilst users in East Scotland were least critical of professional support, planning personnel expressed concern at the prevalence of more traditional views of service provision held by some

social workers. Moreover, when placed alongside more restrictive eligibility criteria for making direct payments accessible to new users (see chapter V), service choices offered looked set to be strictly limited. In turn a more wide ranging use of direct payments - as shown through the demonstration projects – is unlikely to be accommodated into mainstream practice.

The role of CILs in each area provided a particularly interesting insight into individual conceptualisations of direct payments and their interaction with consumerist and independent living discourses in policy implementation. In turn, this revealed a clear overlap between structure and identity shifts through cash payments. East Anglia offered the clearest contrast between these identities where the role of the CIL was utilised as an early point of information and advocacy for users in service transition. By delegating these services to the CIL, the local authority appeared to focus on its own role of 'market facilitator' typified by the quasi-market model of policy provision (see for example, Bartlett, Le Grand and Roberts, 1998). Whilst some users had become interested in the more politicised disability role assumed by the CIL, for the majority its utility centred on the services offered to aid individual choices in service provision. This draws strongly on a consumerist discourse of choice as described by M. Barnes, Harrison, Mort and Shardlow (1999, p. 82):

> Choices are made by individual consumers determining their own needs and pursuing their individual self-interests. It is an essentially private action, with no sense that individual choices will have an impact on wider collective purposes or interests, nor that individuals should take account of those when making choices.

Conversely, where users in West Scotland found the CIL role most useful it was through more *collective* support facilitated through individual involvement. Yet whilst the CIL offered similar support services to the other areas, many users were either unaware of them or viewed them as part of a more politicised disability identity. Indeed, this was raised as a key concern by CIL staff. East Scotland assumed something of a half-way position between those outlined in East Anglia and West Scotland, in that although *all* users had had some contact with the CIL, this was less

privatised than East Anglia, but equally was not solely associated with collective disability roles as shown in West Scotland.

In East Anglia, a comparatively high number and rapid growth of direct payments users would perhaps suggest a high level of access to information and user support. However, it was users in this area that vocalised most discontent with the local authority.. Indeed, increased control and choice offered by direct payments were generally attributed to the work of individual social work personnel, the CIL or user's own persistence in securing a successful service transition. Hence, user critiques of the local authority in East Anglia may be related to perceptions of a more rigid or *Fordist* model of service provision on the one hand, whilst increased accountability and a greater focus on user abuse draws directly on market discourses emerging over the past decade.

User criticisms levelled at the local authority in East Anglia contrasted with those in West Scotland. In these terms, given the more 'welfarist' approach to payments whereby access was restricted through a cash starved indirect payment scheme, users appeared far more resigned to short-comings in the local authority.

Summarising transitions in user identities

Individualised consumer discourses gained more prominence in all three areas when examining identity transitions through direct/indirect payments. Once again, this drew on the notions of choice and control offered by cash payments, but more specifically the role of 'being an employer' consolidated this change. Whilst this shift remained important throughout each of the areas, differences between direct payment schemes in East Anglia and East Scotland and indirect payments in West Scotland centred on the terms and conditions that users were able to offer their PAs. For users in East Anglia and East Scotland, providing better pay and conditions to employees than home care agencies was clearly important. In contrast, cash limits within West Scotland's indirect payment scheme meant that users not only had their hours cut but overall control was eroded. Consequently some dependencies were re-established, either through PAs – as extra hours were carried out as 'good will' or 'friendship' gestures – or as family was called upon to make up payment shortcomings. Although

this could be viewed as an obvious extension of friendship roles, it was the reduction in payment and support that shifted these relationships from that of inter-dependency to dependency (see discussion by Shakespeare (2000) in chapter I).

In all areas successful management of the role of employer needs to be explored in the wider context of 'market development'. Finding the right staff emerged as an on-going problem for a number of users. This related both to individual personalities and the absence of extensive choice in the market for personal assistance in each locality. In acknowledging the need for a more competitive pay structure for PAs, planners in East Scotland may at least begin to focus on the role of personal assistance as an occupation rather than simply an informal care arrangement. Whilst this may be supported through the national ruling that largely excludes the employment of relatives, the contrasting experiences of the user in East Anglia who was unable to employ a family member and the discretion allowed in East Scotland, could be interpreted in two ways. Firstly, East Scotland's discretion may be seen as further acknowledgement that the market for personal assistance is simply not developed enough to offer suitable alternatives to totally exclude the employment of relatives. Or secondly, use of family may be seen as an extension of a dependency discourse still prominent in the local authority's adoption of direct payments. Hence, East Anglia's refusal to adapt 'exceptional circumstances' may imply a stronger consumerist route for policy.

However the direction of local authority involvement in developing the market and user's employer identities may also hinge on external influences. Indeed having established the importance of being the *direct* employer for cash payment users, this role needs to be briefly explored in the context of what has come to be known as the 'South Lanarkshire ruling'. This resulted from an employment tribunal in August 1999 concerning Lorna Smith, PA to Ian Brown who claimed to have been sexually harassed by him (Hunter, 1999). In awarding damages, the tribunal ruled that South Lanarkshire council rather than Brown should be regarded as Smith's employer and therefore responsible for payment. On one level the decision has been presented as a victory for PAs, in seeking to establish stronger employment rights. As suggested through this research, payment users themselves expressed concern that PAs did not have the same protection as most other service sector employees. Therefore, users

who appeared to gain most from direct employment of PAs emphasised the importance of offering good terms and conditions. However at this stage, the ruling does seem to shift the nexus of control away from the individual. Indeed, to present the judgement alongside cash (and time) limits for indirect payments in West Scotland underlines a significant shift away from individual autonomy.

Although findings in each area pointed to the importance of being an employer, managing this new role proved to be more problematic. Boundaries between friendship and employment were often difficult to negotiate and relied on flexibility and co-operation from both users and PAs. As employment control is devolved from local authorities, implicit to this transition is the burden of responsibility of managing these interests. However for many older users in particular, the development of friendships was cited as a further positive attribute to personal assistance. This was explored in more depth by examining user management of personal space – through the issue of privacy. By reiterating some of the problems of establishing close friendships with PAs, users in each area acknowledged the need to maintain informal boundaries. Examples of more formal negotiation of space were given in East Scotland where users contacted PAs as and when they needed support and through two-way radio.

Conclusions

By examining contrasts between different modes of service delivery through the shift to direct and indirect payments, this chapter has begun to explore how the competing discourses have shaped experiences. To reiterate, across all areas a number of common themes have developed. Notably, shifts to cash payments have left users with more control and choice over their service provision – thereby universal support for a more individualised consumer identity has emerged. However, to varying degrees there remain clear gaps in professional knowledge, their support for policy and the widespread availability of a market for appropriate personal assistance. Accordingly, as users assume the responsibilities of being an employer, it may be questioned whether local authorities have fully adapted to their new role. Likewise differences in local policy frameworks have resulted in some contrasting user experiences. At this stage, planning in East Anglia shows the clearest influence of

market discourses. On one level, users welcomed detachment from local authority influence in service provision and the development of an individualised support service through the CIL. However, the local authority decision to increase accountability with the shift to direct payments left many angered by policy change. Users in East Scotland appear to show most overall support for both local authority and CIL roles in supporting their service transitions. This manifests in part through individual support but also through more collective input in CIL activism. But planning restraints with resistance to further market development (this is detailed more specifically in chapter V) looks to limit access to a wider user population. Changes in service delivery for indirect payment users in West Scotland indicated more prescribed levels of individual choice and control. In turn, a more 'welfarist' approach to payments emerged as some of the dependencies sustained through previous service arrangements were re-established due to local authority budget constraints.

In shifting to a more in-depth focus on *how* payments are used, discussion in the next chapter expands on the notion of individual control by exploring its relationship to the concept of independent living.

Notes

[i] It should be noted that discussions of previous user experiences of home care workers did *not* differentiate between those employed by the local authority and those employed by care agencies under contract to the local authority. Whilst this is not explored in the context of this research, it is an area that could be addressed in a future and more in-depth study of changing personnel and employer roles occurring since the implementation of direct payments.

[ii] A summary of users and their key age, gender and employment characteristics are shown in appendices III-V.

[iii] Users may decline support from the CIL, although no cases were cited by CIL personnel where this had occurred.

[iv] Guidance determines a close relative to be a parent, parent-in-law, aunt, uncle, grandparent, son, daughter, son-in-law, daughter-in-law, step son, or daughter, brother, sister or the spouse or partner of any of the preceding (Department of Health, 1997, p. 14-15).

Chapter VII: Money talks?: *Using the direct payment – a shift to independent living?*

Introduction

THIS CHAPTER SHIFTS discussion from examining experiences of the changes in service delivery to examining how cash payments are used. Underpinning commentary is a focus on how independent living and market discourses are used by local authorities in providing the payments and in turn, how they translate into the user's experience. Again this draws on both structural and identity changes addressed in the last chapter. Ideas are organised through two main sections – starting first with *'Care' and the consumer?: using the direct payment – roles and restrictions* and then *Exploring the boundaries of independent living.* Discussion is then extended through a third section which summarises the key themes identified in the chapter and widens debate to examine policy issues more thoroughly.

The first section is introduced by returning to the question of whether direct payments reflect a shift to independent living or simply an alternative mode of organising personal care in a home setting. Although direct payments have been framed in the 1996 Act as an alternative to directly provided community care services, the experience of ILF and indirect payment users (see chapter II) indicated that more flexibility can be gained through cash payments. Discussion begins by examining local policy statements regarding the direction of direct and indirect payments policy in the three areas. In highlighting vague definitions from each area, these are explored more extensively by drawing on dialogue with users. Each of the three areas show a strong emphasis on assessment for payments predominantly by personal care needs. However, it is the interaction between personal care and other areas of day to day living that differs significantly between the areas. In East Anglia, the assessment procedure for direct payments is shown to be especially limited – allowing only a rigid quantification of personal care needs. Yet examples are given whereby user and professional negotiation of payments allows for more flexibility and the development of other aspects of independent living. This is contrasted with users in East and West

Scotland, where overall payment uses are far more restricted to personal care in a home setting.

As discussion shifts to examine the interaction of payments more thoroughly, it underlines how differences in the number of hours allocated in each payment package affect the level of flexibility and user control secured in each area. In East Scotland, the use of payments in a wider sphere is evident only for those with 24-hour packages and the user involved in the demonstration project. More restrictive use is shown in West Scotland. In contrast, policy in East Anglia allows for the provision of smaller packages, which together with a more extensive 'care market', allows users to buy in (personal care) services and sustain a more diverse range of work and social situations. In these terms, it is the emphasis on 'market development' by the local authority that dictates the mode through which payments are used.

The theme of policy interaction continues by drawing on brief examples of how direct payments have been used alongside the other main policy shift to cash payments for disabled people in recent years – funding through the ILF. Again contrasting experiences are shown. These range from combining payments to sustain support in a home care setting to use of direct payments to pay for respite care alongside ILF funding for other support needs, to barriers surrounding direct/ILF payment use and employment.

The section concludes by drawing on another issue of contention raised by users in East Anglia - the imminent introduction of means-tested charges for direct payments users in the local authority. Whilst not implemented at the time of interviewing, a focus at this stage underlines the context for a more restrictive scope for policy use, whereby users in work and with savings will be dramatically affected.

The second half of the chapter – *Exploring the boundaries of independent living* - shifts from examining how users spend their payments in line with the roles and restrictions constructed by the local authorities, to focusing more specifically on their own conceptualisations of independent living. Commentary first draws on questions which asked users whether any aspect of their lives could be improved if a more generous payment was received. User responses between the three areas raise a

number of themes which in turn relate to the wider issues in each locality and views on professional and bureaucratic roles replicated from earlier chapters. In East Anglia whilst half of users maintain that no additional funding would improve their independence, others concede that extra hours would improve job, educational or social participation. In contrast, users in East and West Scotland held lower expectations of what may be funded by a direct/indirect payment. Whilst East Scotland gives some examples of how users lives may be changed through increased funding, those in West Scotland appear to be more concerned with sustaining current personal care arrangements rather than developing other aspects of their individual lives. Again, this reiterates both differences between the policy frameworks and the type of user and their expectations in the three areas.

Discussion extends into examining responses given when users were asked to define what independent living meant to them and whether they saw it as an achievable goal. Although user views showed considerable variation – incorporating individual and medicalised views of disability versus wider social and structural constraints – dominant policy discourses in each area are clearly reflected. In East Anglia, this once again reveals a sustained criticism of bureaucratic requirements from the local authority and wider issues of resourcing. A focus on structural factors is similarly reflected in East Scotland but with users giving a much more positive appraisal of the local authority role. However, a number of users in East and West Scotland draw more strongly on discourses of care and dependency by relating the limits of their independence to self-perceptions of disability. For those in West Scotland, this view is more apparent. Moreover whilst emphasising the importance of the payment in securing increased flexibility and control, not one of the users in this area defined their independence solely through the provision of a cash payment.

The chapter concludes by drawing together themes outlined so far and questions whether the shift to direct/indirect payments in each of the three areas represents a shift to independent living or simply a transition to consumerised care.

"Care' and the consumer': using the direct payment – roles and restrictions

Discussion in chapter II detailed how legislation for direct payments emerged in the overall context of state support for disabled people. Similarly, its appearance on the statute integrated a number of conflicting themes. To reiterate, on one level, this reflected consumerist and independent living discourses – integrating both the 'market freedoms' of the New Right and notions of choice and control from the disability movement. Conversely, its development as an 'appendage' to the 1990 community care legislation suggested that the focus on 'care' would remain prominent in providing support for disabled people, with other activities given a far lower priority. This in part reflected a long term 'cash and care' divide (Fitch, 1995) between central and local government in administering support for disabled people. However by recognising the changing issues surrounding both policy administration and development, commentary in chapter II concluded by questioning whether direct payments would ultimately challenge the 'cash and care' divide. The first section of this chapter begins to explore this issue as discussion focuses both on how local policy documents have defined the uses of cash payments and in turn, how this has been translated into individual user's experience. Hence, this opens up a wider question as to whether direct payments in East Anglia and East Scotland and indirect payments in West Scotland represent a transition to independent living or simply a more flexible mode of providing personal care in a home setting.

Defining direct payments: locating the policy parameters for independent living

As stated throughout this thesis, the 1996 Community Care (Direct Payments) Act was framed as enabling legislation thereby delegating to local authorities the decision whether to develop their own policy. However, national guidance laid out by the Department of Health (1997) and the Scottish Office (1997, p. 5) outline a number of key issues and definitions with regard to the direction of policy. In the context of the original 1997 policy guidance, the emphasis seemed to rest implicitly on supporting personal care needs in a home setting, as the provision of direct payments was defined at the outset as 'a different way of fulfilling existing community care responsibilities' (Department of Health, 1997, p. 1). Whilst the focus of this discussion draws out how payment use relates to independent living, other early research into direct payments

by Glendinning, Halliwell, Jacobs and Tyrer (2000) looks more specifically at how the 'health' and 'social care' divide is reflected through user experiences.

A brief overview of East Anglia's and East Scotland's practice guidance shows examples of an independent living discourse in place. For example, in discussing the powers contained within the legislation, guidance underlines the 'principles of independence, choice and flexibility as the paramount principle of practice in a way that individual service users needs are met' ([East Anglia] Policy and Practice Guidance, 1997, p. 2). East Scotland provides perhaps more clarity, stating that 'independence means being in control of one's life', adding that 'a person's desire to make decisions about their own lifestyles and daily routine is not necessarily diminished by their need for physical help' ([East Scotland] Practice Guidance, p. 1).

In both areas, the parameters of entitlement for direct payments have drawn on the broad principles laid out in the original central government guidance (Department of Health, 1997). At a general level, these have included age – at the time between 18 and 64[ii], assessment as needing community care services and willingness and ability to manage their payments Furthermore, each authority has attempted to clarify *what* the direct payment may be used for. In East Anglia, guidelines remain fairly vague, stating that the payment can only be used to 'buy in personal assistance...those things which have been assessed and are personal to the individual' ([East Anglia], Users Guide to Direct Payments, p. 3). However, in the context of the user leaflet in East Scotland specific categories are defined more clearly. These include domiciliary care; care at home services; aids and equipment; short respite breaks and day care ([East Scotland] Direct Payments Guidance Leaflet, 1998). A much wider scope was given in the practice guidance, categorising support in four main areas: personal assistance; domestic tasks; social/leisure/work related tasks and management of the direct payment ([East Scotland] Practice Guidance, 1998, p. 5). Policy statements for indirect payments in West Scotland focused more broadly on the principles of independent living, emphasising that 'Personal assistance schemes allow the individual to choose who should help them, what they should do, when and where they should do it', adding that 'Payment schemes...provide greater flexibility of support, permitting assistance to be available at the time and place suitable to the disabled person. In this way, they give the disabled person much greater control over

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their lifestyles and activities' [West Scotland], Independent Living Services, Draft Policy Guidance, 1998, p. 6).

From these policy positions, the following section begins to explore how cash payments were used in each of the three areas. Discussion draws on user responses when asked specifically what payments were used for and what they considered to be the most useful aspects of their support packages. A number of categories defined by users across the areas are detailed, including personal care, paid and unpaid work, education, social activities, respite and general practical support.

Cash as care?: Payments and personal care in a home setting

In each of the three areas, the predominance of users with physical impairments meant that a majority used their payments at least in part to support personal care needs. However, the emphasis on this role and its interaction with other functions differed greatly according to locality. In East Anglia, the vague outline of payment uses given in the policy guidance translated into a rigid focus on specific personal care tasks. For example, Claire – a woman in her late twenties - explained her own difficulties in gaining support. She told of how the authority would not cover any need beyond primary care, commenting that 'you basically couldn't get any help unless it [the care need] was going to kill you'. In these terms, the definition of primary care was narrowed further when her incontinence was not covered in the original assessment because it was not deemed to be a 'life or death situation'. However, the limits of the direct payment shifted upon the arrival of a new social worker. With better individual professional support (a theme addressed in chapter VI) despite the rigid quantification of physical needs to 'hours per week', *more* control was gained. So whilst still defining needs under the category of 'primary care', the flexibility of the cash payment helped remove some of the boundaries of the assessment system. The benefits of this negotiation were emphasised by Claire:

> When they allow for primary care it doesn't necessarily take that long. And because your health varies you can use the time for other things. For example, I'm allocated an hour for bathing but it doesn't always take that long so I can use that time for other things.

The issue of negotiating the boundaries of direct payments had clearly dominated Claire's early experience of the policy. The need to use the payment for activities beyond personal care at home was central to her daily living but her experience highlights two differing approaches to gaining more control. At one level *overt* demands for extra hours to integrate additional activities had left her with minimal flexibility. However, through the negotiations of another social worker a more thorough assessment of her physical needs provided a *covert* basis to live more independently. This change in assessment practice may have occurred for one of two reasons. Either the second social worker working with Claire was more familiar with the workings of the local authority bureaucracy, or they had simply exercised greater discretion in the assessment procedure. Given that front-line staff were not interviewed (beyond those directly involved in planning in East Scotland) in the context of this study, this cannot be clarified. However, the question does open up a need for future research into the social work role in the implementation of direct payments.

Although angered by the assessment process, Claire adopted a covert notion of 'working the system', which had left her with much more control in her day to day living:

> It's given me the freedom to muck about with the hours. I don't know if you're supposed to do that – I couldn't care less – but I do.

Similarly for John – a man in his late forties – attempts to secure his support package had resulted in a long dispute with the local authority as hours were rigidly negotiated. For him, having the right amount of hours to support his personal care needs allowed him to carry on with his work as a self-employed accountant. Whilst he was now satisfied with his arrangements, he too complained of the inflexibility of the assessment system, stating that 'sometimes you don't need all the hours allocated but you're frightened they may be taken away from you'.

Whilst the majority of users in East Anglia had been required to access wider support through their personal care needs, as the experiences of Claire and John and additional commentary in this chapter will illustrate, few defined the main advantages of having

the direct payment solely in these 'care' terms. Indeed, this was conceded by the manager of the CIL, who stated that whilst the organisation operated according to the principles of independent living, they had to work within the constraints outlined by the local authority. As he stated:

> [East Anglia] only covers 'priority one' needs – that means if you don't get a direct payment you die. But direct payments can be used flexibly so for example, people can opt-out of having a shower two days per week and use the money to go to the cinema.

In these terms, the role of the CIL in supporting individuals and highlighting payment flexibility, appeared to allow users to embrace a wider range of activities than a conventional community care assessment. This contrasted with a number of users in both East and West Scotland. In East Scotland, the flexibility of personal care support at home was cited by four of the older users (over 60) as the main advantage of having the direct payment. As Morag stated, 'The thing that helps me most is having a bath. Its takes away a lot of the pain by lying in the water. Getting dressed is more important than going out because otherwise you would be in your night clothes all day'. However, in West Scotland the eight indirect payment users who each highlighted the importance of personal care included those across all ages. For example, Fiona in her later thirties, described how her hours allocated through indirect payments were used almost entirely for personal care in her home, but the flexibility in arranging this support after work hours was paramount. This meant that she was no longer totally reliant on her mother to carry out intimate tasks. However as will be detailed later in this section, the use of indirect payments for users in paid employment in West Scotland was rare. Indeed, a more typical appreciation of personal care support was given by Freda, in stating 'the carers bath me, dress me and do my hair which I can't do for myself. The fact that they take me out as well is just a great advantage'.

Shifting the parameters of 'care': payment interaction with other roles
As suggested through the experiences of Claire and John in East Anglia and Fiona in West Scotland, a clear demarcation of roles for payment uses was not generally

described. As discussion in chapter VI showed, the versatility of a cash payment and being the employer gave users more control. This allowed them to change and develop other aspects of their lives. However, whilst all users highlighted the merits of this type of flexibility, limited policy definitions and professional understandings of independent living had caused confusion for some when they sought to clarify exactly what the payment could be used for. For example, Janet in East Scotland had overtly defined 'independent living' beyond the parameters of personal care and spent some of her payment on a cinema ticket for herself and her personal assistant. However, upon sending in receipts to the local authority she was informed that the payment did not include this type of activity. Despite attempting to seek clarity on this position, Janet was still left unsure of the boundaries of the direct payment:

> Nobody seems to know whether it's [the direct payment] for personal care or to help you lead a 'normal life' – but what does that mean?...I should think that it should be everything that gives you an easier life...I ask the social worker every time but nobody knows.

Routes to independence: payments and participation

In East Scotland, Janet's confusion over exactly what could be covered by the direct payment typified those with smaller support packages where – in line with community care assessment criteria - payment access had been gained through personal care needs. Despite the rigid focus, examples of where the payment was being used in a wider sphere – integrating support around employment and social activities - were apparent. However, this type of flexibility and control for those in employment was only evident for users with 24-hour support packages and users involved in the 'demonstration projects'. Six other users were now over retirement age, having given up work much earlier in life because of 'poor health' and seven stated that they were unable to work. For users with 24-hour packages, the divide between personal care and independent living seemed to be fairly ambiguous. Indeed when asking Deborah what she considered to be the most important part of her support, she replied:

> I can't say because I can't do without her. I can't get out of bed on my own but I don't know what the most important aspect of it is...It's the choice I suppose.

Similarly, Lynn gave a more specific example of what she saw as the most important role:

> To be general about it [use of a PA] allows me to make my life as if I was running it myself. For example, I made some soup last night. I did not physically do that but *I* instructed her. It's about using someone else's hands and brains to carry out your wishes.

The alternative to one-to-one personal assistance used by four users in East Scotland also highlighted the importance of flexibility secured by the direct payment. As detailed in the last chapter, users live either individually or in shared flats in a housing project with a team of fifteen support workers with whom contact is made as and when support is required – thereby generating a more clear cut private sphere for users. Like one-to-one personal assistance, support covers a number of areas, integrating personal care, working and social activities. Users emphasised the advantages of the arrangement. For many such as Jim – a man in his late thirties in East Scotland - this type of flexibility had made significant changes to his life. As he described:

> I'm a lot more active now – [outside work] I go out and about a lot more and I don't need to worry about going to bed at a certain time because [when living at home] my parents go to bed early. I can come and go as I like.

However, perhaps the most empowering use of direct payments in East Scotland came through the user involved in the 'demonstration projects'. As detailed in chapter V, these were set up as part of the policy development strategy to examine how the guidance could be used at its most innovative level. Unlike the broader experience of direct payments, the user focus for this stage of piloting had been learning difficulties. To expand on discussion in chapter VI, in the case of Paul a direct payment had been offered to him because he had become fed up with the day care centre he attended and had consequently stopped going. In working with his project worker and determining

change across a range of areas such as housing, employment and education a care plan was drawn up and Paul was assisted in choosing and employing a PA. The employment of a PA for users with learning difficulties highlights a key policy difference with the broader experience of users with physical impairments. Indeed, the thirty-hour direct payment package was framed solely around an agenda determined by Paul. As he explained:

> I just say [to his PA] 'I want to do that' and he says 'OK'. We're going to look at jobs. I want to get myself a job. First of all I want to get out of here [supported housing association accommodation] to get myself a house.

Paul's experience of direct payments was clearly positive. Central to its success was use of the payment across a wide range of life experiences – which he ultimately controlled. Although at the stage of interviewing policy was only being used for persons with learning difficulties as part of the piloting process in East Scotland, the difference with use for those with physical impairments is important. In these terms, there were *no* restrictions on how the payment could be used – thereby indicating a more holistic approach to independent living.

However as suggested earlier, giving access to direct payments with learning difficulties remains a contentious area. Whilst users such as Paul had clearly gained more choice and control in his day to day living since receiving the direct payment, a more mainstream use of the policy remains problematic in East Scotland. Once again, this centres the prominence of an anti-market discourse described in earlier chapters, whereby users are unable to transfer to a direct payment if they are already in receipt of a local authority service. This would make the availability a similar payment package to that of Paul's unlikely beyond the parameters of the piloting process. Consequently, the planning conceptualisation of direct payments in East Scotland as a medium for privatising social services substantially erodes the scope for maximum user control and presents a highly rigid attitude towards service provision.

In East Anglia, despite the rigid focus on personal care needs as the main means of accessing a direct payment several users received packages of only a few hours per week which had allowed them to interact with either employment or other chosen

areas. This contrasted with East Scotland where planners confirmed that smaller direct payment packages had not been accessed to users. Whilst acknowledging that this 'may only be justified because it is more cost effective for the service user and the authority' ([East Anglia] Policy Guidance, 1998, p. 16), their availability had made a significant difference to the daily lives of several users. Anne, a user with learning difficulties, employed a PA through direct payments, but also chose to attend a day care centre twice a week. For Helen, the provision of four hours per week allowed her to employ a PA to help her with physical tasks such as shopping and household cleaning. As a result, she had maintained her career as a freelance journalist.

Similarly for Richard, the availability of on-call personal assistance in his work setting had led to a dramatic improvement in his health and work life. As he explained, prior to receipt of the direct payment he was unable to drink during the day at work because the toilets were inaccessible. However, the receipt of a payment – covering an hour and a half per day – allowed him to call for assistance from a local agency when required throughout the day. Moreover, the flexibility of this arrangement allowed him to build up a surplus of hours, enabling him to attend management meetings in different locations and participate fully in company life. These examples of smaller direct payment packages in East Anglia – either in an employment or social context – provide positive examples of how market and independent living discourses can interact together. Whilst policy promotes this type of mixed approach firmly in the context of market development ([East Anglia] Policy Guidance, 1998, p. 16), and assessment remains centred on rigidly assessed community care needs, its availability undoubtedly allows greater user participation and control across a range of life situations.

Other examples of payment uses in East Anglia also drew on interaction with employment. As detailed in chapter VI, Tom's route to direct payments was unusual in that he had paid for personal assistance out of his own money for ten years before he even realised that he was entitled to support. Therefore, when the option of a direct payment eventually emerged, he carried on paying for the same amount of personal assistance himself but used the extra hours for social activities. Again, assessment for the payment focused on largely personal care and home support, but the flexibility allowed him to use it in a wider sphere. As he explained, the social worker accounted

for the payment in accordance with East Anglia regulations, but in practice he maintained maximum flexibility to supplement his existing package:

> She [the social worker] said, 'what I'll do is fix the hours so that we don't have to give in or go beyond anything that's going to require a means-test...So she said. 'well you can have four hours a day plus an hour for shopping and an hour for cleaning – that's 30 hours a week at £6.50p[iii] which means about £190 – that's just below the £200 pointer where I would have to start asking you more awkward questions.[iv]

Through this additional direct payment package, Tom described the changes to his day to day living:

> Its given me the ability to accept invitations...if you want to go somewhere at the weekend you don't end up crying off because you can't find someone to take you.

For indirect payment users in West Scotland, the interaction of personal care with wider aspects of independent living was far more limited. Only two of the users interviewed – Heather and Fiona – were in employment. Indeed, social work personnel confirmed that out of the total indirect payment user population of 121 only around four users worked. For the majority, when asked if they would consider re-entering employment if offered extended hours to support them, most said no. In contrast to the current New Labour push to extend work opportunities for both disabled and older people (Department of Health, 1999a), the three users over the age of 60 dismissed re-entry to the labour market on grounds of age and disability. Similarly younger users focused overwhelmingly on their own medical appraisals of individual disabilities. For Kate – a woman with physical and visual impairments in her early thirties – the option of work was not one she would consider. Although she indicated this herself, her rather dominant PA interjected 'she was into doing drama at one time. She was going but it didn't work out – you see it's the sight thing'. Conversely, Heather emphasised the importance of maintaining her job as a Social Worker despite medical advice to the contrary. Although in her employment setting, she did not require personal assistance – any support was gained through changes in

terms of access and adaptations – the indirect payment package supported her personal care and physical care needs at home.

Others such as Barbara emphasised the benefits of being able to socialise more spontaneously and extensively since having a PA. Again this drew on the increased flexibility particularly in contrast to previous arrangements:

> Before, I didn't have the same choices. I can say now 'oh I think I'll go to the lunch time bingo, or I'll go and see my friend around the corner'...Before the home-help didn't have the capacity to help me do that, whereas with this independent living [indirect payment] I can.

Moira's use of indirect payments differed from others in West Scotland in that her husband provided the majority of her day to day support, but used indirect payments solely in a respite capacity. Having lost half her hours allocated through the local authority's 'Home Care Service', Moira and her husband had decided that it would suit them both better if he gave up paid work and became her full-time unpaid carer. Consequently the indirect payment package covered just five hours per week respite support for the husband. Whilst the use of cash payments for respite support is an important area of potential policy development, the fact that this type of payment use came about *because* of the reductions in personal care covered by the cash payment indicates how inadequate support restricts choices and control for both user and carer.

'Cash and 'care'': direct payments and the ILF

Discussion in chapter II outlined the framework of benefits available to disabled people. Their distribution originated from two main levels: allocation of cash benefits through the (centrally run) social security system and the provision of care services through local authority social (work) service departments. As suggested in chapter II, two significant changes – the introduction of the ILF and direct payments – look set to challenge this divide (Fitch, 1995). Whilst questioning in the interviews with service users did not focus directly on benefits received (for a fuller account of financial support and the interaction of benefits for cash payment users (see Kestenbaum and Cava, 1998), some users raised issues in relation to how the direct/indirect payment

and other funding sources were used. The main example of this centred on the use of direct payments alongside ILF payments (either through the 1993 or extension fund). Unlike direct payments, entitlement to ILF funding is based on a means-test. The first £200 of any care package has to be paid for by social (work) services. Therefore, it is only users with higher support needs (i.e. larger direct/indirect payment packages) that may receive an ILF award alongside a direct payment. As Kestenbaum and Cava (1998, p. 18) explain, a person on Income Support will contribute half of their DLA Care component towards the cost of their care, plus all their Severe Disability Premium (if eligible for this premium because they live alone and have no one who gets Invalid Care Allowance for providing unpaid care). Likewise, if the person is not on IS, a 'notional assessment' is made of the amount they are considered able to contribute towards their care themselves. This involves a similar assessment to IS with a few significant differences. Full allowance is made for any mortgage payments (as opposed to only the interest component under IS) and £30 per week earnings disregard is applied (as opposed to £15 under IS). As with IS the income of any partner will be included in the assessment.

For Tony in East Anglia, both ILF funding and a direct payment gave him a sum of money from which he could fund both personal care needs and wider social activities. As he explained:

> You see the advantage is that its so flexible – its good for the service users in that I don't think of it in terms of 'hours per week' any more. You've got a set figure per week from the ILF and one for the direct payment and so as far as I'm concerned I can use it how I choose. They've [the local authority] decided that I need those hours and they fund it. Now if I have a figure of £309 per week or something, I could pay someone £4 per hour for 75 hours per week. That's the way I use it, I don't think to myself 'I'm only allowed 43 hours per week' for this and 43 hours for that'.

However given the accountability requirements in East Anglia (see chapter VI), Tony admitted that he had to be careful in his management of each cash sum and keep the payments in different accounts. In this sense, he was unable to combine the money and conceded it had taken him some time not to be so rigid in his use of each sum.

For users with learning difficulties such as Jonathan, access to a direct payment allowed his mother to use the cash alongside ILF funding for three weeks respite support per year. Hence, his parents either used the payment to support Jonathan with the assistance required when they went on holiday or it enabled him to develop wider social interests without parental support.

Given the position of the ILF as a means-tested benefit, users generally instigated discussion in the context of employment. For Sally in West Scotland, the option of work was restricted by her benefit entitlement:

> If I could get full-time work and my care package wouldn't be affected then fine. I don't expect my rent to be paid, I don't expect any benefits that an able-bodied person wouldn't get, but I just think its exploitation because I would have to pay someone out of my wages to get me out of bed. So if I worked full-time, I would be earning less than on Income Support.

Similarly Fiona stated that she would like to increase her work hours but was limited by her benefit entitlements. However, the relationship between employment, cash payments and the ILF was not straight-forward. Indeed, Andy in East Scotland received cash support from three sources: the social work service department (through the direct payment), the ILF and the attendance component of DLA. In addition, he worked full-time as a civil servant. Andy stated that his income was not means-tested and so any increase in salary would not affect his benefit entitlements. His experience clearly differed from those either in work like Fiona or seeking work, like Sally. As detailed in chapter II, the regulations for ILF are set out by central government and not open to local negotiation. Therefore, this issue was raised with one of the planners, although her response was not entirely satisfactory. Indeed, whilst accepting the constraints imposed by the ILF she was not totally clear how support had been organised without means-testing income. However, in attempting to justify this anomaly she explained that this type of arrangement was developed as one of the original indirect payment packages in the area (prior to later moving to direct payments in East Scotland). In turn, social workers negotiated the level of support to be at a high enough level through social work service funding, and based on a means-

test of savings and *not* income to allow employment salary to be disregarded. As a result, Andy's support package may be seen as an example of highly individualised policy negotiation – drawing on the theme of professional support to widen access to independent living, as discussed in chapter VI - and out with the mainstream use of direct payments and ILF funding.

Charging on: direct payments and the issue of charging

The development of charging for community care services has become a key issue for service users since implementation of the 1990 Act. As research by Baldwin and Lunt, (1996) illustrates, wide ranging and varied practices have emerged across the UK – ranging from flat-rate charges to means-testing. Given that direct payments are presented as another form of social (work) service provision, where a charging policy is used, direct payments are included as services for which a levy is to be paid. A broader discussion of the position regarding charges in each local authority is given in chapter VIII. However, in East Anglia the introduction of means-tested charges from May 1999 was raised as a major concern for several users and the CIL. As the director of the CIL explained, the shift from flat-rate charges paid by all users to means-testing would have a dramatic effect on independent living in the area. The change would affect all direct payment users, except those claiming IS. Therefore, anyone in work or with over £3000 in savings would be subjected to a means-test. Unlike East Scotland (see chapter VIII), charging is retrospective and therefore includes both current and potential direct payments users.

For Tom a full-time teacher, the prospect of charges was a great concern and would clearly have a significant effect on his day to day living. He remarked, 'if they take it [the direct payment] away it would decimate me…I'd be right back at square one'. Jean viewed the change as a further check on her independence. Consequently, she was planning to cut down her hours to the bare minimum and pay for all her support herself rather than have her income means-tested:

> Because I do have a small teacher's pension I would end up paying for it anyway so I might as well pay for it. My finances are the only part of my life that's still private…My home is no longer private, but whether I'm rich or poor is my business and not theirs [the local authority's].

Jean's actions provide the most extreme example of user resistance to charging. Although by reducing her hours and funding her own support she limits herself to a residual base of personal care at home, it is the control, privacy and independence secured through self-funding that, for her, necessitates the shift. In these terms, charging for direct payments can be seen to reconstruct policy in a 'welfarist' mode, whereby a more rigorous means-test coupled with increased accountability requirements mirror the framework for social security implemented over the last decade.

The introduction of charging may also be considered in the context of quasi-markets. Whilst conversations with the planners available for interview for this research did not frame policy specifically in these terms, it could be argued that charges represent an important dimension to a market model of social care. This means that service users contribute towards the cost of their services in exactly the same way as other private consumers. Furthermore, in a recent Audit Commission study (2000, p. 22) it is stated that a number of council surveys reflect the view that disability benefits are intended to help with extra costs – thereby justifying charging for service use. A similar argument could be presented in support of using means-tested charges – which impact on user's income progressively rather than through a flat-rate. However given the negative impact of means-tested charges on employment incentives, it would be difficult to sustain this type of argument.

Exploring the boundaries of independent living

So far, discussion in this chapter has focused on how users in each of the three areas have spent their cash payments. This has highlighted an interaction between issues of care, consumerism and independent living as users negotiate their own parameters of flexibility and control within the constraints of local policy guidance. To summarise, discussion has shown examples in East Anglia of individual and professional negotiation of otherwise restrictive care based eligibility criteria. In turn, whilst the local authority has required support to be rigidly quantified, many users have conformed to these requirements on paper but used their payments more widely outwith the boundaries of personal care. The availability of smaller packages of

support has also allowed some users to sustain wider work and social interests. Conversely in East Scotland most older users emphasised the importance of direct payments in looking after their personal care needs. Although users with 24-hour support demonstrated optimum flexibility and control in their day to day living, those with smaller packages appeared restricted in using their payment by policy definitions limited to 'personal care'. Variation in social work knowledge and understanding of the principles of independent living further confused the situation. Other example of user control is shown through the experience of the user with learning difficulties on one of the demonstration projects. However as mainstream policy guidance in East Scotland does not allow wider use of direct payments, for users already in receipt of local authority services, this type of 'mixed economy' approach will not develop. In West Scotland, payment use across age groups drew strongly on care. Very few examples showed interaction with employment, although most enjoyed a more varied social life since receiving the indirect payment.

Commentary in this section now shifts to incorporate a more thorough examination of the notion of independent living established through policy frameworks in each of the three areas. This begins by drawing on speculative responses given when users were asked whether any aspect of their lives could be improved through a more generous payment package. Following on from this, the limits of direct/ indirect payments are explored in the context of user's own definitions of independent living. By examining these meanings and other issues raised, the section concludes by questioning how effective payments are as a mode of securing independence.

Money talks? Exploring the link between cash and independence

Towards the end of each interview users were asked whether a more generous payment package would make a difference to their day to day lives. This issue may be related to wider community care research which has highlighted demands for preventive, low level home care and domestic support for groups like older people (see Clark, Dyer and Horwood, 1998). Whilst most users across each of the areas saw their current support as optimal, some acknowledged that extra funding *would* secure more independence. In East Anglia, half of the users said that they would not change their packages in any way. Those such as Tim and Ian maintained that any

improvement in their quality of life would only come from their own health. However although most were broadly content with their payments, for many this drew largely on a feeling of 'realism' with what the local authority would be prepared to fund. As John said, 'I think the hours are realistic', adding that 'both my PA and friends are flexible enough to give me all the help I need'. In these terms - as shown earlier in this chapter - Claire had fought with the local authority over a number of months to secure a level of support acceptable to her. Whilst now satisfied, she added that 'the assessment doesn't include 'quality of life' things'. Indeed, she had been forced to give up an Open University degree because her package was inadequate to support the extra hours required to attend lectures and complete course requirements. As she explained:

> If they [the local authority] allowed you extra hours to get back and forth, that would make a lot of difference. I tried it for a couple of months last year but it was too difficult…I was studying accountancy and have studied for an Open University degree since 1993 and what direct payments haven't done is help with that. My social worker somehow got me an extra hour per week to attend a lecture, but it just wasn't enough – I needed my PA to write up my notes and she and my husband were putting stuff onto tape for me…Studying kept me going through a difficult patch, but I was completely reliant on my PA as a friend and husband to give me the extra support.

Similarly, for Richard although as described earlier the availability of a small direct payment package had allowed him to continue working, he was increasingly finding that the hours were not enough. Consequently he was reliant on family support, which as he described was not always appropriate:

> Over the past couple of years I've had to take my mum to a computer exhibition to help me. This was understood by colleagues but of course it was terribly boring for my mum. In fact, at one point I turned around and saw that she'd nodded off! Its wasn't her fault but I was really scared that she might start snoring.

Despite examples in East Anglia where direct payments have been used more flexibly to enable support beyond the parameters of personal care in a home setting, experiences like Richard's indicate the limits within which the interaction between personal care and employment operate. Hence, policy allows for *some* flexibility, but as both Clare and Richard's experiences indicate, the assumption remains that personal care remains the main criteria for policy access. Because Richard's personal care needs could be supported in a work environment *and* his package was increased so he was not reliant on his mother, direct payments allowed him to accommodate a work identity. For him, this maximised his independence. However as assessment generally does not cover social and educational activities, Clare's independence was to a greater extent curtailed.

For users such as Peter in East Anglia, the provision of additional payments would allow them to undertake more social activities. As he explained, he had hoped to go on holiday and had thought about asking his PA to come along with him but knew that it was unlikely that his direct payment could cover the additional costs.

The issue of extra costs through disability was also a theme picked up by some in East Scotland. As Lynn stated, 'even if I was able to go on a cheap package holiday, its always double the cost…If you need your PA to accompany you to a concert, again there are extra costs'. Although as detailed earlier, some users were unclear over what could be covered by the payment, most used their PA for some social support. However, evidently the main check to extending this role was finding the additional money.

When asked about the possibility of using extra hours to enter, re-enter or improve employment situations, this only appeared to be relevant for two users. Lynn explained, 'if I had a PA dedicated to my work setting than I could organise a lot more of my paper work than I do'. For Paul – the user involved in the demonstration project – both his PA and project worker at the local day care centre were hoping to secure him a few extra hours to allow them more time to focus on changing key areas of his life, like finding a job and changing his housing. Those such as Deborah, Louise, Simon, Andy and Jim were all satisfied with existing support in their work

environments. Conversely, others of working age such as Emily, Jane and Stewart all discounted work on account of poor health.

Overall as in East Anglia, the majority of users in East Scotland were content with the level of support secured through their payment packages. In these terms, users appeared to have fairly low expectations of what could be funded by a direct payment – even if simply discussing possibilities in hypothetical terms.

In West Scotland, the issue of extra hours raised more prominent concerns for many users - mainly because of local authority budget cuts which had already resulted in reductions to indirect payment entitlements. Therefore, the possibility of receiving additional hours centred more on sustaining existing arrangements rather than developing other aspects of independent living. Indeed drawing on earlier themes, Fiona was trying to secure four more hours to remove dependence on her family for personal care support. As she explained, 'I want my Mum to stop running up and down the road for me'. However, she remained pessimistic about the likelihood of change, adding 'if they [the local authority] don't give them to me, I'll survive because I have good family and friends, but I really would like to replace my mum's role'. As in East Anglia, users were realistic about what they thought the local authority would provide. But in contrast as the experience of Fiona showed, many seemed more resigned to relying on family and friends to fill in gaps in provision. In particular older users like Hazel, described her support in terms of 'being one of the lucky ones', stating that 'I'm fortunate to have close relatives – and that's the way I look at it. Some people don't get help at all – I'm lucky and I appreciate that'. Others such as Barbara, Pauline and Pam said that they would be interested in using any extra hours to attend part-time further education courses, but again appeared more focused on sustaining their existing arrangements than pursuing other goals. Around half of those interviewed said that they would like to be able to go out more. Indeed, as Kate admitted, limited hours meant that she was bored for much of the time and was keen to develop other interests. As suggested earlier in this chapter, the majority of users in this area were not in work and would not consider entering employment under any circumstances. Only Sally raised issues in relation to her work prospects. However as detailed earlier, this was limited within the confines of her wider benefit entitlements.

Defining independence: user views on meanings of independent living

Speculative discussion with users over the role of extra hours and funds to secure improvements in day to day living led to direct questioning over what they considered to be independent living. In earlier chapters, having focused on the more politicised dimensions of 'independent living' emanating from the disability movement, discussion at this stage shows independence defined through a much more privatised and individual sphere. In turn, users were asked to define what this concept meant to them and whether they thought it was achievable. Whilst responses differed considerably - varying from individually medicalised appraisals of disability to wider attacks on social and structural barriers - overall trends linked strongly with the policy framework in each locality. In East Anglia, two thirds of users conceptualised independence in relation to the structural parameters of direct payments policy. Therefore, this drew implicitly on their experiences of both bureaucratic guidelines and resourcing of provision. For example, when Helen was asked whether she considered independent living to be achievable, she replied:

> Yes if [East Anglia] Council were out of the scene – yes definitely. If we could get beyond the idiot demands of their accounting system and separate bank accounts, and telling us that we're naughty girls if we don't do these things.

In turn, once again the increased emphasis on user accountability by the local authority emerged as a significant check on individual independence. Similarly, in response to the same question, Jean explained, 'yes if it were left to me to recruit and run things the way I would like them to run'. For others such as Peter, Tony, Joyce, Anne, Ian, Claire and Richard, their sense of independence was constructed through freedoms secured or restricted by the resourcing of their direct payment package. Thus, whilst Tony saw independent living as achievable he did not consider himself to be independent, adding 'you have to have the resources to achieve it. I need a bigger house. I need more hours in my care package. I need to find the right carers'. Likewise, as Claire stated, 'it's about creating the right environment to live in…it means being able to go to work, mix with people and have a house that you can

function in' From these appraisals, only Anne and Ian were completely satisfied with their payment package and saw their lives as being entirely independent.

A majority in East Scotland drew on similar structural factors in their definitions of independent living. However in contrast to East Anglia, overall assessments of support packages were far more positive. Again, this broadly replicated earlier views on the role of each local authority – whereby users in East Anglia were largely critical of its work and in East Scotland where users were more supportive. In these terms, responses focused on the notions of choice and control secured by the direct payment. As Deborah explained, 'its about people making informed choices whether to stay where they are or move on...I don't think it's the same thing for every one but its about having access to do the thing that's best for them'. Similarly Lynn stated, 'it means the old words 'personal control' – relaxation and by that I mean relaxing into the person you choose to be'. Others such as Jim and Jane drew on their own physical restrictions but still acknowledged a significant level of choice and control gained through direct payments. As Jane noted 'this [receipt of a direct payment] is the only way independent living is possible'. However unlike East Anglia, three users – Emily, Janet and Karen – did not consider themselves to be at all independent. In asking what 'independent living' meant to her, Emily remarked, 'I don't think it means anything to me'. Moreover Janet conceded, 'You can't lead an independent life when you're reliant on others...I don't mind having people with me but I'd prefer to go out on my own and I can't do that now'.

In West Scotland, responses were far more mixed, but on the whole focused more strongly on individual perceptions of their disabilities alongside a wider care discourse. Furthermore unlike East Anglia and East Scotland, none of the users related their conceptualisations of independence to support determined *solely* through indirect payments. Indeed, those such as Fiona and Sally were in a minority in drawing explicitly on wider structural constraints. As Fiona explained:

> When I'm living at home I forget I'm disabled and to me it's an indication that it's working. If I go away without a PA I feel totally frustrated again and feel dependent with my parents helping. I get annoyed with that and realise how much at home things are working well. My flat is accessible and my routines

at home are all worked out. I do what I like and I forget that I'm disabled but take me away from these circumstances and it's awful.

Whilst others such as Alison, Barbara, Pauline and Pam emphasised the importance of finding the right support through indirect payments, they also saw their health as a major constraint to their independence. Yet they all maintained that indirect payments had enabled them to enjoy optimum choice and control over their lives. Older users like Hazel and Kathleen also emphasised increased freedom gained through indirect payments, but defined the advantages of this through a focus on care. As Kathleen replied in response to the question of what allowed her to live an independent life she answered, 'getting someone you can depend on to look after you and who's there for you'. In contrast, Moira, Heather and Suzanne all framed independence solely in medical terms. As Heather maintained:

> My concept of independence is independence from agencies. If it meant the difference between living in a home and living in an institution then no, I don't live in an institution. But if you need assistance, you can't be independent.

Consumerised care or independent living?: summary and discussion

Having examined the way in which users in the three areas used their payments and framed the notion of independent living, this final section continues with commentary outlined in chapter VI and returns to a focus on the main discourses underpinning policy. This begins by exploring the key trends prominent in each area and then develops into a wider examination of more general issues surrounding the themes outlined in this chapter.

Already through discussion of policy planning in chapter V and structural and identity changes gained from a shift to cash payments in chapter VI, an imbalance between market and independent living discourses in the three areas has been shown. At a general level, whilst local policy statements have implied a shift towards an understanding of some of the principles of independent living, user experiences underline the limits of this rhetoric and illustrate a number of restrictions. As chapter VI highlighted the increased freedom and control gained through the shift to indirect

and/or direct payments, this chapter has underlined the importance of *flexibility* secured through payment packages which maximises user control. Hence it is the level of flexibility that appears to differ between each local authority. As suggested, this is at least in part determined by the relationship between market and independent living discourses.

In East Anglia, the limited policy definitions translated into access to a direct payment through a community care assessment process rigidly based around personal care. Placing this requirement alongside the shift to increased 'service accountability' identified in chapter VI and the introduction of means-tested charging for services, raises some important issues surrounding the context of policy implementation. Indeed although both users and the CIL acknowledged ways of using hours more flexibly, this often relied on re-establishing dependencies with family or friends. Therefore, it is perhaps unsurprising that a majority of users cited structural constraints determined by the local authority as the main check on their independence. By focusing direct payment packages solely on limited personal care *and* increasing requirements for user accountability, the scope to frame policy as a means of securing independent living and civil rights is greatly reduced. Furthermore, the proposed introduction of charges draws on another element of marketised welfare, whereby services are residualised and provided without user cost only as a 'safety-net' for the very poorest. Hence, the Conservative Government's original concerns at a national level over accountability and cost efficiency - outlined in chapter III - which prevented earlier development of legislation, reappear locally.

Issues surrounding payment uses and independent living are less clear in East Scotland. Whilst offering a more wide-ranging definition of independent living within the policy guidance, payment use also drew strongly on personal care which tended to be focused around a home setting. Although this was welcomed by many users, maximum flexibility and the interaction of payments for other uses seemed only to be secured either through 24-hour support or the demonstration project. Access to smaller packages does not appear to extend beyond users outside the labour market and therefore these user experiences centre more strongly on care issues. Moreover as suggested, the anti-market discourse limits wider access to direct payments for those already in receipt of local authority services. As will be discussed in more detail in

chapter VIII, this has important implications for policy access in the future – particularly for those with learning disabilities.

In examining user conceptualisations of independent living, structural factors also played a prominent role. However, these were more generally related to the positive aspects of control and flexibility gained through the direct payment. In these terms, whilst the policy framework in East Scotland is less flexible, restricting the size of package available, user *expectation* of what the payment may be used for appeared to be much lower than in East Anglia. Any issue of increased resourcing centred on more general issues surrounding the extra costs incurred by disabled people, rather than perceived short-comings in the local authority role. Furthermore unlike East Anglia, in far more cases individual impairment was cited as the main barrier to independence.

This feeling was more widely voiced in West Scotland, whereby the role of care featured most strongly in user's accounts. At a structural level, although aware of budget cuts in the authority, the majority were simply concerned at sustaining their current personal care packages rather than significantly changing other areas of their lives. Again this draws on the issue of user expectation where although increased flexibility and control was welcomed, many assumed a much more restrictive role for indirect payments. Consequently users on the whole appeared to be far more dependent on family and friends to supplement their support needs. In each of the areas where insufficient payment packages had forced users to rely on other networks of support, it would appear that these relationships shifted from the position of inter-dependency advocated by Shakespeare (2000) and others (see chapter II) towards increased dependency. This is an issue which will be returned to in the context of future policy development in chapter VIII. In general, the overall appraisal of independence in West Scotland focused more strongly on a medical model of disability.

By highlighting the differences in user expectations of direct/indirect payments between the three areas, on one level this may be explained in part by age and individual constructions of age barriers. Indeed, the profile of users in East Anglia shows only one user over the age of 55 and no-one over 60. This contrasts with both

East Scotland - where seven users are over 55, six of whom are over 60 – and West Scotland where eight users are over 55, including three over 60. Whilst the samples are *not* proportionally representative of total user populations, age differentials between the areas may at least in part serve to explain *some* of the contrasting user expectations. This is not to suggest that older users are all focused only on securing their personal care needs in a home environment, but many dismissed the need for support in an employment setting on grounds of age as well as impairment. The use of direct payments for older users is a theme that will also be returned to in chapter VIII.

However, explaining differences in user expectations solely through age is clearly too limited. Indeed, some older users across the areas either used, or expressed a wish to use payments in wider roles. Similarly, some younger users envisaged only restricted 'care' and social roles for payments. Therefore, to understand the differences between the three areas, discussion needs to draw on both wider individual identity and structural issues. In these terms, the type of user by whom a direct payment is accessed may be more specifically related to the role of professionals – a theme outlined in chapter VI. To re-cap, discussion with planners in East and West Scotland suggested that direct/indirect payments were not being offered to *all* potential users as a mainstream service option, and have been restricted mainly to 'difficult cases' – i.e. users for whom local authority organised home care service provision is inappropriate. This drew on both gaps in understanding of the principles of independent living by some social work personnel and, in East Scotland, 'anti-market' sentiments at a planning level. Thus the construction of payment packages in these 'care' based terms is likely to present direct payments as a shift to 'consumerised care' rather than independent living. In contrast, whilst some of the longer term users in East Anglia also gained (the former) indirect payment support because of their individual demands (see chapter VI), the much faster growth of direct payment users suggests that policy is being offered to a more diverse user population. Hence, whilst access to a direct payment in East Anglia remains largely focused on rigidly defined personal care needs, a more flexible 'mixed economy' approach allows users more scope to negotiate their demands. Clearly this still falls short of a payment model based fully on independent living values, but the shift does allow more individual flexibility and choice for a larger user population.

Conclusions

Discussion in this chapter has focused on how cash payments have been used in each of the three areas. In doing this, attention has centred on how independent living and market discourses have been constructed by local planners and understood by users. Whilst use of a direct or indirect payment for users across the three areas has increased flexibility and participation in day to day living, wider structural factors – both at local and central levels - also need to be taken into account. Together, these contribute to users own constructions of their independence. In the next chapter, a number of these themes are re-visited as more recent policy changes emanating from both central and local government levels are examined.

Notes

[i] An abridged version of this chapter appears in Pearson, C. (2000) 'Money talks? Competing discourses in the implementation of direct payments', *Critical Social Policy*, Issue 65, Vol. 20, 4.
[ii] Access to direct payments for older people was made available in February 2000 in England and Wales and July 2000 in Scotland – see chapter VIII for more details
[iii] This figure represents payment prior to deductions made for National Insurance, sickness cover through agency staff and general insurance costs.
[iv] After £200 of social (work) service funding per week, users have to apply to the ILF for support, which as detailed later in this section is means-tested.

Chapter VIII: Cash under control?: *Developments in Direct Payments - redefining the boundaries of policy inclusion?*

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Introduction

THIS CHAPTER FOCUSES on more recent policy discussion by examining changes to direct payments made since implementation of the original 1996 Act and completion of fieldwork for this research. These are explored at both national and local levels. The first section of the chapter outlines national changes made under the New Labour Government. Three main areas are highlighted: giving access to direct payments to older people; publication of new policy guidance and the extension of direct payments to parents of young disabled children and carers. The emergence of policy around these themes integrates a new dimension to the restructuring of welfare, whereby the onset of devolved legislative powers in Scotland accentuate policy difference with England and Wales.

In the second section, moves to widen access to direct payments in the three authorities are discussed. In East Anglia, a restructuring of independent living services has significantly raised the profile of direct payments as a mainstream service option for all eligible users receiving a community care assessment. Commentary shows planners instigating a proactive response to national policy changes – allowing immediate access to payments for older people as changes are brought in. Likewise, steps have been taken to ensure a similar transition for younger users and carers. This is contrasted with East Scotland, where planners have acknowledged a reluctance in social workers to promote direct payments as a mainstream service option and the introduction of direct payments to older people has been made without making any structural changes.

As access to direct payments widens, are difficulties experienced by disabled groups in exercising voice have emerged. In particular, impending access to direct payments for other groups has also had a significant impact on planning in West Scotland. As the CIL has raised the profile of their campaign to secure formal adoption of direct

payments, concerns are focused on lobbying from local carers' groups and their impact on the local authority, which introduces the possibility of direct payments being implemented through a more narrow focus of 'care', rather than independent living.

The position of persons with learning difficulties is also discussed. Whilst revised policy guidance in England and Wales offers more inclusive criteria, planners in East Anglia remain dissatisfied with the definitional changes offered. In contrast, Scottish Executive planners have delayed their revisions with the intention that guidance may enable wider inclusion for this group.

For planners in East Anglia and East Scotland, development of direct payments has been affected by wider changes in each authority. The impact of the 'South Lanarkshire ruling' together with the introduction of charges are discussed. In particular, charging provides a key example of how local policies need to take account of wider change in order to secure a meaningful level of independent living for users. The section finishes with a more detailed focus on the issues surrounding planning for direct payments in West Scotland.

The third section of the chapter provides a more in-depth appraisal of policy change in relation to the broader structure and identity themes outlined throughout the thesis. In returning to this framework, commentary addresses the need to analyse change at a number of levels. This incorporates a focus on how structure and identity roles have been constructed by both central and local policy makers.

Redefining direct payments?: Changes from the Centre

Implementation of the original direct payments legislation in April 1997 came only a month prior to election of the New Labour Government. On a national scale, the shift to a Labour administration assumed the potential to alter both the organisational structure and the overall direction of direct payments policy. In terms of organisational change, local diversification of direct payments emerging through early indirect payment schemes and sustained through the 1996 Act, became indirectly accentuated with the advent of the Scottish Parliament and its new devolved

responsibilities for social services. Likewise, although changes in the direction of policy have so far included broadly the same areas of reform, it is the speed at which this has occurred that has varied - with legislation in Scotland at least six months behind England and Wales. This section details the main changes emerging from national policies. The implications of these shifts in each of the areas used in this study are examined more thoroughly later in the chapter.

The first policy change for direct payments under Labour came in November 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. The same change was announced in the Scottish Parliament on 2 December by the Deputy Minister for Community Care, Iain Gray (Scottish Parliament Official Report, 1999, col. 1119). In England and Wales, the ruling was implemented in February 2000 and in Scotland, July 2000.

Inclusion of older people was followed by publication of new direct payment guidance in England and Wales (Department of Health, 1999) – replacing the original framework (Department of Health, 1997). The purpose of this update was 'to set out the [Labour] Government's view of the issues for local authorities in exercising the powers given to them by the Act' (Department of Health, 1999, para. 3). Whilst some changes and modifications to earlier guidance were made – and these are outlined in the following sections - the basic framework remained unaltered. This still allowed local authorities the option to proceed with schemes and to develop policy in line with existing local 'care markets'. In this sense, the broad rationale for direct payments devised by the Conservative Government was left in place, but a clear emphasis was given to extending policy use to a far wider user population (Department of Health, 1999, para. 2). However whether this extension of policy is directly attributable to New Labour is questionable. Continual lobbying by disability activists and groups like Values into Action clearly had a significant impact on change, although New Labour were evidently willing to accommodate these demands in their first term.

At the time of writing (autumn 2000), reform of the original guidance in Scotland (Scottish Office, 1997) has yet to emerge – only brief changes including extending

payments to older people have been made through a Scottish Executive Circular released in June 2000 (Circular No. CCD4/2000). By delaying publication, Scottish Executive planners decided to allow time to focus more specifically on the areas requiring change; thereby acknowledging some of the broader difficulties in implementing policy per se and with specific reference to Scotland. As part of this process, a series of seminars have been planned for early 2001, inviting local authority planners, users, disability organisations and other interested parties to participate and identify issues of concern. These will be returned to shortly. However, three and a half years after legislative change, the overall picture for direct payments in Scotland looks poor. Research from Witcher, Stalker, Roadburg and Jones, 2000 indicate similar findings, showing policy implementation at a very early stage. Indeed, Witcher *et al* (2000, piii) found that only 13 out of 32 local authorities in Scotland have fully operational or pilot direct payment schemes – with a total of 143 users.

Having supported the ethos of direct payments and the extended access to older people, the Labour Government has sought to widen policy coverage further. This began in England and Wales where through the provisions of the 2000 Carers and Disabled Children Act, a three-fold change to direct payments has emerged. Firstly, parents or guardians who look after disabled children will be entitled to a direct payment – allowing them to decide what services to buy for their children. Secondly, the Act introduces a statutory duty on local authorities to provide services directly to informal carers to meet their assessed needs (as determined by the 1995 Carers (Recognition and Services) Act. In turn, local authorities will be given the opportunity to offer direct payments as part of this support package. Thirdly, 16 and 17 year olds will be able to access direct payments. Parallel legislation in Scotland has yet to emerge - changes for the parents of disabled children will be introduced in the Social Services Bill in Autumn 2000 and parliamentary time has been set aside in the 2001/2002 session for a Bill to develop direct payments for carers. Again Scottish Executive planners emphasised the need to consult on these changes with interested parties before proceeding.

Clearly this type of expansion of direct payments introduces an important shift in the overall framework of policy. As stated in earlier chapters, Section 1(4) of the 1996 Act prevents most users from employing relatives with the direct payment, thus

distancing itself from what Ungerson (1999, p. 585) terms, a 'straightforward commodification of informal care'. However the inclusion of parents of disabled children and carers signifies a change in the profile of policy users. This extension of access to other groups redefines '*user* control' through a third party. In one respect, the disability movement may be uncomfortable with this change as it could be interpreted as a shift away from a model of direct payments informed by independent living principles and *user* control. Conversely, the inclusion of third parties may also be understood as a significant step in widening policy access to user groups who have until now been limited or excluded from receiving a direct payment. These are issues that will be returned to as changes in each area are examined more thoroughly.

Redefining direct payments?: Change in the local areas

For each of the local authorities used in this research, implementation of direct payments legislation in April 1997 has had a varying impact on the ethos of local service provision. In East Anglia and East Scotland, there has been a move from indirect to direct payments alongside contrasting attempts by planners to promote the use of policy as a mainstream service option. In West Scotland, policy momentum has been much slower as direct payment planning has been delayed by wider local authority reorganisation, lacklustre disability activism and an anti-market concern over the nature of service change. The following section explores the impact of the dominant discourses surrounding the policy promotion in East Anglia and East Scotland as planners react to national policy change. Likewise, some of these key issues are raised in conjunction with West Scotland's efforts to secure adoption of direct payments.

Promoting payments: Accessing a wider user population

Overall, East Anglia demonstrated the most proactive response to national policy changes in developing wider access to their payment scheme. This has been organised around key changes in planning personnel occurring since the outset of this research. At the core of these changes has been the creation of a new post – an Independent Living Services Manager – who has assumed the lead planning role for direct payments policy. Hence by transferring policy responsibility from service management for physical and sensory impairments to a wider remit of independent

living, at face value, planning is now presented as being more inclusive. In these terms, direct payments form one of a range of housing, transport and employment policies.

Therefore, as suggested throughout this thesis, direct payment planning in East Anglia appears to be the most progressive. This was established from the outset of this research during initial interviews with planners in September 1998 and prior to publication of central government guidelines, when the local authority and CIL were already in the process of piloting ideas to give older people access to direct payments. Thus by the time policy was implemented in England and Wales (February 2000), the authority had funded a new advocate post at the CIL to deal with incoming referrals, allowing payments to be immediately offered to this group as a mainstream service option. Moreover, the number of direct payment service users in East Anglia had continued to grow at a far quicker rate than in East Scotland. By September 2000, this gave East Anglia the second highest number of direct payment users in the UK (ADSS, 2000). As detailed in chapter V, early automatic referral of potential payment users to the CIL clearly contributed to a more routine allocation of direct payment packages. For the Independent Living Service Manager, part of the success of this process had centred on developing advocacy and training services for users to draw upon. As stated earlier, this had led to new funding for an additional post at the CIL to cover advocacy services, however for training a wider restructuring has occurred – shifting responsibility from the CIL to the local disability organisation in charge of the payroll service. By separating roles in this way, the planner made direct reference to the updated policy guidance in England and Wales (Department of Health, 1999, para. 13) which states that 'it may...be preferable to separate any support role from an advocacy role on behalf of any individuals to avoid any conflict of interest'. This left East Anglia with a distinctive framework of support structures, operating independently from the local authority and focusing more strongly on a model of individualised consumer control.

Given that issues surrounding cost-efficiency had been presented most strongly in East Anglia throughout the early planning process (see chapter V), the cost of embellishing the network of support services was raised with the Independent Living Service Manager. Indeed, he conceded that the expense of developing the payroll

service into a wider independent training service had been a concern, particularly in the context of promoting 'best value' in the local authority. However, although an audit had yet to be carried out to cost the transition to direct payments, he acknowledged that policy probably *was* saving the authority money, but emphasised that the focus of any assessment would centre on their cost *effectiveness* rather than more crude counts of economy. Also in East Scotland, planners have yet to cost the shift to direct payments and felt unable to comment as to whether changes had saved any money. Therefore although it is not possible to expand discussion of cost efficiency in the context of the areas in this study, research by Witcher *et al* (2000, para. 7.8) suggested that direct payments can lead to a more efficient use of social work resources. Furthermore, Hasler (1999) found that West Sussex Social Services saved £30,000 from their first 15 direct payment users. In light of this considerable sum, it is likely that similar savings will be made by East Anglia and East Scotland. Nevertheless the challenge for the disability movement is to ensure that these savings are reinvested in independent living services.

East Anglia's push to allow early direct payment access to older people contrasted with the position in East Scotland. Only after guidance was published by the Scottish Executive in June 2000 (Circular No. CCD4/2000) were instructions passed around practice teams in the authority informing staff to offer payments to older people. No additional service changes were made to facilitate this change.

By April 2000, East Anglia had appointed a development worker to explore the issues surrounding access to direct payments for 16 and 17 year olds and carers. Once again, East Scotland were awaiting guidance from the Scottish Executive before instigating any changes. Unlike in East Anglia, planners felt that they needed this legislative backing prior to making service changes – even on a trial basis. Indeed an example was given of when the authority had wanted to make a direct payment to a carer. Given that under existing legislation this type of transaction was unlawful, planners sought advice from the Scottish Executive – to ask whether the payment could be made as a pilot case - but the request was turned down.

Indeed, in East Scotland although around 60 users had transferred from an indirect to a direct payment, making direct payments a mainstream service option to new users

proved to be a much slower process than originally envisaged by planners. As previously stated, this type of access had been held back until May 1999 and was restricted to those not already in receipt of a local authority social service. By autumn 2000 only 55 users[i] were included in this category. For the lead local authority planner this was the main issue of concern. Indeed, despite a substantive training exercise, planning staff had become increasingly aware of shortcomings in social worker's knowledge of direct payments. As the lead planner commented:

> They [social workers] don't really seem to understand them yet. When people are getting them [direct payments] it tends to be more out of desperation – because they're seen as difficult cases and existing services can't meet their needs.

Therefore it had become clear that social workers were not offering payments as an option on an equal footing with other community care services. As the lead planner observed, 'staff are finding it difficult to take on board that direct payments are just another way of delivering services'. Indeed, on one level this type of route to direct payments mirrors the initial use of cash payments in the local authority (see chapter V) where only 'difficult cases' gained access. As noted in chapter VI, this type of gap in professional understanding of independent living has been exposed from the outset of policy implementation. Moreover, it is an issue of concern highlighted in other early studies of direct payments in England (Maglajlic and Brandon, 2000, p. 111) and Scotland (Witcher *et al*, 2000, para. 7.10). In East Scotland this could be seen as a particular problem because users are largely dependent on social work staff to inform them of service choices. Contact with the main advocacy service - the CIL - comes only through individual user enquiries, rather than as a matter of automatic referral from the local authority (as in East Anglia). Hence, users not directly involved with the CIL are reliant on social workers as their primary source of information.

Promoting payments: In search of a voice

In West Scotland, likely implementation of direct payments for carers in Scotland raised a number of issues for disability activists still trying to secure adoption of the 1996 Act. The possibility of legislative change in Scotland had led to lobbying by

local carer's groups. For the CIL, this had opened up concern that the local authority appeared to be more willing to accommodate carers' needs than their own. As one CIL representative stated, 'carers' groups seem to have more political clout than disabled people'. Given that cash payments – through an indirect or direct route – have formed a key part of the disability agenda in West Scotland for the last ten years, a scenario whereby carers' demands may exert more political influence again highlights the weakness of disability activism in the area. This was reiterated by a CIL representative:

> We don't seem to be as politically active here – so I don't think we can blame the fact that carers are listened to rather than us...I think they just got their act together and are more organised.

However as well as taking the political initiative away from disability groups, the likelihood of direct payment access for carers raised more pertinent issues for the CIL. As suggested earlier in this chapter, by allowing carers to directly buy in support services, some disability activists may see the notion of *user* control as being substantially eroded. This was reiterated by the CIL representative who highlighted an example of where this tension may arise stating that, 'If a young disabled person wants a direct payment but their parent felt that they couldn't cope with it, and it was considered more appropriate for the parent to have the direct payment, then there's a real conflict...'.

As this study has highlighted, use of indirect payments in West Scotland has centred overwhelmingly on the provision of restricted hours for personal care in a home setting (see chapter VII). Therefore, the possibility of transfer of direct payments to carers around the same time as disabled persons may simply serve to reinforce this framework of policy and shift the policy direction further away from the rationale of independent living.

Throughout this thesis, discussion has shown access to direct payments for users with learning difficulties meeting with only marginal success. This has led national organisations such as Values into Action to lobby government for change – campaigning for more inclusive guidance than that laid out in the original 1996 Act.

In the context of revised Department of Health policy guidance for authorities in England and Wales, some key changes have been made. This begins by stating that local authorities 'should consider how to include people with different kinds of impairment...' (Department of Health, 1999, para. 2). Whilst the clause stipulating that direct payments should only be offered to those '...able to manage them (alone or with assistance)' (see chapter V) remains in place, this is supplemented by the statement that '...they [the local authority] should avoid fettering this discretion by making blanket assumptions that whole groups of people will be able to do so' (Department of Health, 1999, para. 18). In turn although users with learning difficulties are not mentioned directly, revised guidance appears to accentuate the need for a more individualised and inclusive approach to policy access.

However, planners in East Anglia remained unsatisfied with these revisions. As the Independent Living Service Manager stated, 'we asked for more clarity regarding learning difficulties and this is no clearer'. In turn, it was felt that no further changes to the existing position for users with learning difficulties could be made until firmer definitions from central government were outlined. Therefore access for this group remains permissible – with 16 users now receiving a direct payment[ii] - but is not promoted as a mainstream option in the same way as for users with physical impairments. Planners in East Scotland demonstrated a similar reluctance to proceed with change. Whilst some momentum to give access to payments to users with learning difficulties within local policy limits[iii] had been shown (see chapter V), again it was felt that policy could not be extended further without suitable legislative back-up. Once again, Scottish policy development for this group differed slightly. As stated, revised policy guidance had been delayed in order to address key issues for change. Indeed, one of the areas of concern highlighted by Scottish Executive personnel was the need to clarify definitions for the use of direct payments for users with learning difficulties and mental health problems. For the planner in charge of re-drafting the guidance, the terms 'manage', 'ability' and 'control' were especially problematic in their current form. In turn, she emphasised the need for new Scottish guidance to re-define these terms in order to encourage a higher take-up of policy from these groups. Further to this impetus for change, calls to widen access to payments for these users were outlined in a national review of services for persons with learning difficulties in Scotland (Scottish Executive, 1999). Contained within

this document was the acknowledgement that 'direct payments could play a far bigger role in the future' (Scottish Executive, 1999, para. 40) and the recommendation that 'by 2003, any one who wants a direct payment should be able to have them...' (Scottish Executive, 1999, p. 24). Therefore, whilst Scottish policy development for this group looks set to proceed within a more inclusive framework in the long term, currently it leaves a considerable inequity between user groups.

It must also be understood that the inequity between direct payment user groups extends beyond a physical impairment/learning difficulty divide. As earlier research cited in chapter IV indicated, policy remains almost redundant for persons with mental health problems (see Maglajlic *et al*, 1998) and minority ethnic groups (Bignall and Butt, 2000). Sensory impairments also appear to be underrepresented in user profiles. Again, these are issues that were acknowledged by local planners although no specific action was being put forward to instigate change.

Promoting payments: wider policy concerns

In both East Anglia and East Scotland where direct payments were in place, another key issue raised by lead planners in the context of recent policy development was the 'South Lanarkshire ruling'. As discussed in chapter VI, this refers to the employment tribunal decision in August 1999 which ruled that the local authority *not* the individual should be named as the employer in awarding damages in a case of sexual harassment between an indirect payment user and his PA. In light of this ruling, East Anglia's planners were forced to examine all aspects of policy with the county solicitor in order to confirm that the authority would not be troubled by it. Having satisfied the process, a written statement was produced clearly outlining the *user* responsibilities as the employer in a direct payment package. Similarly in East Scotland, legal services were required to clarify the local authority position. As the lead planner noted, 'it just confirmed to us that direct payments were the only way forward'. In this sense, having removed all third party roles a clearer relationship between user and employee has been created. Speculatively this may re-emerge as an issue if more mixed payment approaches – involving a third party – are introduced into mainstream policy use in order to give a higher number of users with learning difficulties access to payments.

Charging ahead: direct payments and local charging policies

Whilst the development of a more comprehensive network of user support services in East Anglia implied a stronger commitment to both consumer and independent living discourses underpinning direct payments, wider local authority changes affecting users undermined this shift. As briefly mentioned in earlier chapters, from May 1999 the local authority introduced a policy of means-testing all local authority services offered through a community care assessment. Although charging for services is not a new development (see Baldwin and Lunt, 1996, p. 11), the 1990 community care reforms drew strongly on an assumption that individuals should contribute financially to their own care needs. Whilst the enabling model used both in community care and direct payments gives local authorities the responsibility to decide whether or how to charge users, in England and Wales it is assumed that around nine per cent of income will be raised from service charges (Audit Commission, 2000, p. 22). This does *not* apply in Scotland. Therefore, for many English and Welsh authorities the scope to impose *no* service charges is limited, though not unfeasible. A number of different types of charging policy have emerged (see Baldwin and Lunt, 1996, p. 22) – ranging from a flat rate fee to means-testing of all or partial service use. Likewise, the decision to use one system in favour of another draws on a number of factors, including the political complexion of the authority, financial considerations and the role of active lobby groups (Baldwin and Lunt, 1996, p. 31).

Although the notion of any service charge remains problematic in the context of a social model of disability, those which rely on a means-test present the most conflict with the principles of independent living, as users in work or with savings are penalised. Hence, it is in these terms that conflict arose between disability groups and the local authority as plans to implement this type of charging policy were implemented.

For a number of years, East Anglia operated a flat-rate charge levied at all users irrespective of services received. However, in 1998 budget shortages within the authority led to proposals to bring in a means-tested charging system. This required all users to complete a financial assessment form – including those already in receipt of a direct payment. The main framework of the policy is aligned to IS means-testing

arrangements. This allows users to have a total capital disregard of £3000 and an income disregard set at current IS levels before the means-test begins.

Whilst Liberal and Labour council members[iv] raised concerns about the charging policy and requested that the Director of Social Services examined other options, the main opposition came from a high profile campaign against charges mounted by service users, the CIL and the local forum for disabled people. As the Chair of the CIL recalled, 'there was a massive uproar – I've never known such a response in [East Anglia] - letters to every MP, Secretaries of State, all the members of Social Services Committee and a petition with 5000 signatories'. However, *none* of the alternative proposals – such as a higher flat-rate charge - put forward by the combined forces of the disability movement were taken into account. Liberal and Labour members abstained from voting and changes were passed through.

Unsurprisingly, the introduction of charges has presented a source of major disagreement between CIL and local authority planners. This opens up a key point of conflict between the market and independent living discourses underpinning direct payments. More specifically, it focuses on the inequity between discourses as the limits of disability activism in securing policy change are shown. The Chair of the CIL emphasised this point in stating, 'Social services cannot talk about equality, they cannot talk about independent living, when they bring in a means-tested charge that means that single, working disabled people can *never* - as long as that policy is in place and they need personal assistance – they can never be equal…It's just rhetoric – that's all it is'. Moreover, this placed a considerable strain on the link between the CIL and local authority when working together on service development. As the Chair conceded, it had at times been hard 'sitting round the same table in planning meetings when certain officers discuss equality issues'. Nevertheless an effective working relationship with the local authority needed to be sustained in order to maintain an input into wider policy change for independent living services.

For the Independent Living Service Manager, the conflict between charging and his own remit of independent living had also raised some difficult issues. Discussing this in August 2000, 15 months after policy was enforced, he voiced concerns with regard to the local authority's approach to charging, employment incentives for users and

broader social policy change emanating from central government. In doing so, he acknowledged difficulties over the contradictory position of policy – particularly in relation to the revised guidance for direct payments. This stipulates that 'local authorities should ensure that charging policies do not act as a disincentive to work' (Department of Health, 1999, para. 27). Indeed when placed alongside the introductory paragraph to the guidance which states that direct payments, '…promote independence, and…aid social inclusion by offering opportunities for rehabilitation, for education, leisure and employment for people in need of community care' (Department of Health, 1999, para. 1), it is difficult to reconcile local authority continuation with this type of policy. Similarly, within the context of the *New Deal for Disabled People* (see also chapter II for more details) policy contradicts the central government emphasis on getting disabled people into work. Although charging is not mentioned specifically, 'removing obstacles to work' forms a key policy goal (Department of Social Security, 1998, para. 17). Whilst these were all issues that the Independent Living Service Manager was going to raise in the forthcoming review, he conceded that it was highly unlikely that any changes would emerge.

Although planners in East Anglia seemed unlikely to amend their charging policy in the immediate future, other recent research into direct payments (see Hasler, Campbell and Zarb, 1998) has acknowledged the difficulties associated with charging and users in employment. Hasler *et al* equate charging with the notion of 'value for money'. In these terms they suggest that in local authorities – like East Anglia – where direct payments have been framed in part through market doctrines of flexibility, choice and control, implementation may result in savings being made. Consequently, this should permit *lower* charges. This places East Anglia's framework for direct payments in a contradictory position. On the one hand investment in policy development, support and advocacy services suggests a genuine commitment to direct payments within a wider independent living strategy. Conversely, although overall savings for direct payments have yet to be established, the shift to a more stringent charging structure points to a policy drive centred on residualising expenditure on service provision for disabled people.

East Scotland also had a charging policy in place, requiring users to undergo a means test. However, this did not cover all services offered through a community care

assessment. For example, 'care at home services' – or the direct payment equivalent - were means-tested for charges, but day care services were not. Again, this raises another issue in the context of the experiences of different user groups, direct payments and their experiences of independent living. Under this policy, new users offered a direct payment to buy in day care support would also be able to enter part time employment without being means-tested. As stated in earlier chapters, day care users are more usually persons with learning difficulties. In contrast, a user with physical or sensory impairments receiving 'care' in a home environment would be limited in their employment opportunities owing to charging rules which operate a similar means-test to East Anglia. Although the charging policy has been in place for approximately two years, unlike in East Anglia, it was not implemented retrospectively. Therefore all former indirect payment users interviewed for this study remained unaffected by policy change. However, in both areas clearly this will be a key issue for new direct payment users and looks set to be increasingly problematic in the context of promoting direct payments in a framework for independent living.

Still planning for direct payments – negotiations for change in West Scotland

Whilst planners in East Anglia and East Scotland were seeking to offer direct payments to a wider user population, the CIL in West Scotland was still trying to secure confirmation from the local authority that they would proceed with implementation. As detailed in chapter V and in subsequent discussion, the lack of policy momentum for direct payments has centred on delays emanating from local authority reorganisation, lack lustre disability activism and fears of privatisation. However, over the last year (1999-2000), the CIL has engineered a more concerted effort to build up the profile of direct payments within the local authority. This renewed attempt began with the production of a briefing paper giving basic information on direct payments, which was sent out to every councillor in the authority. In response, the CIL was invited to meet with the Chair and Deputy of the Social Inclusion Committee. Interest at this level represented a significant shift towards securing a higher profile for direct payments and was acknowledged by the local authority lead planner as being a key factor in establishing momentum to pilot changes. From this stage, a working group for direct payments was set up. This was led by the Principal Officer for Physical Disabilities and also included other social

work staff such as personal assistant advisors and representatives from the CIL. No direct representation was given to users or planners associated with learning difficulties or mental health problems. Again, this reiterates the overall problems in establishing direct payments for these user groups and – more specifically – their exclusion at the planning level in West Scotland (see chapter V).

Having achieved more political interest within the local authority, planners eventually agreed to proceed with a six month 'demonstration project'. However, again this was substantially delayed and beset with problems. As detailed shortly, these stemmed largely from the availability of only a small cash limited budget, but even the terminology used in referring to the process provides an interesting example of the difficulties experienced. Drawing on the development of direct payments in East Scotland, West Scotland's CIL have been keen to promote similar use of demonstration projects as a means of securing permanent policy change. Yet, as one of the CIL representatives described, 'even with the pilots, we [the CIL] wanted to call it a 'demonstration project' and they a 'pilot scheme'. I know it's a play on words but if you're 'demonstrating' you seem to be showing how it *will* work. With a pilot, there's an implication that change is only short term and an experiment'. Eventually, planners agreed that the term 'demonstration projects' could be used in working group meetings, but with the condition that 'pilots' were to be used when discussing policy with local councillors.

However for the CIL, lack of funding was the fundamental concern and indicative of the difficulties and overall lack of commitment to policy development in the area. As one of the main CIL representatives involved in the direct payments campaign remarked, 'there's still that real fear of backdoor privatisation – not from the immediate planners - but the elected officials higher up. You keep asking yourself 'why is there no progress? Why is there no budget? And you keep coming back to the same thing'.

In securing only limited funds for the demonstration projects, the CIL expressed the fear that once monies are exhausted, access will be denied to new users – thereby mirroring the problems experienced with the indirect payment scheme (see chapter V). This was an issue also raised by the lead planner. His long-term aim in trying to

secure policy change centred on gaining local authority commitment to offering direct payments as a mainstream service option. As in East Anglia and East Scotland and in keeping with national policy guidance, this would see funding allocated from general community care service budgets and offered as requested by users. However, senior management in the local authority have argued strongly in favour of using a designated budget for direct payments. In turn, the lead planner explained how this push towards specialised funding had been framed. Once again dominant anti-market sentiments were shown to influence policy direction:

> They [senior social work service management] have a view that [opting for a unified budget] won't be very popular in the sense that it will undoubtedly result in redundancies in the short to medium term. If that were to take hold, we'd be talking about the Home Care service having a reduced funding base and probably there would be a reduction in home helps...Of all the people associated with Social Work Services, they get the best press from the public - if jobs went it would be politically unpopular.

Despite concerns over any potential loss of jobs, as suggested, the lead planner remained keen to develop direct payments through a unified community care budget. Certainly given the history of service cuts and ethos of provision in West Scotland (see chapter V), this would appear to be the most appropriate route to challenge some of the more deep-rooted problems with regard to the targeting of budget cuts for disability and independent living services in the local authority. Indeed, if direct payments were to be funded from a separate budget, it is likely that this would not only make provision more susceptible to any future cuts but it would also frame 'independent living' as a specialised service – rather than part of an overall ethos of provision. Therefore, failure to establish direct payments as a mainstream service option may simply result in a recurrence of the funding problems experienced through indirect payments.

Further problems emerged through the recruitment process for the demonstration project. The working group decided that selection for inclusion should come primarily from existing indirect payment users, with additional numbers made up from those on the waiting list and other targeted groups. Immediately, this presented a contrast with

the demonstration project approach used in East Scotland. As first outlined in chapter V, the main purpose of the projects in East Scotland was to 'test out' the limits of direct payments policy – thereby exploring the most innovative use of payments for user groups like those with learning difficulties. Therefore, this excluded anyone already in receipt of a cash payment. Whilst attempts were made to represent specific user groups in West Scotland's projects – mainly by writing to organisations representing sensory impairments, learning difficulties and mental health - this was met with limited success. Moreover, far fewer indirect payment users wanted to be involved than initially envisaged by planners. As the CIL representative remarked, 'there was a feeling from those already receiving one [an indirect payment] of 'at least I've got one' and not wanting the hassle of changing schemes'. Indeed, this type of response was in keeping with the overall user view of the indirect payment scheme in West Scotland (see chapter VII), where despite reduced packages, many expressed the sentiment of 'being one of the lucky ones'. Others did not want to be involved because of a perception of increased responsibility assumed through a *direct* payment route.

Limited interest in shifting schemes from existing indirect payment users provoked another series of problems relating to financing the demonstration projects and again caused further delays in the starting date. As more users were required from the indirect payment waiting list, this re-established local authority concerns over increased costs. For those switching from indirect to direct payments, funding has already been set aside. Therefore the shift requires only a re-routing of contingency funds - *to* the user and *from* the third party organisation - rather than increased overall costs (see chapter V). However for users receiving a payment for the first time, new money is needed. As the CIL representative noted, problems and delays in securing these additional funds again highlighted difficulties in gaining a long-term commitment to policy from the local authority:

> I think there has been a recognition that it would be difficult to start a new package and then come back at the end of the demonstration project and say 'sorry we're not going ahead with it'. So they've had to find money for at least a year so if they don't go ahead they have time to identify an alternative.

Again, this shows another important difference with East Scotland's demonstration project, whereby the local authority had already committed to implementing direct payments by the time the projects were in place. Therefore, users involved in the project had their funds secured on a permanent basis. In contrast, as planners in West Scotland only allow for the availability of short term funding, a question over the future of direct payments in the locality still remains.

Demonstration projects in West Scotland eventually began in July and August 2000. This included a total of eight users switching from indirect to direct payments and six from the indirect payment waiting list. Both figures represent users with physical impairments. Two additional users with learning difficulties were also included. Despite attempts to gain access to other user groups – such as those with sensory impairments and mental health problems (through local support organisations) - no interest was shown through this route.

In the longer term, despite delays and reluctance from senior management in the authority, the lead planner remained convinced that direct payments would be implemented. As he explained, 'I think it's recognised by senior managers that the disabled community in [West Scotland] are very keen to have the option'. Whilst the efforts of the disability movement in West Scotland have clearly aided the momentum to implement policy in West Scotland, he added, '...and sooner rather than later we think it might become a mandatory requirement'. Ultimately, the stronger commitment from central government to develop direct payments may act as the final push to secure policy change.

After completion of the six month demonstration projects a report was to be submitted to the Council, recommending an implementation strategy. From this stage, planners hoped that full implementation of direct payments in West Scotland would occur from April 2001.

Having detailed the main changes occurring in each of the three areas, discussion now moves to explore these shifts by in a wider theoretical context.

Central and local changes: *summarising the recent shifts in direct payments*

Discussion in this chapter has shown how developments from central and local government have affected the way in which direct payment policies are being implemented in the three authorities. From the centre, structural change brings direct payments in line with broader New Labour policy restructuring. This began with the devolution of key areas of government to the Scottish Parliament. Whilst cash payments evolved from the late 1980s within a highly localised framework – with notable contrasts between Scottish and English authorities – devolution has accentuated this differentiation within the UK. As shown, Scottish reform of the original policy guidance (Scottish Office, 1997) has been much slower than in England and Wales. Although this could be seen as a consequence of 'policy overload' for the new legislature, it may also represent the need for new guidance in Scotland to accommodate long standing suspicions of direct payments. From conversations with Scottish Executive planners, this looks to involve a more sustained effort by them to present policy in a 'social justice' or independent living guise – thereby allaying professional fears of service privatisation and job losses (this theme will be returned to shortly). In England and Wales, updated policy guidance issued in 1999 saw direct payments translated into New Labour rhetoric. Wider Blairite themes such as the promotion of 'social inclusion' (Department of Health, 1999, para. 1) were introduced into policy discourse. Likewise, overall changes to policy content and structure remained limited as guidance reaffirmed its commitment to New Right doctrines of cost efficiency, choice and control (Department of Health, 1999, para. 25) and maintained the enabling powers of the legislation.

New Labour's pledge to make direct payments more widely available (Department of Health, 1999, para. 2) has led to an extension of policy to older people in both England and Scotland. This has been matched with a pledge in the 2000 Carers and Disabled Children Act to introduce direct payments to these groups. Parallel legislation will emerge in Scotland after a consultation process. However, despite this renewed focus on proxy control – where in some cases a third party will help users with payment management - updated English guidance failed to develop a substantive clause to increase access for users with learning difficulties. Although a broader emphasis on differential user needs was given in the new guidance (Department of

Health, 1999, para. 19), omission of a specific focus on learning difficulties may prevent a significant growth in access to this group. Indeed the lack of clarity on this issue has been picked up by Scottish Executive planners, who have acknowledged the need to directly address policy access to persons with learning difficulties in their redrafting.

Extending direct payments to a wider user population looks set to have a considerable impact on the construction of user identities as local areas proceed with policy change. As earlier discussion showed, planners in East Anglia have been particularly keen to enable a higher number of direct payments users and ensure policy promotion as a mainstream service option. However, these changes serve to reinforce some of the earlier contrasts in structure and identity roles emerging from user experiences of direct payments (see chapters VI and VII). To recap briefly, since completion of user interviews for this study, there has been considerable local authority investment in developing direct payments as part of an overall independent living strategy has been seen. This may be understood as part of an independent living discourse. Nevertheless, in developing a more individualised and independent service for users to draw on, change also reinforced the compatibility of a strong consumerist dimension within this approach. Consequently, the expansion of the support network looks has consolidated the aspects of consumer control welcomed by users (see chapter VI) by shifting its association further away from a 'collective disability identity'.

However, the construction of direct payment user identities becomes more complicated when examining other aspects of policy alongside changes in East Anglia. The introduction of means-tested service charges is likely to erode considerably the independent living and consumerist policy discourses, as users are penalised financially, and wider participation in employment is made more difficult. This conflicts not only with the demands of the local disability movement, but also with New Labour's national focus on social inclusion. Moreover when placed alongside other aspects of East Anglia's framework for direct payments, a more dominant New Right discourse is revealed. Commentary in chapter VI showed assessment in East Anglia using a rigid measure of personal care needs as the basis for a direct payment. This was matched by a more stringent system of accountability,

focused on attacking 'user abuse'. Therefore, when placing charging, rigid assessment and accountability of payments together, the policy framework shows distinct parallels with the main features of the Conservative Government's social security reforms in the late 1980s. Although local authorities are unfamiliar with giving cash to users, change may be directly linked to the more punitive discourse of welfare reform, where residualisation of individual entitlement to state support was matched with a more sceptical view of benefit claimants (see for example, Moore, 1989). This pushes direct payments away from an independent living agenda. Instead a more prominent political unease from both the Conservatives and New Labour in allocating cash to *any* recipient of welfare services is apparent (Pearson, 2000, p. 473). Consequently, East Anglia's direct payment user identity is moved away from that of an autonomous consumer towards being a recipient of a residualised social security cash benefit.

Whilst East Anglia has seen direct payments promoted in the context of a marketised structure of service planning, in East Scotland the 'anti-market' discourse highlighted at the outset of policy development (see chapter V) has remained a prominent feature. As such, independent living values have failed to become part of service professional's understanding of social care provision. In turn as social work staff remain the initial point of access to potential users, perhaps unsurprisingly direct payments have received a far slower uptake in East Scotland. By sustaining the social worker role as the 'gate-keeper' to direct payments, promotion and access has remained intrinsically linked to individual staff's own conceptualisation of policy. Consequently, direct payments have not been routinely accessed as a mainstream option to community care users. This evidently contrasts with East Anglia, where a more independent and specialised infrastructure has been developed. Indeed, although East Scotland's CIL offers a similar network of services, access is still dependent on individual user contact rather than automatic referral.

It is from these policy structures that a more diverse user identity *between* localities has been sustained. As shown earlier, on one level the development of independent advocacy support, routinely accessed through a community care assessment in East Anglia invokes a more consumerised identity for users. In contrast, users in East Scotland are still required to make their own contact with CIL services to benefit from

their support. As suggested in chapter VI, this makes a more direct association of service support in East Scotland with a collective disability identity. Hence, by limiting the potential to assume a consumer role, users remain lodged in a more dependent social worker-client relationship. However like in East Anglia, wider policy change also affects these constructions of user identities.

Indeed, although both current and potential users in East Scotland appear to be subjected to a more welfarist and dependent policy structure, wider policy changes may, by default, allow for more overall individual control. One example of this comes with the imposition of charging. Because charges are not implemented retrospectively, unlike in East Anglia, direct payment users interviewed for this study will remain unaffected by means-testing. However the coverage of charges - affecting only certain service areas - will result in a differential impact on new payment users. For the majority – those with physical impairments – targeting 'care at home services' looks set to limit employment and wider social opportunities. In these terms, the local authority may be inclined to reassess these policy boundaries. Like East Anglia, planners have also been forced to examine the impact of the 'South Lanarkshire' ruling. As suggested, this has pushed the authority to reaffirm its commitment to individual responsibility and control over direct payments. Moreover, if the Scottish Executive's pledge to inform new guidance through consultation and proceed with a more inclusive policy agenda is enacted, it may enable more individual autonomy over payments in Scotland as a whole. But as suggested, this is reliant on planners eroding fears of service privatisation and engineering an understanding of independent living amongst social work personnel.

Owing to the still precarious position of direct payments in West Scotland, a focus on structure and identity roles in West Scotland is more speculative. However as in East Scotland, fears over service privatisation have remained one of the main checks on West Scotland's attempts to implement policy. As documented throughout this research, policy development has been stifled by this type of anti-market discourse, service cuts from local authority reorganisation and limited disability activism. However more recently, heightened activity from the CIL has enabled a higher profile for direct payments in the local authority and secured funding for demonstration projects. Whilst change has been very slow to emerge and the long term future of

direct payments in the locality still has yet to be confirmed, the local authority's decision to proceed with piloting must be directly equated with increased lobbying by the CIL. Nevertheless, although this shift highlights the importance of activism in gaining a political momentum for the restructuring of services, control over the final decision whether to implement policy or not remains with the local authority responding to wider pressures from central government.

A parallel may be drawn between East Anglia and West Scotland whereby despite sustained campaigning against the introduction of charges, *all* objections were ignored and changes made accordingly. The recruitment process for the demonstration projects perhaps serves to illustrate the boundaries within which indirect payments have been framed and direct payments emerge. This has seen many of the current indirect payment users reject a shift to direct payments *because* of the increased control allowed through the transition. Furthermore, the long-term uncertainty over direct payments in West Scotland may restrict user control to a temporary stage for the individuals involved in the piloting.

Input from other groups has also impacted on potential service restructuring and negotiation of user identities. This has seen lobbying for direct payments by carer's groups. As stated, the perception from the CIL that carers are gaining more political influence not only reiterates the weakness in disability activism but when placed alongside the cuts in existing indirect payment packages, policy implementation may ultimately reinforce direct payment use through a more 'welfarist' or 'care' based discourse.

Indeed, policy development needs to fully integrate some of the wider issues surrounding 'control' and the roles of users and third parties. The lobbying and research base established over the past few years to promote the use of direct payments for persons with learning difficulties (see for example, Holman and Collins, 1997; Holman and Bewley, 1999; Dowson, 1995) provides a useful basis for examining some alternative models of user control in direct payments. This would begin to address the access divide between physical/sensory impairments and learning difficulties and mental health problems. As stated by planners in East Anglia and East

Scotland, policy must allow more flexibility in this area to ensure that a wider range of users can access policy in the long term.

Conclusions

By updating discussion surrounding the development of direct payments since the completion of fieldwork for this study, this chapter has sought to clarify the issues emerging from national and local levels and their effects on structure and identity issues surrounding policy. Overall, change under New Labour has seen attempts to give access to direct payments to a wider population of users and establish policy as a mainstream service option. This has also come at a time when devolution to the Scottish Parliament has accentuated a differential rate of change between local authorities, as Scottish legislation has developed at a much slower rate.

For local planners, these changes alongside other initial problems with establishing direct payment schemes, have presented new challenges. Whilst East Anglia has shown the most progress in developing direct payments as a mainstream option within a wider structure of independent living services, rigid assessment, tighter user accountability and the onset of charging for direct payment users have substantially eroded the social justice underpinnings of policy. Conversely, restricted use of direct payments in East Scotland and delayed implementation in West Scotland, still remain intrinsically linked to anti-market discourses and a lack of understanding of independent living emanating from senior management and social work personnel. Therefore, although in each of the three areas disability activism has played a vital role in securing policy change, the limits of their influence remain prescribed by planners. Although extending access to groups such as carers and parents of disabled children is undoubtedly a positive move, discussion concludes by suggesting that policy development needs to encourage a more in depth appraisal of issues such as user control to eliminate a divide between discourses of 'care' and individualised control.

Notes

[i] Exact figures cannot be given as East Scotland has had practical problems with its audit system.
[ii] Figure correct at the time of policy development update discussion with planner – autumn 2000.

[iii] This relates to the rule in East Scotland stipulating that direct payments cannot be given to any one currently in receipt of a local authority service (see chapter V for more details).

[iv] At the time of policy change, the Conservative Party formed the majority in the Council.

Chapter IX: Discussion and conclusions

Introduction

ONE OF THE KEY AIMS established at the outset of this thesis was to present the emergence of direct payments legislation as a unique example of a social policy which offers its users 'empowerment through cash'. However as discussion has shown, the emergence of policy – including changes made through indirect payments – has incorporated far wider theoretical and analytical shifts which, in turn, contribute significantly to the overall restructuring of welfare. This final chapter seeks to clarify these changes by summarising the main findings highlighted in this research.

Discussion is divided into two main sections. These broadly focus on the key issues outlined in the research questions underpinning this thesis (see chapter IV) and are followed by a final summary of the central themes of this research.

Understanding and implementing direct payments

The importance of understanding direct payments in relation to structure and identity issues has been strongly advocated throughout this thesis. Accordingly, the following section summarises the impact of the main discourses underpinning policies in each of the three areas used in the study.

Payments and policy implementation: an overview

By exploring policy responses to direct payments in three different locations, findings have highlighted three distinctive approaches to implementation of direct payments legislation. Difference between user experiences has been found not only to be dependent on whether a local authority implements the legislation, but also on the way in which this is done. Consequently, this has emphasised *diversity* in the experiences of different groups of users and *localisation* of policy in how the key discourses have been used to underpin change. To re-cap at this stage, East Anglia was seen to react quickly to change - drawing on a tradition of indirect payments, lobbying from an active disability movement and a local authority committed to developing a 'local care market' in response to the 1990 NHS and Community Care

Act. Consequently, a relatively high number of users accessed direct payments over a short period of time. Although also keen to use their experiences of indirect payments as a basis for policy development, East Scotland reacted to change more slowly but with progress integrating local disability activism over the past decade into the direct payments planning strategy. The scheme now in place includes mainly former indirect payment users, but wider implementation of policy as a mainstream option has proved more difficult to achieve. In West Scotland, the local authority has remained uncommitted to fully implementing direct payments. Whilst indirect payments have been offered, the scheme has been subjected to budget cuts over the past few years and has not taken on any additional users throughout this time. Although now more active in promoting policy change, local disability groups have traditionally only played a limited role in raising the profile of issues in the area. From these broadly contrasting positions, the key issues and impact of dominant discourses underpinning these policy responses are summarised and discussed in more detail in the following section.

The meaning of direct payments: independent living and market discourses

This research has explored how independent living and market discourses impacted on policy development at central and local government levels. This has also required a focus on the impetus for policy change from a growing disability movement and more specifically through the work of CILs, with calls for change made both nationally and locally. This idea was set in place in chapter II as direct payments were introduced into the network of state support for disabled persons and expanded upon in chapter III through a more detailed appraisal of the policy background. Discussion at this stage showed how local cash payment initiatives led to a more formal adoption of policy through the 1996 Community Care (Direct Payments) Act. To re-cap briefly, campaigning for direct payments became a core demand from an expanding disability movement across the UK in the late 1980s and early 1990s. This centred on the premise of user control and empowerment offered by directly providing cash to users. Whilst initial hostility to policy from the Conservative Government centred on fears over cost-efficiency and accountability for public monies, disability activists sought to challenge this position through a research base in order to highlight the enhanced flexibility and control offered to users. As BCODP/PSI research findings (Zarb and Nadash, 1994) showed, the potential for cost savings through cash payments, a more

favourable response from the Conservative Government and a repositioning of policy support emerged. Consequently legislation for direct payments was adopted. However rather than enforcing mandatory implementation from the outset, local authorities were given the option to develop schemes as policy was promoted as part of a wider consumerist agenda in community care planning.

Market freedoms?

Writing in 1991, C. Barnes suggested that the disability movement had something to gain from both the political left and right. Certainly, the legislative path to direct payments broadly supports this contention – whereby at face value key concepts such as 'control' and 'empowerment' have been linked in with both the New Right and disability movement's own definitions. However as local planning issues have been explored more specifically in each of the three areas used in this research, a clearer picture of the relationship between these two positions has emerged. In East Anglia – a traditionally Conservative (although New Labour at the time of fieldwork) controlled authority – the most comprehensive and widely used direct payment scheme was shown. Underpinning this scheme was the flexibility offered to users by the local authority's use of 'marketising' individual packages through the community care assessment procedure. In other words, new and old users were offered a wider range of hours to meet their assessed needs. Furthermore, in keeping with the *enabling* model offered through the original community care framework, the local authority role was narrowed to organising the direction and (residual) funding of policy. This has opened up a more formal role for the local CIL. Indeed, not only has collective action played an integral part in initially securing policy change, but this role has formed a new and innovative part in the overall service framework for direct payment users. This has seen the CIL automatically involved in providing users with specialised individual support in managing their transition to direct payments, demonstrating a commitment to independent living in policy planning. However, this became substantially weakened by the prominence of more traditional New Right values. Notably, the shift to a more stringent and sceptical system of accountability for direct payment users suggested that the local authority was uncomfortable with its new responsibility of allocating cash. It may also be argued that the approach adopted by the authority echoed the more punitive era of social security monitoring established in the late 1980s. Similarly, the onset of means-tested charges repositioned

direct payments away from an independent living model and towards a more residualised welfare policy. This will be returned to shortly.

For local authority planners in East Scotland, whilst a long term planning partnership with the local disability movement had been maintained – resulting in establishment of the first cash payment scheme in Scotland – direct payment use has also been ultimately determined by market relationships. As detailed in chapter V, senior managers were not willing to pursue direct payments as a service option for all users if it led to job losses. Therefore in contrast to East Anglia, direct payment access to a wider user population has been limited by an *anti*-market discourse, which prevents existing local authority service users from entering the scheme. Consequently, access to policy for those already in receipt of a local authority services has been denied in order to protect the local authority's role as a service provider in the local 'care market'.

Whilst East Scotland developed its direct payment scheme within the confines of an anti-market discourse, similar resistance in West Scotland contributed to the local authority's failure to implement policy. In this area, despite offering one of the few indirect payment schemes in Scotland, a combination of anti-market resistance, a chaotic aftermath of local authority reorganisation and a weak disability movement resulted in only a cash limited indirect payment scheme based strongly on a 'welfarist' discourse of 'care'. Again, this is an issue that will returned to later in this chapter.

The apparent difficulties of dealing with local authority attachments to service provision as well as scepticism of direct payments as a privatisation tool have also been picked up by Priestley (1999). Although drawing on research carried out prior to implementation of direct payments, he argues that local authorities with a strong attachment to collective service provision have faced a 'dual assault'. On one side, this has come from disability groups pushing for service reorganisation in line with an independent living ethos and on the other, from a central government drive to establish local 'care markets' (Priestly, 1999, p. 119). This position has been complicated further in a Scottish context as the emphasis on marketising community care services has been less acute than in England and Wales (see for example,

Maxwell and Titterton, 1996). Such differentiation within the UK has allowed Scottish local authorities to maintain more service provision within the context of community care. Given the market discourse through which the Conservative Government adopted direct payments, it is perhaps unsurprising that more traditional 'Old Labour' authorities like East and West Scotland have raised ideological resistance to integrating direct payments as part of mainstream service provision. For West Scotland in particular, the combination of a weak disability movement and local authority fears of privatisation have proved to be an effective alliance in delaying policy change. However as chapter VIII highlighted, more recent cohesive action from the local CIL – resulting in a piloting stage for direct payments – coupled with a heightened profile for direct payments from central government, looks set to place strong pressure on the local authority to formally adopt direct payments in the long term.

Using cash payments: issues for users and planners

As the focus of chapters VI and VII shifted to examine the user view of cash payments in three areas more carefully, this section provides a final overview of how dominant understandings of direct payments affected user and planning roles in direct and indirect payment schemes.

As chapter VI began to address the broader implications of local shifts to cash payment schemes (both direct and indirect), enhanced user control and flexibility in day to day living emerged as a consistent theme. However, whilst schemes were shown to be almost universally successful in attacking what was termed as *structured dependencies through service provision*, access to policy information proved to be more problematic. In these terms, a general inconsistency in service professional knowledge and understanding of the independent living model became apparent. To some extent, East Anglia was able to overcome this through the automatic involvement of their CIL at the early stages of organising payment packages. This allowed the CIL to operate in a 'service broker' role. As such staff worked with users, helping them to maximise payment flexibility, but in a way that many interpreted as being detached from a disability identity. However in East and West Scotland, a clear gap was exposed by users between the ethos of support espoused by CIL workers and those of social work professionals. Furthermore, as some of the planners described,

professional views of cash payment schemes often drew on individual fears of direct payments as a means of privatisation and attacking local authority jobs or as an added burden on users. Given that social workers formed the first point of call for most users, effective access to direct payments in areas where policy is adopted may only be achieved if professionals have a clear understanding of the principles of independent living informing change. Clearly, this is an issue that merits more direct research with service professionals themselves, but it was a perception presented consistently by users and planning staff. Moreover in both East and West Scotland, although a range of support services were offered, contact with the CILs was dependent on individual user involvement. In these terms, users often equated the CIL role with a more overtly politicised and collective disability identity. Whilst some users were keen to involve themselves with this type of identity, others clearly rejected it.

Breaking down the 'cash and care' divide?: Payments, 'care' and consumerism

Direct payments were introduced as an alternative service option to directly provided community care services. As emphasised throughout the thesis, the benefits of increased user flexibility and control are clear with either mode of cash payment, however the structural constraints framed by national and local planners have undoubtedly eroded their full potential. In other words, for most users receipt of a cash payment on its own was not considered enough to secure independence. Once again to briefly re-cap, although East Anglia allowed for a more wide ranging structure of payment packages – from just a few hours per week to 24-hours support and with users able to mix their payments with other areas of social service provision - assessment was rigidly quantified in limited personal care terms and subjected to strict accountability and eventual means-testing. Therefore whilst users in this area appeared to use their payments to participate more widely in day to day living, their expectations were higher. Moreover, those using their payment to access support in employment stood to lose most from the implementation of means-tested charges. This resulted in many users citing structural constraints from the local authority as the main check on their independence.

In East Scotland, the range of hours in payment packages for those interviewed was far more restrictive. This also drew strongly on a limited focus on 'care', as the

interaction between personal care and other areas such as employment was only apparent for those with 24-hour support or those involved in the demonstration projects. Although the demonstration projects provided a useful example of how direct payments could be successfully used by persons with learning difficulties, widespread expansion to those currently in receipt of local authority day care was disallowed because of the council's desire to retain control of this area of service provision. As in East Anglia for new users entering the scheme, a means-test was to be enforced – thereby restricting employment incentives. However, users appeared to be more content with their support than their counterparts in East Anglia. Individual conceptualisations of independent living drew much more strongly on positive structural factors of flexibility and control offered by the payments and most users were largely uncritical of the local authority role. Indirect payment users in West Scotland offered a similar appraisal of independence, although many drew on a much stronger focus on 'care' and a medicalised view of disability. Chapter VII offered some speculation as to the differences in user expectations and their constructions of independence. Although users in East and West Scotland were older on average than in East Anglia this may have provided only a partial explanation of the differences found. Political affiliation and traditional ('Old Labour') support for the 'local welfare state' – alongside the limited interest among professionals in accessing payments - may offer alternative dimensions for understanding individual responses.

In a critique of the 1990 community care reforms, Richard Wood (1991) was one of the leading voices to argue that disabled people did not want or need care. Instead, he called for personal assistance - through direct payments - to allow disabled people to live more independent lives and achieve their own goals. Although more recent critiques of care by Shakespeare (2000) and others (see chapter II) have redefined the concept of care and emphasised its importance in the context of *interdependency*, it still remains problematic for all groups when support services are inadequate to meet basic needs. Nearly ten years on from the implementation of community care, despite the availability of direct payments in some areas, findings from this research would suggest that restricted packages of personal care remain common to the overall policy experience of users. If disabled people and increasingly other groups like parents of disabled children and carers are all to maximise their independence, personal assistance per se is not enough – policy needs to both adequately cover individual

needs and to be positioned in a more empowering framework of state support. Therefore direct payments must not be restrained either through interaction with other policies (such as means-tested charges or benefits such as ILF) or resource limited community care assessment procedures.

At a wider structural level, discussion briefly returns to ideas put forward in chapter II by Fitch (1995). He suggested that the advent of consumerism placed a fundamental challenge to the 'cash and care' divide in state support for disabled people between central and local government - thereby raising the possibility of a new framework. Clearly, all three cash payment schemes examined in the study have at least in part been developed through the rhetoric of user control, and the versatility of having a cash payment allowed most users to participate more fully in day to day living. Moreover, in chapter VII examples were shown where users also in receipt of ILF funding welcomed the increased flexibility gained from receiving two main cash payments to buy in their support. However the possibility of entering or re-entering work had been largely dismissed because of the position of the ILF as a means-tested benefit. Whilst there have been changes in the administration of 'cash and care', the underlying issues of dependency informing state support still remain broadly unchallenged. Consequently as commentary in chapter VII suggested, this positions direct payments as part of a transition to 'consumerised care', rather than as a framework for a fundamental shift towards independent living.

Being a cash consumer: changing disabling identities?
Whilst local authority planning relationships with market discourses in developing schemes have proved to be highly variable across the three areas, chapter VI showed the shift to a consumerist or employer identity was largely welcomed by *all* users. Central to its success was the choice and flexibility offered by the transition and role of 'being an employer'. In these terms, this may be seen as the main victory for both direct and indirect payments and indicative of an important identity shift both in terms of day to day organisation of support services and the conceptualisation of a 'disability identity'. For C. Barnes (2000), this not only has implications for the disabled person *as* an employer but, he argues, such a role needs to understood as part of a wider reappraisal of 'work' and its position in a 21st century labour market:

> [There should be]…recognition that regardless of their role within the 'conventional' labour market, people with accredited impairments and labelled 'disabled' are both producers and consumers of a vast array of services upon which many so called 'able bodied' people depend.

> (C. Barnes, 2000, p. 21)

As commentary in chapter VI indicated, a number of issues emerged which must be addressed particularly in the context of developing a disability identity based on 'production'. Firstly, users in each of the areas told of difficulties in finding the right staff to employ as PAs – and in some cases this proved to be the major draw back to their experience of cash payments. This was reiterated by the lead planner in East Scotland, who raised concerns regarding the local service sector's long term ability to meet the needs of a growing number of direct payment users. In turn, this links into a second area whereby the importance placed on being a *good* employer was emphasised by a number of users. Therefore as C. Barnes and planning personnel in this study have implied, if the real potential for employment expansion through personal assistance is to be realised, local authorities must be able and prepared to fund a competitive pay rate and support services. Underpinning these proposed changes is the need to promote the role of the disabled employer more positively – particularly in light of the negative press received through the South Lanarkshire ruling.

Direct payments: future agendas, concluding comments

Since implementation of direct payments in 1997 and, indeed, the undertaking of this research, direct payments have begun to appear more extensively both in a range of policy studies (see for example, Hasler *et al*, 1999; Ungerson, 1999; Glendinning *et al*, 2000; Witcher *et al*, 2000 and Maglajlic *et al*, 2000) and on the policy agenda. As chapter VIII indicated, more recently direct payments have been promoted as a model of community care service provision for an extended user population. Indeed areas resistant to change – like West Scotland – look set to face increasing pressure from central government levels to finally proceed with policy implementation. However, findings from this research would suggest that unless central government departments and local planners promote policy more enthusiastically and evenly, direct payments will remain marginalised as a service option – particularly in Scotland. Clearly, there

is scope for 'third parties' such as carers and parents of disabled children to benefit from direct payments, alongside a more supportive structure for users with learning disabilities but these roles must be developed in the context of individual autonomy and control for *all* parties. Moreover, if this policy rhetoric is to be promoted at a meaningful level, this will require a thorough examination by central and local government of the position of direct payments in the wider spectrum of state support for disabled people.

Similarly, effective policy use will be reliant on local authorities embarking on wide scale education of service professionals – equipping them with a full understanding of direct payments as a means to achieve independent living. As local authorities begin to evaluate the cost-effectiveness of the transition to direct payments, any savings made through this shift need to be re-invested in providing the necessary infrastructure for user support. Inevitably, this returns to a focus on local authority relationships with the market. In these terms, disability activism must continue to remain involved in promoting the evident advantages of direct payments for users and to develop their role in sustaining a framework of advice and user support.

Market and independent living discourses need not be incompatible in the implementation of direct payments, but a balance needs to be struck between the two. There needs to be a clearer understanding of the points of tension, as well as agreement, coming from these distinctive policy traditions.

Appendix I

Sample access letter sent to cash payment users *(letters sent through the CIL in East Anglia and Social Work Services Departments in East and West Scotland)*

Date

Dear Sir or Madam,

Strathclyde Centre for Disability Research: Independent Living Project

I am a researcher at the Strathclyde Centre for Disability Research and am interested in hearing the views of people in [area] who use [direct payments]/[independent living schemes[i]]. I would like to arrange brief interviews with as many people as possible to informally discuss their experiences. I hope to use the findings as part of my Ph.D research and to inform policy planners of user's views and experiences as [direct payments]/[independent living schemes become more widespread.

If you feel you might be interested in taking part please complete the form overleaf and return to me in the enclosed stamped addressed envelope and I shall contact you in the near future.

Many thanks for your help.

Yours faithfully,

Charlotte Pearson

Discussing your views of [direct payments]/independent living schemes:

These meetings could be arranged as home visits or at a mutually convenient location:

I would/would not be interested in meeting to discuss my views/experiences of independent living *(please delete as appropriate)*:

Name:... ... ...

Address:... ... ...

... ...

... ...

... ...

... ...

**Contact
phone number:**... ... ...

All information will be treated in strict confidence

Thanks for your help with this study

For further information please contact:
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Lilybank House
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G12 8RT
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Appendix II

Interview schedule for user interviews

Background information
Could you tell me a bit about yourself? (Frame around the following areas):

- age
- employment
- interests
- family/friends
- living arrangements
- day to day activities
- social/leisure interests
- group memberships

Receipt of cash payment:

- how long has payment been received?
- how was scheme heard about?
- why/when was change made – explore reasons around changes:

- previous service provision
- personnel involved (explore professional roles)
- why change seemed appropriate,
- expectations

- differences before and after payments (relate back to earlier categories if appropriate)
- problems experienced (may relate to employer issues)

Being the employer:

- explore issues around finding a personal assistant
- advantages
- disadvantages
- role/tasks – also ease of asking
- privacy
- defining the relationship – explore friendship/employer balance
- any changes?
- future roles?

Views on independent living:

- What does 'independent living' mean to you? (Do you feel you have an independent life?)

- Is independent living achievable?

- Explore barriers/benefits and relationship with cash payment

Appendix III

Summary of key user characteristics[ii]: *East Anglia*

Name	Gender	Age	Paid employment
Anne	Female	40-44	No
Claire	Female	25-29	No
David	Male	30-34	Yes
Helen	Female	55-59	Yes
Ian	Male	35-39	No
Jean	Female	50-55	No
John	Male	45-49	Yes
Jonathan*	Male	30-34	No
Joyce	Female	55-59	No
Natasha	Female	30-34	No
Peter	Male	35-39	No
Richard	Male	40-44	Yes
Tim	Male	40-44	No
Tom	Male	40-44	Yes
Tony	Male	40-44	No

Interview was carried out with Valerie, mother of Jonathan

Appendix IV

Summary of key user characteristics: *East Scotland*

Name	Gender	Age	Paid employment
Andy	Male	35-39	Yes
Bill	Male	60+	No
Carol	Female	45-49	No
Deborah	Female	25-29	Yes
Duncan	Male	45-49	No
Elsa	Female	60+	No
Emily	Female	30-34	No
Frank	Male	60+	No
Jane	Female	30-34	No
Janet	Female	55-59	No
Jim	Male	35-39	Yes
Karen	Female	30-34	No
Louise	Female	25-29	Yes
Lynn	Female	40-44	Yes
Maureen	Female	60+	No
Morag	Female	60+	No
Paul	Male	45-49	No
Simon	Male	25-29	Yes
Susan	Female	60+	No
Stewart	Male	45-49	No

Appendix V

Summary of key user characteristics: *West Scotland*

Name	Gender	Age	Paid employment
Alison	Female	55-59	No
Barbara	Female	55-59	No
Elizabeth	Female	60+	No
Derek*	Male	45-49	No
Fiona	Female	35-39	Yes
Margaret*	Female	55-59	No
George	Male	55-59	No
Hazel	Female	60+	No
Heather	Female	35-39	Yes
Kate	Female	30-34	No
Kathleen	Female	60+	No
Moira	Female	50-54	No
Pam	Female	40-44	No
Pauline	Female	55-59	No
Sally	Female	30-34	No
Suzanne	Female	45-49	No

* Interviews for pilot stage only

Notes

i Whilst West Scotland's scheme is referred to as 'indirect payments' throughout this thesis, many users are more familiar with the name 'Independent Living Scheme' – therefore this term was used in access letters.

ii All names have been changed to protect individual anonymity.

Glossary

Throughout this research every attempt has been made to follow the definitions of impairment and disability used by the disabled people's movement. These are:

Impairment: lacking part or all of a limb, or having a defective limb, organism or mechanism of the body.

Disability: the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from the mainstream of social activities (UPIAS, 1976, cited Oliver, 1990, p. 11).

The following abbreviations are used throughout this thesis after being cited in full the first time they appear in the text.

AA   Attendance Allowance

ADA   Americans with Disabilities Act

ADSS   Association of Directors of Social Services

BCODP   British Council of Disabled People

CIL   Centre for Independent Living

CORADP   Committee on Restrictions Against Disabled People

DA   Disability Alliance

DIAL   Disability Information and Advice Line

DIG   Disability Income Group

DHSS   Department of Health and Social Security

DPI   Disabled People's International

DPTC   Disabled Persons' Tax Credit

DSS	Department of Social Security
DWA	Disability Working Allowance
FC	Family Credit
HNCIP	Housewives Non-contributory Invalidity Pension
IB	Incapacity Benefit
ICA	Invalid Care Allowance
ILF	Independent Living Fund
ILT	Independent Living Transfer
IS	Income Support
ISB	Invalidity and Sickness Benefit
NCIP	Non-contributory Invalidity Pension
OPCS	Office of Population and Census
PA	Personal Assistant
PSI	Policy Studies Institute
RADAR	Royal Association for Disability and Rehabilitation
UPIAS	Union of the Physically Impaired Against Segregation
VIA	Values into Action
VOADL	Voluntary Organisation for Anti-Discrimination Legislation

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