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**A comparative study on the effects of community care
charging policies for personal assistance users**

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Abstract

The purpose of this qualitative study was to examine the effects of community care charges for personal assistance users. This was achieved through establishing the views of personal assistance users on charging policies; how they impacted upon the lives of personal assistance users and level of choice and control personal assistance users have over the support they are paying for.

Six semi-structures interviews were held with key informants from both England and Scotland, since the two countries have different sets of guidance on community care charging. This was accompanied by an extensive review of available literature on the subject.

This dissertation argues that the barriers to independent living created by charging are partly caused by weaknesses in the charging policy guidance for both England and Scotland, resulting in local authorities interpreting this guidance differently. Also the community care assessment does not afford personal assistance users complete choice and control over the support they receive and how they receive it, even though they end up paying for it.

If charging is to remain then personal assistance users should be given the right to accessible information. The Scottish limit on capital should be increased to the same amount as the English limit, and ideally the limits on savings imposed by both the ILF and all local authorities should be either substantially increased to enable personal assistance users to save for a deposit on a home or a vehicle, or removed altogether. Savings accounts specifically for purchasing disability-related equipment and adaptations should be disregarded, as should student loans, grants and other education-related income.

Charging policies should not charge on the basis of employment-related state benefits, occupational pensions or earned income, as this indirectly creates a disincentive to work. Finally the assessment of disability-related benefits has left personal assistance users with insufficient income to cover their disability-related expenditure, therefore an additional benefit should be created to cover disability-related expenditure, leaving the DLA 'care component' to pay for personal assistance.

However all of the participants concurred that the best way of removing the barriers to independent living created by charging is to abolish it altogether.

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Chapter 1: A Cost to Living Independently

This introductory chapter will begin by addressing the background, relevance, aims and objectives of this study, setting out the structure of the rest of the dissertation. It then provides background information on the development of both independent living and personal assistance funding schemes in the UK.

Background

As a personal assistance user who receives funding from the Independent Living Fund and my local authority's direct payments scheme, I am affected by charging policies. From personal experience I have found that charging has created a number of barriers to independent living. Variations in charging policies, with some local authorities opting not to charge at all, affect where I decide to live. I may be charged for the full cost of my support if I have capital above a certain threshold, thus preventing me from saving for the future. In addition, charging impacts on my level of disposable income and my ability to cover the cost of my disability-related expenditure. Therefore this study has particular relevance to both me and others in a similar situation.

Aims and Objectives

The purpose of this study is to examine the effects of 'community care' charges for personal assistance users. To establish whether charging creates barriers to independent living, the following research questions will be addressed:

- What are the views of personal assistance users on charging policies?
- How do charging policies impact upon the lives of personal assistance users?
- What level of choice and control do personal assistance users have over the support that they are paying for?

In order to answer these questions, key informants from both England and Scotland will be interviewed, as there are significant differences between these two countries guidance on charging (DH 2003; COSLA 2006). It is hoped that this study will demonstrate that charging is counter-productive to the community care policy objectives of promoting individual choice and self-determination (Priestley, 2004a).

Organisation of this dissertation

To provide a background to the current situation, the remainder of this chapter gives an overview of independent living and sources of funding available for personal assistance.

With reference to a wider body of research, the second chapter examines the development of charging policies in England and Scotland, ethical issues around charging personal assistance users, the effect on their lives and the legitimacy of taking disability state benefits into account when charging.

The third chapter documents and discusses both the methodology and data collection strategies used for the study.

The fourth chapter compares the amount of choice and information available to personal assistance users with that available to both other consumers and council tax payers. It argues that if charging was treated as a legitimate commercial transaction, then personal assistance users would have the same protection under the law as any other consumer.

The fifth chapter examines the barriers to accessing higher education, employment, geographical mobility, pensions and savings created by charging. It concludes that charging policies are based on the

assumption that personal assistance users will not lead as full lives as non-disabled people.

The sixth chapter investigates how charging takes income that would otherwise be spent on both meeting the additional costs of disability and day-to-day living costs. Because of this some disabled people opt not to accessing the support they need. It concludes that charging constitutes an infringement of human rights and a barrier to social participation and social inclusion.

The final chapter identifies key issues that have emerged and presents policy implications. It argues that, for personal assistance users to achieve independent living, their disability-related costs must be met and they should not be financially penalised through charging.

Independent Living

The independent living movement started in Berkeley during the sixties, when a group of disabled students came to recognise their own right to self-determination and self-respect (Driedger 1989; Barnes 2004; Hasler 2004; Mercer 2004; Gillinson *et al* 2005). This led to the birth of the first Centre for Independent Living (CIL), which enabled them to lead full and active lives similar to their non-disabled peers. Meanwhile in the UK a consumer group of physically impaired people was formed (Campbell

and Oliver 1996). The Union of Physically Impaired Against Segregation went on to formulate the social model of disability (UPIAS 1975; Oliver 1983), the theoretical basis for the campaign of the British independent living movement for human and civil rights. The social model distinguishes the biological (impairment) from the social (disability), asserting that it is the organisation of society which disables people with impairments.

Disabled people have persistently challenged the concept of 'community care' (Finkelstein 1999; Barnes and Mercer 2003a; Priestley 2004a). With respect to independent living this term is not helpful, as 'community' suggests life outside a residential institution and 'care' implies a sense of a need to be looked after (Morris, 1993). Therefore the implication is dependence upon the community (Barnes, 1991; Morris, 1993; Oliver and Barnes, 1998). It is also misleading, confusing feelings of sentiment with the provision of assistance whilst failing to acknowledge that disabled people are disadvantaged through society's failure to meet their requirements (Barnes 2001). It can mask the control that operates in many relationships where one person is substantially dependant on the other (Swain *et al* 2003). Shakespeare (2000: ix) states that the term "is value-laden, contested and confused, particularly in the way it combines an emotional component and a description of basic human services." From an independent living perspective the word

is patronizing and misleading, as it implies that disabled people can never achieve any degree of independence:

Disabled people have never demanded or asked for care! We have sought independent living which means being able to achieve maximum independence and control over our own lives. The concept of care seems to many disabled people a tool through which others are able to dominate and manage our lives. (Wood 1991: 199, cited in Shakespeare 2000)

Independent living as defined by disabled people has challenged professionals' equating the term with self-sufficiency, since this is an unnecessary, unproductive and an unreachable goal for many disabled people (Brissenden 1986; HCIL 1990; Morris 1993; Shakespeare 2000; Swain *et al* 2003; Barnes 2004; MacFarlane 2004; Mercer 2004; Stewart 2004). Brissenden (1989) asserts that this practice:

teaches us that unless we can do everything for ourselves we cannot take our place in society. We must be able to cook, wash, dress ourselves, make the bed, write, speak and so forth, before we can become proper people, before we are 'independent.' (p. 9, cited in Morris 2003a)

Instead the movement has defined independent living as having control over how support is provided, who provides it and when (MacFarlane 2004). Practical assistance should be available to enable disabled people to make their own choices and achieve their aspirations (DRC 2005).

Funding Personal Assistance

The use of personal assistants (PAs) was identified as a basic requirement of disabled people if they are to achieve independent living (Davis 1990). Cash payments are the best way of paying for PAs because they give the maximum amount of choice and control (Zarb and Nadash 1994; Hasler 2004; Ellis 2005).

Up until 1986 many disabled people had begun to live independently using money from either their local authority or 'Domestic Care Allowance'. When the Government withdrew this benefit disabled people organised a campaign to challenge the decision, resulting in the creation of the Independent Living Fund (ILF). This is a national fund which provides money specifically to enable disabled people to live independently (Morris 1999; Pridmore 2006).

Direct payments schemes became legal in the UK on April 1st 1997 through the enactment of the Community Care (Direct Payments)

Act 1996. Direct payments are budgets from local authorities with which someone, who has been assessed for 'community care' services, can buy the services they need to take control of their lives and live independently in the community (Pridmore 2006). The requirements of direct payments users are assessed by social services in the same way that they would be assessed for direct services. Based on this assessment, users are provided with regular cash payments instead of services. They can use this payment to purchase personal assistance, such as washing or dressing; and assistance with household tasks such as cleaning or laundry. Direct payments users can also receive money from the ILF providing they are getting more than £200 per week in local authority funding.

Conclusions

The ILF and direct payments enable disabled people to decide what, how and when they receive assistance (Carmichael *et al* 2002; Hasler 2004; Maglajlic *et al* 2000; Stainton and Boyce 2004). However they fall short of the movement's goal of a right to independent living. For example, the extension of direct payments to carers has taken choice and control away from some disabled people, thus weakening the link to independent living (Hasler 2003). Some local authorities have used a narrow interpretation of the legislation, only allowing the purchasing of support in the form of a personal assistant with a direct payment (Hasler

2003; Pearson *et al* 2006). Payments may only cover limited tasks in a person's home, rather than allowing them to go out or get to work (Pearson *et al* 2006). There is evidence of ignorance around the principles of independent living in social workers (Hasler *et al* 1999; Pearson 2004; Pearson *et al* 2006). Market forces and the privatisation of care services are threatening the continued existence of user-led support organisations (Barnes and Mercer 2003a). Finally means testing and charging can deter disabled people from using personal assistance (Lamb and Layzell 1995; Holmes *et al* 2003; Priestley 2004b).

Chapter 2: A Tax on Disability

This chapter reviews available literature concerning charging, focusing on the development of charging policies, the ethics and effects of charging personal assistance users for essential services; and the validity of charging assessments examining disability benefits.

The Development of Charging Policies

Government allocates funding for services on the assumption that 9% of domiciliary services revenue will be met through charging service users (Priestley 1999). Local authorities have the option to charge Direct Payments users under section 17 of the Health and Social Services and Social Security Adjudications Act 1983. This gives them discretionary powers to charge for 'social care' but not 'health care'. However the act also states that they should not require disabled people to pay more than is "reasonably practicable."

A Royal Commission was established in 1997 to look at the funding of long-term care, concluding:

The costs of care for those individuals who need it should be split between living costs, housing costs and personal care. Personal

care should be available after an assessment, according to need and paid for from general taxation... (Royal Commission on the Funding of Long Term Care 1999: unpagged)

This conclusion was rejected by the Government for England (DH 2000). Minister John Hutton advocated an alternative of improving services and support for 'carers' with revenue raised from charging, stating:

I do not believe that making personal care universally free would help us in achieving any of those objectives. (Hutton 2001)

However money raised by charging does not necessarily contribute towards providing additional / better services, as it becomes part of the overall budget for all local authority services (Campbell *et al* 2002). Therefore it is just as likely that this money will fund other services such as education, refuse collection, etc.

In 2002 the Scottish Parliament accepted the recommendation of the Royal Commission and implemented free 'personal care' for older people. This has created a fairer system without undue extra public spending and supported a greater number of older people to stay in their own homes, whilst not leading to the feared reduction in informal support

provided by relatives and friends (Bell and Bowes 2006). In 2006 the Welsh Assembly decided to renege on the commitment in New Labour's election manifesto to provide free 'home care' in Wales, based on a projection of the cost (Coalition on Charging Cymru 2006; Bell 2006).

The Audit Commission recommended that guidance be issued in order to ensure a consistent approach (Carpenter 2000). But although guidance was published for England by the Department of Health (DH 2003), different guidance was published for Scotland by the Convention of Scottish Local Authorities (COSLA 2006). The former states that Direct Payments users should be charged as if they were receiving equivalent direct services (also see DH 2005), whilst the latter does not address this issue.

Since 2002 earned income has been disallowed by the means tests conducted by the Independent Living Fund and local authorities in England (DH 2003), but not Scotland (COSLA 2006). The policy for England was changed as a response to evidence assembled by the Joseph Rowntree Foundation (Kestenbaum 1998; Howard 2002) and political lobbying by key disabled activists (Morris 2005a). However its aim of avoiding disincentives to work is effectively negated by the means test for the Disabled Facilities Grant which fails to disregard earned income (Prime Minister's Strategy Unit 2005).

The Ethics of Charging

It is wrong to raise money for public services solely from the people who use those specific services; a fairer and more efficient way to raise funds is via taxation (Campbell *et al* 2002). Many disabled people feel that charging is a tax on disability (Mason 1999; NCIL 2000; DCIL 2001; Elder-Woodward 2001; Holmes *et al* 2003), an additional financial penalty directly related to impairment and the need to use services. Unlike other taxes, the contribution to the cost of public services can be increased almost without limit through charging (DCIL 2001). Elder-Woodward (2001) makes the point:

Don't we pay our Community Charges, just as anyone else? Don't these taxes pay for council services, including social work? So why should one service be free at the point of delivery and not another?
(p. 11)

Policies which charge according to the amount of support provided are hitting hardest those with the highest level of impairment (Mason 1999; Campbell *et al* 2002) and therefore have very little scope to reduce or withdraw from services (Chetwynd *et al* 1996). Mason (1999) feels that by society not accepting responsibility for the disadvantage faced by

disabled people by paying the full cost of their support, it is heading back to the philosophy of Social Darwinism and 'survival of the fittest':

More profoundly the sentiment behind means-tested charges lifts a veil on the less attractive side of society's attitude towards its disadvantaged - and says 'we cannot afford you', 'you are worthless'. So opening the door to (generating the suitable climate for) the now regular public considerations of measures to 'rid' society of 'these dependants'. (p. 265)

He goes on to suggest that as demand has grown for 'community care' services, so too have practices to ration them by increasing the eligibility criteria; restricting the services available or simply delaying the whole response process. Unofficially local politicians admitted to Mason that charging is used as a way of limiting the demands on services. However this promotes greater dependency on family and friends since changing the criteria for a service does not nullify the existence of impairment or need.

The right to independent living is a human right, as opposed to a civil or even constitutional right (Morris 1993; Campbell 1997; Hasler *et al* 1999; Holmes *et al* 2003; Houston 2004). This of course calls into question both the moral and legal justification for barriers to autonomy

such as means testing, charging and budgetary restraints (Ellis 2005). Indeed Campbell *et al* (2002: unpagged) argue that current charging guidance

may contravene the Human Rights Act because Article 25 of the Universal Declaration says: Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of... disability... To provide services such as education, policing, etc. without charging and then to charge for those services that provide "security in the event of disability" is discrimination.

Mason (1999) found no evidence to show that charging is cost effective, as the true costs of the assessment and collection process are not taken into consideration. Carpenter (2000) showed that an average of 25 – 40% of revenue raised by charging is swallowed up in administrative costs. Both NCIL and the Coalition on Charging have called for a proper debate on the cost benefits of free personal assistance (Campbell *et al* 2002; Holmes *et al* 2003) but such a debate has not occurred.

The Effects of Charging

There is considerable evidence that disabled people are more likely to live in low income households (Barnes 1991; Disability Alliance 1975; Martin and White 1988; Thompson *et al* 1988; Thompson *et al* 1990; Swain *et al* 2003; Lardner 2006) – a situation that can only be exacerbated by charging. For example, 47% of the disabled population of working age is economically inactive, compared to 15% of the non-disabled population (Office of National Statistics 2003). Amongst disabled adults of working-age in the UK, 30% live in poverty (Palmer *et al* 2005). Indeed, around 45% of disabled people live below the official poverty line (Barnes and Mercer 2003b).

The charging guidance says that disabled people's incomes should not be reduced below the minimum levels of Income Support or Pension Credit, plus a buffer of no less than 16.5% in Scotland (COSLA 2006) or 25% in England (DH 2003). This reduces disabled people to a level of income considered just sufficient to live on, but makes participation in the community difficult (Morris 2005c). In addition, means testing both disabled people and their partners' incomes in Scotland effectively takes away any financial incentive to work by maintaining their level of income at little more than the amount they would get if unemployed and receiving benefits (Howard 2002; COSLA 2006) and may lead to relationship difficulties (Maynard Campbell *et al* 2000).

Holmes *et al* (2003) conducted a questionnaire survey to assess how the newly-implemented guidance on charging (DH 2003) was impacting on their lives of disabled people and carers in England. The majority said current policies had a negative effect on their income and lifestyle; and had encountered a lack of information from local authorities on changes to charging policies. As a result of the new policies a number had stopped or cut back on the services they needed. Although the majority had not found charging a barrier to gaining employment, a few were deterred from seeking employment because of the impact on their 'care' package.

The British Government promised to address the discrepancies in charging policies between local authorities (Campbell *et al* 2002). However both the England and Scottish guidance give councils substantial 'discretion' when designing their charging policies (DH 2003; COSLA 2006). This created variations which act as barriers to disabled people moving from one area to another (Mason 1999; Morris 2003a; Holmes *et al* 2003; d'Aboville 2006), and thus may prevent them taking up job opportunities (Kestenbaum 1998; Howard 2002).

Disabled people with savings of more than £6,000 (in Scotland), £12,750 (in England) or £11,500 (for the ILF) pay an extra pound a week

for every £250 they have above these limits (DH 2003; 2006; COSLA 2006; ILF 2006). In addition, savings over £18,500 disqualify disabled people from the ILF and savings over £21,000 in England may result in them paying the full cost of their community care package. These policies conflict with other Government statements encouraging 'saving for a rainy day' (Mason 1999) and prevent disabled people saving sufficient sums to meet disability-related expenditure such as adapted vehicles, aids, equipment and home adaptations (NCIL 2000).

Finally disabled parents are less likely to be charged for 'young carers' services than support for them in their parenting role. This creates a perverse financial incentive to identify the children of disabled parents as being 'in need' (Morris 2003b; 2004).

Benefits and Disability-Related Expenditure

Disability-related benefits may be taken into account as part of the charging assessment (DH 2003; COSLA 2006). However these benefits were not introduced to pay for personal assistance (Large 1990, cited in Barnes 1991). The introduction of Attendance Allowance in 1970 was an attempt to cover the extra "costs of disablement in the widest sense" (Thompson et al 1988: unpagged), with the need for 'attendance' serving as a means of identifying the most 'severely' impaired people (Thompson

et al 1990; Barnes 1991). The Government at the time called it a comprehensive universal benefit (Disability Alliance 1975).

However when the Disability Living Allowance (DLA) was introduced in April 1992 for disabled people under 65, their Attendance Allowance was replaced by the 'care component' of DLA (Noble *et al* 1997; Berthoud 1998). The new name ignored the fact that the benefit was never been intended to pay for 'care' (Campbell *et al* 2002):

...even though the care component of DLA is a way of identifying those with needs rather than supposed to be spent on care, there is still a commonly held belief that it is 'supposed' to be spent on care (Tibble 2005: 34).

By renaming the payment in terms of 'care', it became easier to justify local authorities taking part or all of it away from an individual in the form of a care charge (Baldwin *et al* 1996; Berthoud 1998; Tibble 2005). Additionally it indicated a more paternalistic approach, moving away from 'attendance' (i.e. to accompany and assist) towards the more pejorative concept of 'care'.

The levels of disability benefit are based on the Government's official estimates of disability-related expenditure (Tibble 2005). These

estimates have received considerable criticism over the years. For example, in 1988 the Office of Population, Censuses and Surveys (OPCS) survey estimated the additional cost of living with an impairment to be £6.10 per week (Martin and White 1988). Critics pointed out that this was a gross under-estimate due to a whole host of reasons. These included basing the research on the individual model of disability, focusing on actual expenditure rather than the amount an individual needed to spend if they could afford to, and ignoring the fact that expenditure rose with the severity of the impairment by presenting an average cost (Thompson *et al* 1988; Thompson *et al* 1990; Oliver 1990; Abberley 1991; 1992).

More recently, Smith *et al* (2004) estimated the minimum disability-related expenditure required in order for disabled people to maintain an equitable quality of life, based levels of 'need' (with participants being given the opportunity to self-define their level). Variability in community care charges meant that estimates on the impact of personal assistance costs could not be made. The report concludes that:

...even if receiving maximum benefits and having no personal assistance costs, disabled people still experience a substantial shortfall in income. For disabled people solely dependent on benefits, irrespective of the type or level of their need, levels of

benefits fall approximately £200 or more short of the weekly amount required for them to ensure a minimum standard of living. These figures suggest that benefits meet only 28 per cent of the costs of those with low-medium needs; 30 per cent of the costs of those with intermittent / fluctuating needs; 35 per cent of the costs of those with hearing and visual impairments, respectively; and 50 per cent of the costs of those with high support needs. (p. 78)

Therefore if disability benefits do not cover the costs of disability-related expenditure, then it is difficult to justify the current practice of taking away part or all of these benefits through charging. Moreover the estimated shortfall of £200 per week in disability benefits does not take care charges into account.

Although charging assessments should also take into account the additional costs of disability-related expenditure (DH 2003), both Holmes *et al* (2003) and Smith *et al* (2004) found that clear guidance for determining these additional costs elusive. In addition, the add-on costs related to employing PAs are also not taken into account (Howard 2002), as demonstrated by this quote from a personal assistance user:

I feed all my carers, those coming from outside as well as those living inside and my allowance from the Independent Living Fund is

£30 whilst direct payments does not actually have a food budget at all. (Carmichael *et al* 2001, cited in Carmichael *et al* 2002: 803)

It is therefore reasonable to surmise that both the failure of the benefits system to fully cover the cost of disability-related expenditure and the practice of taking disability benefits through charging have significantly contributed to disabled people's poverty (Elder-Woodward 2001; Holmes *et al* 2003). The new Independent Living Bill proposes to partly address this issue by taking disability benefits out of the charging equation (Ellis 2006).

Conclusions

This chapter has reviewed previous studies on charging. The most recent study (Holmes *et al* 2003) solely focuses on England and prior work may no longer accurately reflect the current situation for personal assistance users since the introduction of guidance for both England (DH 2003) and Scotland (COSLA 2006). Nevertheless this body of work indicates that charging creates a number of barriers to independent living which may well not have been removed by this guidance. It therefore seems an opportune time to be conducting this study.

Chapter 3: A Comparative Study

This chapter describes the study's research strategy and the rationale for selecting it. It follows the structure advocated by Grix (2004) of setting out the ontology, epistemology, methodology and data sources.

Ontology

Blaikie (2000: 8) defines an ontology as “the claims or assumptions that are made about the nature of social reality, claims about what exists, what it looks like, what units make it up and how these units interact with each other.” By declaring an ontological position at the outset of a study, the precise nature of theoretical positions and arguments can be clarified (Lewis 2002, cited in Grix 2004). As previously stated at the beginning of the first chapter, my ontological position is that of a personal assistance user who, through personal experience, has found charging to be a barrier to achieving independent living. Undoubtedly this position will influence both my analysis and my arguments. It has been argued that the results of partisan research merely reveal the researcher's own bias (Hammersley 2000). However it has also been argued that there is “no independent haven or middle ground when researching oppression” (Barnes 1996a: 110). Therefore I believe that it is better for researchers

to be open about their own bias and motives, since there is no such thing as objectivity in social research.

Priestley (1997) asserts that, with respect to emancipatory disability research, the social model of disability provides an ontological and epistemological basis. However this study does not claim to follow the emancipatory paradigm. This is because it is a student project with few resources and is therefore not controlled by a disabled people's organisation. It is unlikely that it will achieve emancipatory outcomes and the results will not be disseminated in an accessible format (Zarb 1992; Oliver 1992; Stone and Priestley 1996). However the social model will still be used as an ontological basis, with the study aiming to identify the reality of social barriers created by charging policies.

Epistemology

Blaikie (2000: 8) defines an epistemology as a set of "ideas about what can count as knowledge, what can be known, and what criteria such knowledge must satisfy in order to be called knowledge, rather than beliefs." With respect to this study, the epistemological position taken is again based on the fact that I am a disabled person who subscribes to the social model of disability. This approach is interpretive, based on the theory that all knowledge is socially constructed and the product of a particular historical context (Oliver, 1992). Therefore the measure for

knowledge validation prioritises the views and experiences of disabled people themselves and dictates that knowledge should conform to the theory that disability is a form of social oppression.

Methodology

This empirical study employs a qualitative, primary analysis of data gathered from a sample of key informants. The in-depth interviews conducted were semi-structured as opposed to structured or unstructured. This format was chosen as it enables the researcher to elaborate on any unexpected issues which may arise during the course of the interview (May 2001). It also gives the flexibility to clarify responses, challenge theories and establish common meanings. The interview schedule is included as an appendix.

I emailed prospective interviewees to invite them to be interviewed, clearly stating the aims and objectives of the research. This email also offered to meet any travel expenses and access requirements necessary. Ideally the interview process advocated by Barnes (1992a) would have been used, whereby a preliminary meeting takes place before the interview to outline the objectives and discuss the participant's involvement. In addition to this, a third meeting is held after the interview to discuss the research findings and for the participant to comment on

them. However due to this being a student project with limited time and resources this was not possible.

Instead the interviewees were given the opportunity to look at the interview schedule prior to participating. This was either done via email or immediately before the interview took place. Each interview was recorded with a digital Dictaphone. These recordings were then analysed manually and all quotes pertinent to the study were transcribed. This analysis was done manually, as opposed to using a software package, due to time and resource constraints. The transcripts were then emailed back to the participants in order to give them the opportunity to make amendments and additions. Due to time constraints participants did not have a great deal of time to make any alterations. Two out of the six interview transcripts were amended by participants. The reviewed transcripts were then encompassed within the study. The timetable for completing the work was as follows:

May – June:	Identify and formally approach participants
17 July – 8 September:	Conduct the interviews
30 August –	Analyse and transcribe the recordings.
13 September:	Email transcriptions to participants.
25 September:	Deadline for receiving amended transcripts.
29 September:	Completion of the dissertation.

Data Sources

The people selected for interviewing needed to be very familiar with personal assistance schemes and charging policies. Only six interviews were held due to the constraints of time and resources – three in England and three in Scotland. Because of the very small sample, interviews were restricted to key informants - experienced people with direct, expert knowledge. These willing participants were selected through personal and academic connections. The sample is purposive and based on convenience (Blaikie 2000), as I have chosen people who are relevant and significant to the research. All of the interviews were confidential, so pseudonyms have been used to refer to individuals. The following pen pictures describe the background of each participant:

England

Patrick is a personal assistance user in his early forties who has chaired a direct payments user group and a local organisation of disabled people. He works as a freelance disability equality trainer. He does not receive 24-hour support but believes that he should be entitled to it. He receives funding from his local direct payments scheme and the ILF.

Barbara is in her mid-sixties. She struggled with direct services for 7 years with no control over the support she received or who provided that support. In 1991 she got onto a pilot indirect payment scheme and, later on, direct payments. She has chaired her local CIL and a user-led advocacy group, as well as a couple of national organisations of disabled people. She has sat on social services committees and facilitated training around increasing the take-up of direct payments. She employs 6 PAs and receives assistance 24 hours a day, funded by the ILF and her local direct payments scheme.

Sarah-Jane is in her early fifties and lives in Yorkshire. She has had her impairment since birth and went to a segregated school along with her sister who is also disabled. She has been working formally in disability equality for 14 years doing research, training and consultancy, sometimes around independent living. Sarah-Jane is a member of her local direct payments users' group. She has employed her own personal assistants since she took on Community Service Volunteers in 1982. Currently she virtually requires 24 hour support and receives funding for personal assistance in the form of direct payments and money from Access to Work, but not the ILF. She still has to top up this funding with her own money.

Scotland

Zoe is in her mid-twenties and has been working as an inclusive living advisor for a CIL in Scotland for 2 years. She has a personal assistant provided throughout her working day and an on-call service from 8pm to 4am. Her support is funded by the ILF and her local direct payments scheme.

William is in his late fifties. After graduating, he joined a team of researchers at Lancaster University surveying the employment difficulties of disabled people, before pursuing a career in the field of social work. He has worked as a development worker for a couple of organisations of disabled people. Before retiring he was Senior Social Work Officer for people with physical and sensory impairments in a Scottish local authority, responsible for day care, residential care and job coaching. He retired due to health reasons in 1999. He and his wife receive 24-hour personal assistance with funding from both direct payments and ILF.

The final interview in Scotland was a group interview conducted at a Centre for Independent Living based in a large city. The members of staff who participated were:

Victoria: A part-time independent living officer who also receives direct payments and pays charges.

Tom: A part-time independent living officer who has participated in campaigns against charging in Scotland. He also works as a personal assistant for someone who pays charges.

Liz: The CIL manager, in charge of all the support services with a remit around campaigning and strategic development. Liz also receives support through direct payments.

Jon: An independent living co-ordinator with a particular remit around direct payments and ILF.

Five out of nine participants were women, one was an older person and none were from Black or minority ethnic communities. Ideally the sample of interviewees would be representative of a range of different groups of disabled people. Whilst it must be acknowledged that such sampling would enable the inclusion of a range of differing experiences and perspectives, this proved unfeasible given the limited time and resources. Instead I worked with a small sample size which was both purposively and convenience sampled.

The majority of people interviewed had physical impairments, and none of those interviewed declared having either a sensory impairment

or learning difficulties. Undoubtedly both of these impairment groups face barriers to independent living through charging, and interviews with people from these groups would have substantially contributed to this study, but once again lack of time and resources made this impossible. However all of the participants selected have either worked for a CIL, been a board member of a CIL or have participated in personal assistance user support groups. Therefore they were encouraged when answering the questions to reflect on not just they own experiences but also the experiences of other disabled people.

To what degree the participants selected can be said thought to be representative is entirely subjective. It could be argued that I have chosen a biased sample in that I have selected people from the independent living movement who subscribe to the social model of disability. All I can say in response is that I have been upfront about my commitments and beliefs.

Problems Encountered

A couple of interviews were postponed to a later date due to unforeseen circumstances. William's vehicle breaking down delayed his interview and the researcher's PA falling meant postponing the journey to interview Sarah Jane for 10 days. In addition, the limitations of the Dictaphone when recording a number of voices resulted in a poor quality

recording of the group interview. This may have resulted in the loss of some data from this particular interview.

Conclusions

This chapter has examined the process of research design. It has looked at the issues of ontology, epistemology, methodology and data collection relevant to this work. This provides a framework for the study as a whole. The following three chapters examine various barriers to independent living created by charging. Findings from previous studies are juxtaposed with the opinions and experiences supplied by participants.

Chapter 4: A Denial of Consumer Rights

The Scottish guidance on care charging states that:

A market-oriented view suggests that 'paying' for services enhances the service users' willingness to comment on the services as a consumer. (COSLA 2006: 8)

One interviewee elaborated on the analogy between consumers and those who pay for community care services:

“If charging were treated as a legitimate commercial transaction, disabled people would have the same protection under the law as any other consumer. We would be allowed to choose what service we got, when and where we got it from; and freely complain if the service wasn't up to standard. We would be part of the design and delivery of services, monitoring and evaluating; involved in their development. But none of that exists.” [William]

Therefore this chapter will compare the rights of those who pay community care charges to those of other consumers. The Unfair Terms in Consumer Contracts Regulations (1999) for the UK stipulate that a contract is unfair if both the consumer has not been able to influence the substance of the terms, and the terms either:

1. Have a detrimental effect on the rights of the consumer;
2. Have not been expressed in plain, intelligible language; or
3. Deny the consumer the right to complain to the Director of Fair Trading or another qualifying body;

Although these regulations apply to neither local authorities nor the Independent Living Fund, it is enlightening to apply these criteria to assess the fairness of community care charging. Therefore this chapter will begin by examining whether personal assistance users can influence their community care packages during assessment; and what recourse exists if they are dissatisfied with the outcome. It will then look at the abundance and accessibility of information about charging. The subsequent chapter will examine the effect charging has on the rights of personal assistance users.

Choice

Community care assessments undertaken by professionals do not always result in the disabled person receiving the type and level of support that they themselves would choose (Barnes *et al* 1995; Oliver 1996; Drewett 1999; Maynard Campbell *et al* 2000; Wates 2003;

Priestley 2004a). A number of interviewees from both England and Scotland expressed dissatisfaction with the process:

“The community care assessment doesn’t take into consideration people’s ambitions and their goals. It gives them a very, very basic service. They’re life isn’t allowed to change after the day of their community care assessment. There can be no progress for them.”

[Tom]

“[Community care assessments] categorise a lot of your needs – they almost break your life down into tasks, which I think is unrealistic. For example, I wanted my PA to work an extra hour at night, as I don’t get home till 5.30 and they finish at 6pm, so half an hour isn’t a lot of time to eat, to read my mail and do cleaning. But I had a hard time arguing that I needed someone from 8am to 6pm, as the assessment was only allowing me 20 minutes to use the toilet, an hour to eat, etc.” [Zoe]

“I felt that there was very much an emphasis on giving me as less hours as possible. I wasn’t encouraged to claim something like a 24-hour care package. They wanted to give me the bare minimum they could get away with. If I wasn’t assertive then I think they would have got away with that. They kept stressing that they’re

limited by budgets... so you almost felt guilty asking for so much.”

[Patrick]

As a result of Patrick not receiving the support that he feels he needs, he is still reliant on family members to provide additional assistance, even though he is paying a charge for that support. He strongly feels that his assessment failed to meet his needs that, so much so that if charging was abolished, he would use the money saved to pay for more hours of support. Other interviewees cited instances where assessments had restricted people by not taking certain aspects of their lifestyle into account:

“My sister really ought to have overnight care... The guy doing her community care assessment said she should be temporarily catheterised at night in order that she doesn’t need care. Once she’s in bed the only way to get her out is with a hoist. She’s on her own in a 4 bedroom house and it would take more than half an hour for her PAs to reach her. What happens if there was a fire... or a power cut? What if she’s ill or burgled?” [Sarah-Jane]

“In their wisdom they decided to take off every committee that I ever went to for their benefit, as they didn’t see that as an essential need. The fact that if I stayed in my home or in my bed 24/7 then I

would still need to go to the toilet never seem to enter their heads.
It took me 7 years to get any level of good support, and about 12 to
get 24-hour support.” [Barbara]

“Somebody had taken to alternative medicine and was on a certain
diet because they had cancer. But the local authority wouldn’t
take their dietary requirements into account as the diet hadn’t been
medically prescribed.” [Jon]

Charging personal assistance users necessitates that a financial
assessment be conducted as part of the community care assessment.
Barnes (1991) comments on: “the indignity of assessment by a visiting
social worker who will require proof of income and expenditure” (p. 117).
Maynard Campbell *et al* (2000) cite how such assessments can put a
strain on a relationship with a cohabiting partner, since they may be
expected to make a financial contribution. Interviewees recalled the
indignity of this process:

“It’s quite invasive having someone scrutinizing your finances all
the time... always having to prove why you need something and
why you can’t afford it. If they think the teabags you buy are too
expensive they they’ll tell you. They expect you to budget so that
you can afford to pay their charges.” [Victoria]

“A financial assessment... is absolutely horrible. It screws you up totally, not because I’ve got anything to hide, but it’s very invasive. My sister goes to their office with her paperwork. She doesn’t want them coming to her house as they look round and form a view of you and your resources... from what they see. That’s even more invasive.” [Sarah-Jane]

The unequal power relationship between social workers and their clients may also affect the outcome of the assessment (Oliver 1994; Shakespeare 2000). In a similar way to those interviewed by Priestley (1999: 92), Sarah-Jane is afraid that her support may be cut if she is too forthright during her assessment:

“Even though I’m as strong as I am as a disabled person, I’m scared that if I asked for everything I need, they would actually retrench and I would lose out.” [Sarah-Jane]

If personal assistance users had the same rights as other paying consumers then they would have recourse to a higher body when dissatisfied with the results of their assessment. But two of the independent living officers interviewed, Zoe and Victoria, confirmed that the appeals procedure rarely works in favour of the direct payments user.

Therefore they have to pay for support that they may feel is insubstantial or inappropriate. Moreover, like some of those interviewed by Holmes *et al* (2003), they may be in a situation where they are unable to survive without the support on offer:

“I have no choice but to pay charges. I can’t go without my care package as I don’t have a living relative who could provide support.” [Barbara]

“My wife and I don’t have any family who could assist us, so basically we have no choice but to pay for every bit of help we get, including that which is not recognised by funders, i.e. gardening, DIY, cleaning the car.....” [William]

“I don’t have family who would be capable of providing the level of support that I need. I have nobody living with me, my sister has the same impairment as me and my parents are far too old. Therefore I had no choice in paying the care charges.” [Sarah-Jane]

Personal assistance users are put in a position where they are forced to pay for the assistance they use, even though they may disagree with their social worker’s assessment of their need. This

situation could be partially resolved by self-assessment, whereby disabled people are supported by their peers to make informed choices about their needs (Disability Alliance 1975; HCIL 1990; Zarb and Nadash 1994; Priestley 1999; Elder-Woodward 2001; Gillenson *et al* 2005) and thereby gain the consumers' right to choice over what they are paying for.

Information

Accessible information is an essential requirement for disabled people to access public services and attain independent living (Davis 1990; Clark 2002). Both the guidance on charging for England (DH 2003) and Scotland (COSLA 2006) stipulate the need for local authorities to provide clear information on their charging policy. However the majority of respondents to the survey conducted by Holmes *et al* (2003) felt the information on charging provided by their local authority was insufficient. This was corroborated by the experiences of every participant in this study:

“The local authority has nothing in black and white that people can read on how they work out the charges.” [William]

“The amount that will be charged is in the contract and many people miss it. The contracts are highly inaccessible – tiny black writing on a white background. They do offer alternative formats, but that’s on the back of the contract so you’re supposed to have read it by the time you reach that bit.” [Zoe]

“I just got a letter to say that they were looking into the charging policy and I was instructed to go and meet with the care manager. I never got a copy of the policy. To be honest with you, the woman who interviewed me knew very little about the policy and absolutely nothing about my care package.” [Barbara]

A number of interviewees commented that prospective personal assistance users going through the assessment process are informed pretty late on that they’ll be charged:

“A woman... had been through the whole assessment process for a direct payment, but no-one had mentioned up till that point that there will be a charge. Often people will back out at this point, but if they’d had that information at the beginning then they could’ve made their minds up whether it’s more affordable to recruit someone individually rather than go through the process... I have known people who have pulled out at this stage because they’ve

got such a limited income. They decide they prefer to struggle on and rely on family, rather than lose what little income they've got."

[Victoria]

"In my professional experience, I have never heard a care manager offer information of charging. People normally find out about it when they misunderstand direct payments and ask if it will affect their benefits. They get told that it won't but they will have to pay the charge." [Zoe]

If informing people about charging late on results in that person choosing not to take up direct payments, then the assessment process will have been a waste of both the person's time and the local authority's resources.

Although the English guidance (DH 2003) specifies that "charges should not be made for any period before an assessment of charges has been communicated to the user" (p. 24); the Scottish guidance (COSLA 2006) makes no such recommendation. This led to one interviewee in Scotland only being informed that she would be charged after she had been using community care services for a number of years:

“When I did my community care assessment I didn’t know anything about the charging policy... When I left university and moved about two miles down the road, the on-call service became difficult for the agency to provide... At that point they offered me direct payments. They then said that I now have to be charged and that I should have been charged for all those years, so they tried to hit me with a £19,000 pound debt. I told them what they could do with it! Anyway they wrote it off, which they had no choice but to do, and I started paying a charge – which really annoyed me as no-one told me when I had my community care assessment that I’d have to pay.” [Zoe]

The English guidance also specifies that “any increase in charges should also be notified and no increased charge made for a period before the notification” (DH 2003: 24). However this is not necessarily adhered to, since one respondent to Holmes *et al* (2003) was informed via telephone of a 200% backdated increase. The Scottish guidance does not address this issue at all. One Scottish interviewee reported that the maximum charge in his area had risen from £7 to £8.50 per hour the previous year with no warning.

Similarly only the English guidance specifies that the amount to be charged should be communicated promptly before the first bill is sent.

The following quote from a Scottish interviewee indicates that this practice does not occur in Scotland:

“There’s one guy who I work with who has just turned 18 and is on direct payments. Of course, people under 18 are not charged, but if you’re over 18 then you are charged. When he moved onto adult services he got a new contract that didn’t say why he was being charged, it just said what his new amount was as his local authority pay the direct payment net of the user’s contribution... which forces you into paying it. ...The fact is he just got a new contract saying what his contribution was – he didn’t get a letter and he didn’t get a visit from his social worker to tell him why there was a charge.”

[Zoe]

Both the English and Scottish guidance say that clear written information on how charges have been calculated should be sent to direct payments users after their assessment. However a number of interviewees, including those charged by the ILF, had no idea how their charges had been worked out. Two interviewees from Scottish CILs had tried unsuccessfully to obtain the charging formula:

“I had to phone the income maximisation team... to try and get the formula for working out the charges but they won't release or publicise this formula.” [Victoria]

“Even though this CIL has the remit to support people to get a direct payment, we have been entirely unable to get hold of the calculation that works out the care charges. One request resulted in the response ‘I'm a guardian of the public purse, so I can't give you this information.’” [Zoe]

Conclusions

Through moves to create local financial accountability, council tax bills now have to specify the percentage change between that and the previous year for both the charges for services included (i.e. police, fire authorities, etc) and any special expenses (DTLR 2001). Authorities also have a statutory obligation to publish information on how they budget and spend revenue raised through council tax (LGA 1999). Direct payments users pay additional local taxation to their council through care charges. However the consumers of ‘community care’ services do not have the same rights to information and accountability afforded to consumers of other council services.

Chapter 5: A Barrier to Progression

As stated in the previous chapter, one of the criteria for assessing whether a contract is fair is whether it has a detrimental effect on the rights of the consumer. This chapter examines how charging can hamper a personal assistance user's progression through life by negatively impact upon their right to an education, employment, geographical mobility, a pension and savings.

Higher Education

Young disabled people are only half as likely to access higher education compared to their non-disabled peers (Morris 2005c). The barriers that stop them include access to written information (Hutchinson *et al* 1998), buildings (BCODP 1994), transport, assistance, signers, barrier-free learning and residential environments (Integration Alliance 1992), the inclusivity of the curriculum (Bolt 2004), lack of positive role models (Barnes 1996b), and special education (Barnes 1991). This study has found evidence in Scotland that charging can also prove a significant barrier:

“They even take student loans as capital! Can you believe that? I was shocked! You've got one government department saying you

need it to live on, and another government department saying that it's capital. So if I'd have got a loan then it would have been taken by charging and I would still have had to pay the sum back which is bloody awful!" [Zoe]

As well as the regulations on savings, charging assessments may not take all of a disabled student's living costs into account:

"I've got one young client who is 19 years old and still lives at home, but pays for digs when she's at university. Her charging assessment wouldn't consider the rent she was paying for digs as she was down as living with her parents. This happens all the time because there's very little they'll take into account other than gas and electricity." [Zoe]

Although the above two quotes refer to Scotland, there is nothing specific in the English guidance (DH 2003) to prevent the same situations occurring in England (although the higher savings threshold may prevent the first scenario). Students receiving ILF funding also face high charges:

"Young people on ILF are still charged, but based on their parents' income. We've had a couple of situations where there's an 18-year

old going on to university and they've both told they'll be charged £90 a week as they're being charged on their parents' salaries."

[Jon]

Moreover the financial disadvantages caused by taking earned income into account when calculating charges can act as a disincentive to higher education:

"One of the big draws for going to university is that you'll earn more – this is how the government justifies students paying fees. But what's the point for me when I won't be able to earn more because of charging." [Zoe]

Employment

Disabled people face a number of barriers to gaining employment, including recruitment policies, underemployment, attitudes, inaccessible work environments, discriminatory person specifications, medical screening, lack of qualifications, geographical mobility and the welfare system (Barnes 1992b). In addition, just under a quarter of the disabled respondents to the English survey by Holmes *et al* (2003) were deterred from seeking employment because of charging, despite the guidance for England dictating that charging policies should avoid creating disincentives to work by disregarding all earnings in charge assessments

(DH 2003). People in England who were interviewed for this study had also found charging to be a barrier to working:

“I struggled with staff problems at my company and I did actually consider giving up work, making everyone redundant and living off my capital until it came below the threshold. I would have been better off.” [Sarah-Jane]

The guidance for England states that disabled people receiving Income Support or Job Seekers’ Allowance – Incapacity Benefit, whose overall income equals the defined “basic” levels, should be exempt from charges (DH 2003). Since both of these benefits are employment-related, effectively this means that disabled people can avoid charging by giving up employment and thus qualify for these benefits. Therefore charging is still a disincentive to work in England.

In Scotland charging is even more of a disincentive since earned income is still taken into account (COSLA 2006):

“Charging creates a massive disincentive to work... it took me two months to decide whether to work or not. Working actually put me in a much worse off position... partly because they wouldn’t disregard the money I spend on petrol to travel 35 miles each way

to work and back every day. I was working for exactly the same amount of money that I'd get on Income Support and DLA, as the policy took all earnings above £700... but I was spending more on petrol." [Zoe]

"When I went back to work after being on Incapacity Benefit I was much worse off. My work was based at home so I didn't have any transport costs but I was significantly worse off... It's like you're allowed to work but you're not really allowed to progress or get a top job. If you're a disabled person then you've got to stay at a certain level and you're not allowed past that level." [Liz]

"Most disabled employees are probably working part-time. They would find themselves really, really worse off if they decided to go full-time, as that's when they really get hit by charging. It's a big disincentive. Let's face it, most people won't want to get a part-time job just to earn the same amount that they'd get on benefits; they want the full-time job with the big money. But that's when they are really stung." [Tom]

The secrecy around how charges are calculated (discussed in the previous chapter) and variation between different charging policies creates uncertainty concerning how employment will affect a person's

charges. This was also noted by Howard (2002). The interviewees in this study described how charging can affect the decision to take a particular job:

“Until you’re in the position of being in work you’ve not clear on what you’ll be paying in charges. You’ve got to take the job and then find out what the actually costs are to you.” [Victoria]

“When a client took up work a couple of weeks ago, she asked me how much she was going to be charged. So I phoned the council... but couldn’t get an answer. I think people need to make an informed choice if they’re to be willing and able to take up a direct payment, but this isn’t possible under the current system.” [Zoe]

Moreover once in work some Scottish authorities will take all earned income above the amount the disabled person would have received through unemployment benefits. This may discourage people to seek promotion, look for a better paid job or even stay in work:

“The policy of Murray council was to take all of my income above £700 per month. Every single penny! ...When I started here I was part-time and my income was £750, so they were taking like 50

quid. But when I went full-time it went up to £900 a month, out of which I would have only been getting £700, which to me is absolutely shocking. So I wrote to my MSP, as it's a devolved issue, and eventually went to see Andy Kerr who is the Minister for Health and Community Care, who was entirely useless and just said that benefits are a reserved issue. I said it's not a benefits issue, it's a work issue – stop these negative assumptions.” [Zoe]

These findings indicate that charging is still a significant barrier to disabled people taking up employment.

Geographical Mobility

Geographical mobility has become especially important in both the search for work, and for people already in work to move to other parts of the country in pursuit of promotion. In present circumstances geographical mobility is extremely difficult if not impossible for many disabled people (Barnes 1992b), partly due to the lack of accessible housing (Drake 1999; Stewart 2004; Thomas 2004; Thomas *et al* 2005). Other factors are the uneven implementation of direct payments across the UK (Priestley *et al* 2006) and variation between local authorities' charging policies (Mason 1999; Campbell *et al* 2002; Howard 2002; Morris 2003a; Holmes *et al* 2003; d'Aboville 2006).

For example, William and Barbara live in different areas and both receive funding from their local authority and the ILF. But whereas William only pays charges to the ILF, Barbara is also charged £7.60 per week by her local authority. Such discrepancies are common:

“I’ve thought about moving to Argyll, but I think their charging policy is even more draconian than my local authority’s policy so that put me off.” [William]

“In Sterling they waive all the charges to the Independent Living Fund, who don’t take income into consideration so I’m a hell of a lot better off. Because I’m not on benefits my contribution is about 30 quid a week, but if I was on benefits it would be £75 as they would take my Severe Disability Premium as well... All the various charging policies in Scotland are different, because the guidance is so slack. You got the biggest postcode lottery that you’ve ever seen. Murray council take all of your income over £700, and Sterling and Glasgow are similar if they don’t waive the charge to the ILF, but they at least have a taper, which is fairer and suggested by the COSLA guidance.” [Zoe]

The introduction of free personal care in Scotland has led to further differences between local authorities:

“One of the local authorities has interpreted free personal care as people not being helped with meals, whereas in other parts of the country people have actually got free personal care.” [Jon]

Also the secrecy around how charges are calculated, as discussed in the previous chapter, again results in disabled people being prevented from making an informed decision about where to live:

“People can sometimes find themselves in a situation where they can’t decide whether or not to move somewhere else because they won’t find out what the charging policy is unless they actually move.” [Jon]

All of these issues arise from the guidance for both England and Scotland giving too much discretion to local authorities in the design of their charging policies.

Pensions and Savings

Older disabled people are placed at a relative disadvantage as income from an occupational pension is not disregarded in the same way as earnings from employment (Morris 2003a; 2005b; Coalition on Charging

Cymru 2006). This has an impact on people who are charged by either their local authority (English or Scottish) or the ILF:

“I have a really good friend who was a nurse before she became disabled. She has a pension and doesn’t need an awful lot of assistance. But she was assessed to pay all the charges which were really making her life intolerably.” [Sarah-Jane]

”The ILF charge us half of our DLA care component plus... they also take my pension into consideration. The same amount of superannuation is taken into consideration for my wife as well as myself... My wife and I both get incapacity benefit. We are both recipients of ILF funding. So we are both charged on the same income, my pension, which I think is unfair. Our contribution is £222 per week... but I don’t know how the ILF work this figure out.”
[William]

The practice of assessing capital means that disabled people are not allowed to amass any money during the course of their lifetime, and may be unable to save for things such as a car or a deposit on a home. This seems to conflict with other Government statements discouraging ‘empty-nesters’ (Mason 1999; NCIL 2000; Holmes *et al* 2003).

“I had a client with a couple of TESSAs and the local authority actually forced her to sell them before they came to maturity so she lost out.” [Jon]

“I know I’m being watched to see how much money I’ve got. They ask for your bank account details. There’s no point in saving above a certain amount of money because I know they’ll take it off me. I would never look at buying a house because I wouldn’t be able to save enough for a deposit. If you don’t give them your bank details then they’ll charge you the full whack, so you’ve got no choice.” [Victoria]

“When I knew that my capital was more than the local authority allowed, I opted to pay the maximum contribution which was £50 per week when I started. It then went up immediately to £60 per week, as I started in February and they change the rates in April, and the next year it went up to £80 per week. Then it went up to £100 per week, on the basis that it was going to be £120 per week. Fortunately, or maybe unfortunately by that time my capital had gone down to such an extent that I managed to get a nil assessment...” [Sarah-Jane]

Limits on savings may result in disabled people being unable to save sufficient sums for additional disability-related expenses such as replacement vehicles, aids, equipment and adaptations (NCIL 2000). Unlike the Scottish guidance, the guidance for England asks councils to consider “circumstances where individual users may have particular needs for savings” (DH 2003:15). However no clear directive is given on what particular circumstances they had in mind. This had led to some (but not all) authorities disregarding savings specifically to cover disability-related expenditure:

“She has to work very hard to keep her savings under the limit. But her car cost over £30,000 as it’s one that you can drive from a wheelchair, and then she’s got a lift and hoists and an electric wheelchair. She wants to retain capital to replace these things, but the local authority won’t disregard that capital in the charging assessment. At least my local authority has agreed that if I have a fund specifically for repairing or replacing my equipment then they will disregard it.” [Sarah-Jane]

The financial assessment of savings has led to some disabled people spending whatever money they have to avoid giving it away through charging:

“I get an allowance from the Thalidomide Trust... Say one year I get a big lump sum in the bank, to be honest I’d spend it rather than save it... as I would begrudge paying it back to them [the local authority].” [Patrick]

“If my savings go above the level set by the ILF then I put them into my house. When I retired I got £25,000 but I couldn’t keep it because of charging, so I paid off the mortgage.” [William]

“My gran... asked me would inheritance affect my charges. The only way they wouldn’t touch it was if I put it straight into property within six months. She died in June and the lawyer looked into it but couldn’t see a way of hiding the money. I’m determined to find a legal way to keep the money, so I’m just going to have to put it into a house and get a mortgage. I’ll be fine as long as I live in it, but if I don’t then they’ll make me sell it and take the capital.” [Zoe]

The overall effect of pensions and savings being taken account is that disabled people are prevented from making financial plans for the future in the same way as non-disabled people.

Conclusions

This chapter has demonstrated how charging creates barriers for personal assistance users seeking to go to university, seek employment, move to another part of the country, get a pension or save for the future. These are activities that typically non-disabled people may undertake as they progress through life. Therefore it appears that charging policies either intentionally penalise personal assistance users for seeking to lead full lives; or more likely fail to anticipate that disabled people will aspire to fully participate in society:

“A lot of it is to do with the fact that the spending and employment power of the disabled person hasn’t been fully recognised. Sadly people like me, who require a high level of support normally don’t usually work so they’ve never been able to look at these ridiculous loopholes.” [Zoe]

Chapter 6: A Barrier to Independent Living

This chapter examines how charging creates barriers to independent living by taking income that would otherwise be spent on the additional costs of disability, putting some people in a position where they cannot afford to have support. It then evaluates the human rights implications of charging for essential support, and concludes by considering why Scotland's system for free 'personal care' has excluded disabled people under 65.

Disability-Related Expenditure

In the study by Holmes *et al* (2003) on the effects of the charging guidance for England (DH 2003), 14 out of 32 disabled people felt charging had a negative effect on their income and lives. As already discussed, past research has shown that benefits do not adequately cover disability-related expenditure, let alone care charges (Smith *et al* 2004). All of the people interviewed in this study agreed with this view:

“All I get is DLA, and the cost of my electric wheelchair, let alone the cost of my car eat up all of that. I have additional costs of food... they don't take into account feeding PAs... If I want to go for a weekend away with my partner, the only hotels with hoists are

4 star hotels. So not only have you got less money, but doing what you want to do costs more.” [Sarah-Jane]

“I’ve got a big 2 litre WAV that I had to buy. My wife is doubly incontinent so our tumble dryer is on 18 hours a day to cope with the dirty laundry. Our PAs are up all night so we’ve got lights on day and night. All of these things, and more, are not taken into consideration.” [William]

“The public transport system isn’t fully accessible so you have to take taxis. Holidays are a complete nightmare. I don’t have a relative to go away with so I have to take a PA, which means that I’m paying double. Even if you’ve managed to accrue any money from your direct payments or ILF funding, you’re not allowed to use that money to pay the additional expense of taking a PA on holiday with you.” [Barbara]

Maynard Campbell *et al* (2000) also noted that the additional costs of requiring a PA to accompany a disabled person on holiday are not taken into account. In addition, interviewees were asked what they would spend the money they would save on if they hadn’t had to pay charges:

“I would use the money saved on the luxuries that I expect to gain from work, the same luxuries that any other citizen would expect.”

[Zoe]

“I would spend the extra money saved on food and other normal, daily living costs that everyone incurs. I’m not as comfortable nor as well off as I would have been if I were able-bodied.” [William]

“I probably wouldn’t have gone into overdraft. I would have been able to afford a decent holiday. Charges have meant a lower standard of living compared with somebody else in my situation whose been working all their life and has a professional qualification. Basically I have to be more careful and have lower expectations than my peers.” [Sarah-Jane]

Tom suggested that a fairer system would be to split the DLA care component into two, thus specifying how much of it can be taken through charging:

“The DLA care component should just cover care and the government should introduce another component to cover all of the other disability-related costs that attendance allowance previously

covered... Most people are being left with nothing to cover those costs.” [Tom]

Therefore for this study’s participants, charging not only takes away income that should be spent on meeting the additional costs of being disabled, but also money that would otherwise be spent on day-to-day living costs. This is especially the case in Scotland where earned income, as well as benefits, is taken into consideration.

Cessation of Support

There is evidence that charging prevents some people from receiving support. A few of the older people interviewed by Zarb and Oliver (1993) had stopped having assistance in the home because charges had been introduced. Barnes (1997) found that older people considering direct payments were fearful of additional personal cost implications. In the study by Holmes *et al* (2003) on the impact of the charging guidance for England (DH 2003), 6 out of 33 disabled respondents had decided to stop accessing services altogether and a further 3 had considered reducing the level of service they received. The interviewees in this study confirmed that charging deters people from applying to the ILF:

“I know plenty of disabled people who would benefit from the ILF, but they won’t apply for it because of the charging... It amounts

now to something like £72 per week because they take half your DLA care component and your Severe Disability Premium... For many disabled people who have to pay this charge towards their care package, basically they're just existing – not living.” [Barbara]

Another participant who works for a Scottish CIL said that it was quite common for people not to take up direct payments once they learnt what the charge will be. This decision can also affect other family members:

“People who choose not to take up direct payments because they can't afford the charges will go back to relying on family members for support or just struggle on and do without. And then they'll be frightened to look at direct payments again, cause what's the point of giving up what little money you have to get outside the door if you've got no money to spend once you're out there?” [Victoria]

Therefore charging is effectively preventing some disabled people from accessing the support they have been assessed as needing.

Equality and Human Rights

Independent living is a human right (Morris 1993; Campbell 1997; Hasler *et al* 1999; Holmes *et al* 2003; Houston 2004). All of this study's

participants were angry that disabled people are made to pay for this right:

“I think that to pay to have to get out of bed in the morning is iniquitous in this day and age. I think that to be enabled to do the basic things that everyone else can do should be a human right.”

[Sarah-Jane]

“What you’re buying with your charge is a human right, and I don’t believe that anyone in our society should have to pay for a human right. No-one else pays to go to the toilet or to get out of bed in the morning.” [Zoe]

“Independent living is a right. It’s not a privilege or an extra service; it’s an entitlement, a right that non-disabled people don’t have to think about. It should be a right that we don’t have to pay for, regardless of income.” [Patrick]

“Charging is unfair. Why should disabled people be charged for getting up in the morning and going to bed at night? Do non-disabled people have to pay this? I don’t think so!” [Barbara]

Barbara went on to express the view that no-one should have to pay charges, regardless of how wealthy they are, since in the interests of equality, a non-disabled person would never be expected to pay to have their human rights upheld:

“I don’t even think that a disabled person with compensation, local authority funding and a very big salary should have to pay charges as disabled people don’t ask to become disabled... They shouldn’t have to pay a tax on being disabled – whatever their income is.”

[Barbara]

The comparison to taxation (Mason 1999; NCIL 2000; DCIL 2001; Elder-Woodward 2001; Holmes *et al* 2003) was also made by another participant:

“I don’t have any kids going through school, but I’m still paying for the education system through council tax. I don’t mind this because I think education is a right, so I don’t begrudge paying for the education service, nor other services that I don’t use. There are very few accessible public buses that I can use. But I don’t mind paying for the public transport system as I believe it should be a right. So this is why I begrudge being charged for my personal support.” [Patrick]

Many services being delivered under the label 'social care' include tasks that can also come under 'health care' (NCIL 2000). Indeed it has been shown that personal assistance users do not distinguish between 'health' and 'social care', as both are viewed as part of their overall requirements for assistance (Glendinning *et al* 2000; Glasby *et al* 2004). Similarly one interviewee could not understand why the former is free and the latter is charged for:

“Politicians have not really understood the principle that, like healthcare, social support should be free at the point of delivery... because it's more cost effective to provide support within the community than to pay the health costs resulting from the injury and ill-health caused by lack of social support. People should have a right not just to keep healthy, but to participate equally in society. They're two sides of the same coin.” [William]

William goes on to elaborate on where he thinks the idea behind care charging may have come from:

“...a hangover from the Victorian age when only the rich in the big houses could afford personal support. The politicians who devised the National Assistance Act possibly thought that if you needed

personal support then you should be able to cough up. In any case, home care was first considered as a service to non-disabled pregnant mothers, not people who needed personal support due to physical impairment. As such, it was possibly seen by some as an add-on 'luxury', not an 'essential', to improve the life chances and quality of life for children. But that's not the scenario today.

Personal support is needed to bring about social inclusion. Without personal support there won't be equality." [William]

All of this study's participants expressed the view, concurrent with the available literature, that charging constitutes an infringement of human rights and a barrier to social participation and social inclusion.

Campaigning for Change

There has been considerable resistance to charging from disabled people's organisations. Seventy percent of the organisations sampled by Barnes *et al* (2000) actively campaigned on disability rights issues, including charging. The National Centre for Independent Living believes that charging is socially unjust (NCIL 2000). Inclusion Scotland state in their manifesto:

Not only does means-testing and charging for independent living services inhibit the motivation of many to work, save and

participate as responsible citizens, but it is effectively a double-taxation on those who have already paid national and local taxes, which like our non-disabled peers are levied on us for our security and support by the state. Taking earned income, pensions and savings into consideration when calculating charges to support the social inclusion of disabled people in society is discriminatory and repressive. In fact, making disabled people pay for our inclusion in society could be argued to be tantamount to institutional intimidation, venality and extortion; and as such should be outlawed (Inclusion Scotland 2006: unpagged).

The Scottish disability movement assumed that the introduction of free 'personal care' would include disabled people:

“We assumed that free personal care in Scotland would be for everyone. So the disability movement didn't lobby as hard as the older people's organisations.... Even the public assumed that it included everybody.” [Jon]

A number of possible reasons as to why this did not happen were put forward by participants:

“There are a lot of elderly people in Scotland and if you can secure their vote then you’ve got a good chance of forming the next government. But you’re not going to get elected on the back of just disabled people’s votes.” [Tom]

“The decision... was driven by cost. Politicians have more emotive feelings of care and protection towards older people... Also the grey vote is important.” [William]

“It’s the children of grey vote who stand to inherit from their parents and saw their money being eroded by charging.” [Sarah-Jane]

The decision seems to have also caused inner turmoil within the Scottish Labour Party:

“I know from my own involvement in the Labour Party that community care charging has rattled a lot of MSPs and activists, particularly because a lot of the people campaigning for it to be scrapped are actually in the party. So it’s caused a lot of chaos in one of the governing parties, but I doubt whether this will lead to charging going away.” [Tom]

Morris (2005b) points out that the Scottish distinction between 'personal care' and 'social care' in deciding which services should be free may have opened up inequalities between different groups of disabled people and created further barriers to independent living. Participants indicated that disabled people have difficulty with the artificial distinction between personal and social care:

"Differentiating between personal and social care is hard sometimes. For example, say you're staying in a hotel – that's social, but you still need personal care wherever you are." [Patrick]

"A lot of the stuff that elderly people want are things like someone to do their shopping, but these things are charged. It's free if you need someone to feed you, but you're charged for someone to make your meal. You're allowed two baths a week – if you want more then that's considered a luxury and you'll have to pay for them. So free personal care in Scotland isn't what it seems." [Zoe]

Zoe also commented on the barriers she'd encountered whilst campaigning against charging:

"One problem is, when people hear about charging, they genuinely think 'that's ridiculous'. Even social workers have responded in

disbelief when I've told them that, out of my wages, I pay more in charges that I get to keep." [Zoe]

However she was optimistic that, if students, young people and young disabled people could push this issue, then charges (or at least assessment of earned income) could be abolished in Scotland:

"Anne Maguire [Minister for Disabled People] was sympathetic and pointed out that I wouldn't have my earnings taken into account if I lived in England but Andy Kerr, who's responsible for charging in Scotland, was just non-responsive. We did a campaign, with disabled people lobbying MSPs as they went into Parliament but none of them would have their picture taken with the banner. But it did spark a review of community care legislation by the health committee, which basically says that free personal care for the elderly didn't cost the country in a few years time more than it would have if it hadn't existed; and also that it constituted age discrimination not allow it to people under 65. I think, come the legislation at the end of the year, that age grounds would be a good challenge." [Zoe]

Conclusions

This chapter has looked at how charging creates barriers to independent living, absorbing income which was meant to pay other disability-related costs and, in extreme cases, preventing disabled people from accessing independent living services altogether. This would seem to directly conflict with the Department of Health's aim "to increase individuals' independence and choice by giving them control over the way the services they receive are delivered" through direct payments (DH 2005: 82). It would also equally seem to conflict with the Scottish Executive's aim to uphold the right "to live an independent life, rich in purpose, meaning and personal fulfilment" (Scottish Executive 2005: 9). In short, charging denies personal assistance users basic, fundamental human rights.

Chapter 7: A Way Forward

This final chapter draws on the themes and issues outlined in the previous three chapters to present an evaluation of the effects of community care charging in both England and Scotland; and suggest ways in which the barriers to independent living could be removed.

England versus Scotland

This study has highlighted a number of differences between England and Scotland in how community care charging has been carried out.

The widely publicised policy of free ‘personal care’ for people aged 65 is a significant step forward in Scotland, although it would be better still if this policy was open to all disabled people. However this study found that the Scottish definition of ‘personal care’ does not encompass many of the aspects of personal assistance such as shopping, going out, etc. In addition assistance is rationed, so that for example if someone wants assistance to have more than two baths per week then they will have to pay for that assistance themselves.

It was also found that less specific guidance in Scotland around informing people of charges has led to them being presented with large, backdated bills that they were completely unaware of.

The assessment of earned income in Scotland is another major difference, removing the incentive to work for many Scottish personal assistance users.

Finally the Scottish limit of £6,000 on savings not taken into account is approximately half of the limit set by both the ILF and English local authorities. This has the effect of hampering disabled people trying to save for equipment such as electric wheelchairs and adapted vehicles; and may adversely affect disabled students applying for a student loan.

Therefore in order to avoid being disadvantaged by charging as much as is possible under the present system, a personal assistance user who is employed and not funded by the ILF would be well advised to live in England until the age of 65 to avoid losing earned income, then move to Scotland to have some of their personal assistance provided for free.

Removing the Barriers

This study has found that community care charging negatively impacts upon the lives of personal assistance users, creating barriers to independent living. This section will discuss improvements that could be made to the present charging system. The next section will discuss abolishing charging altogether, the only sure-fire way of completely removing all of the barriers.

The community care assessment does not afford personal assistance users complete choice and control over the support they receive and how they receive it, even though they end up paying for it. A holistic self-assessment process supported by local user-led organisations would ensure that they could make informed decisions about what support they required. In addition, financial assessments should be less invasive or even scraped altogether.

Many of the barriers discussed are caused by weaknesses in the charging policy guidance for both England and Scotland, resulting in local authorities interpreting this guidance differently. Much tighter guidance, or more ideally regulation, would ensure consistency and enable personal assistance users to move from one local authority to another without worrying how they will be affected financially.

If charging is to remain then personal assistance users should be given the right to accessible information concerning charging before their assessment; an accessible contract detailing how their charge has been calculated; and accessible prior notification of changes to the amount they pay.

The Scottish limit on capital should be increased to the same amount as the English limit. Ideally the limits on savings imposed by both the ILF and all local authorities should be substantially increased to enable personal assistance users to save for a deposit on a home or a vehicle, or removed altogether. Savings accounts specifically for purchasing disability-related equipment and adaptations should be disregarded, as should student loans, grants and other education-related income.

The English guidance should not base exemption from charging on employment-related state benefits, as this indirectly creates a disincentive to work. Equally the Scottish guidance should disregard all earned income for the same reason. Both local authorities and the ILF should also disregard income from pensions, as this loophole creates inequality for older people.

Finally the assessment of disability-related benefits has left personal assistance users with insufficient income to cover their disability-related expenditure. Therefore an additional benefit along the lines of the discontinued attendance allowance should be created to cover disability-related expenditure, thus leaving the DLA 'care component' to pay for personal assistance.

However since the implementation of all of these steps would reduce the possible income from charging to the newly-redefined DLA 'care component', it is probably simpler and more economical for the government to abolish charging altogether and pay this money directly to the independent living funders.

Abolishing Charging

In the view of all of the people interviewed for this study, community care charging amounts to an additional form of taxation solely levied at personal assistance users. It works contrary to the UK Government's commitment to social inclusion (Campbell *et al* 2002) and the community care policy objectives of promoting individual choice and self-determination (Priestley, 2004a).

There is considerable evidence to suggest that an end to charging would not lead to the often-alleged public outcry over increases in taxes.

The introduction of free 'personal care' in Scotland has not led to undue extra public spending (Bell and Bowes 2006). A telephone survey targeting people aged 50 and over and carers in Scotland found only 5% thought older people should be responsible for funding their own 'care' (NFO System Three Social Research / MORI Scotland 2001). This was backed up with focus groups, where there was a large majority opinion in favour of free 'personal care' (Jones *et al* 2001). A similar survey in England found that a third of its participants favoured a policy of the costs not being borne by disabled people and carers, whilst only 4% thought recipients of community care services should pay the entire cost (DRC 2006). This same poll concluded that half the public support an increase in tax to fund better social care, whilst just a quarter opposes such a move.

This study has also found a considerable amount of resistance to charging from disabled people's organisations. Although the opinion of both these organisations and the public seem largely in favour of abolishing charging, the testimony of the interviewees in the previous chapter indicates that the barrier to change lies with convincing the politicians of the need for reform.

This study concludes that personal assistance, like healthcare should be freely available. Since both are a human right, it is unfair and

illogical to fund the latter service through general taxation whilst expecting users of the former service to pay a contribution.

Appendix: The Interview Schedule

1. What is your name?
2. Where do you live?
3. Which local authority are you under?
4. How old are you?
5. Please briefly describe yourself and your involvement with direct payments and charging?
6. Can you describe your impairment and the personal assistance you require?
7. Did your community care assessment take all of your requirements into account?
8. Does your local authority charge direct payments users?
9. When were you informed that you may have to pay charges?
10. Was clear, accessible information available on the local authority's charging policy?
11. When were you informed of how much you would have to pay towards the cost of your personal assistance?
12. When you were informed of how much you would be charged did you consider reducing the number of hours of personal assistance you receive or even choosing not to receive support?
13. If you had done this, who would have provided the additional assistance that you require?
14. Do you feel that your disability-related benefits cover the cost of all your disability-related expenditure?
15. If charging was abolished, how would you spend the money that you currently spend on charges?
16. If one week you choose to use less personal assistance for whatever reason, is this reflected in the charge that you pay for that week?

17. Has charging had an impact on deciding whether or not to take up employment?
18. Has the local authority's charging policy had an impact on you deciding where you should live?
19. Are you aware of any local authorities close by that charge less / more / don't charge at all?
20. Disabled people with savings of more than the upper limit defined by the Charges for Residential Accommodation Guidance may be asked to pay a full charge of a service. Has charging had an affect on your ability to save money for your future?
21. How might this possibly affect you in the future?
22. Are there other ways in which charging impacts on your life?
23. Do you think charging policies are fair?
24. Should disabled people have to pay charges at all?
25. Have you ever participated in any campaigns against charging?
26. Were these campaigns successful or not and why?
27. Do you wish to make any other comments?

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