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Paying the piper and calling the tune: a study to consider how the opportunity to employ workers using cash payments affects the support relationship

Thesis

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Paying the Piper and Calling the Tune: A Study to Consider how the Opportunity to Employ Workers Using Cash Payments Affects the Support Relationship

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Abstract

Paying the Piper and Calling the Tune: A Study to Consider how the Opportunity to Employ Workers Using Cash Payments Affects the Support Relationship

This thesis is about direct payments; the name given to cash payments made by local authorities to disabled adults, to enable them to buy their own care. Many people use their direct payment to become an employer by recruiting a personal assistant to provide their support, and it is this direct employment relationship, between disabled adults and their employees, that is the focus of the thesis. The study examines the history and policy of social welfare in Britain showing that the use of cash payments has been a recurring theme in care provision, and is part of an evolving process. The present government has demonstrated ongoing commitment to the radical increase in the numbers of disabled adults accessing user-controlled support, such as direct payments, however the direct employment of support workers is poorly understood with most research focusing on the interests of disabled adults whilst ignoring the perspective of workers.

The study investigates the effect of cash and direct employment on the support relationship in one local authority in England. It uses a grounded theory approach, with two questionnaires to measure job satisfaction and stress, and in-depth interviews with respondents. It explores and compares the experiences of eight direct payment relationships with eight traditional service delivery homecare relationships. The research provides a comparison between direct and non-direct employment, together with an examination of the experiences of both parties in the relationship.

The analysis of the data reveals the inherent complexity of care relationships and shows the importance of the concept of power in helping to understand the impact of direct employment on these relationships.

Dedication and Acknowledgements

This work is dedicated to the memory of my much loved parents Jeanne and Ken Sewell, who died during the course of it's progress, and have left an irreplaceable gap in my life.

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Chapter 1 Introduction

I'm the piper, I pay the money
(Freda, Direct Payment User)

My interest in direct payments started in 1999 when in my role as commissioning officer for Staffordshire social services, I was asked to manage the contract for the organisation providing a support service to a direct payment pilot project. Since 1997, following the implementation of the Community Care (Direct Payments) Act 1996, local authorities have been able to make cash or direct payments to disabled people[1], so that they can purchase their own support. People using direct payments can buy whatever support they wish, as long it meets their needs, as assessed by the local authority. This may involve buying special equipment, eating out in a restaurant, visiting friends and relatives, employing a personal assistant[2] to help with everyday tasks and so on. The employment of personal assistants has always been a key element in the use of direct payments, and most users choose to spend the money in this way (Zarb and Nadash 1994; Glasby and Littlechild 2002). It is this aspect of direct payments that I found of particular interest; the opportunity for disabled adults[3] to directly employ their own

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[1] The term 'disabled people' refers to people with a disability aged 18 to 60 years. The term disability is used to reflect the views of the disabled people's movement and the social model of disability where disability is defined as *'the disadvantage experienced by an individual as a result of barriers that impact on people with impairment and ill health'* (Prime Ministers Strategy Office 2005:4).
[2] A personal assistant has been defined as *'the person employed via a direct payment to provide practical, day-to-day support to a disabled adult* (Hasler with Stewart 2004:3). I also refer to personal assistants as 'employees' or 'direct employees'
[3] I use the term 'disabled adults' for ease of writing to refer to people with a disability aged 18 years and over. This also encompasses older people.

support workers. My work in social services made me interested in the implications of direct employment on the care relationship, whilst as a woman I wondered about the impact on the largely female workforce of care workers.

In response to the legislation, a direct payment pilot scheme was started in Staffordshire, in April 1998, operating in the south of the county: Lichfield, Tamworth, Burton on Trent and Uttoxeter. As part of my work I reviewed the pilot scheme (Leece 2000), tendered the support service and extended the direct payment scheme to cover the whole county. I went on to conduct further research to look at the use of direct payments by older people (Leece 2001), direct payments for carers of disabled adults (Leece 2002a), the recruitment of personal assistants (Leece 2002b), direct payments to parents of disabled children (Leece et al 2003), and to write a book about direct payments for practitioners (Leece 2003a). By this time I had become fascinated by the relationship between direct payment users[4] and their personal assistants. I was intrigued to find out whether paying their workers wages directly altered the support relationship, and how this relationship compared with that of traditional service delivery such as homecare, where workers are not employed by disabled adults, but by a local authority or homecare agency. It is important that the direct payment relationship is not seen and judged in isolation from similar care provision, such as homecare, as the comparison between direct and non-direct employment of care workers is a crucial part of understanding the effects of cash payments in care relationships. For many disabled adults the alternative to direct payments is the receipt of homecare, and for workers too the jobs are a source of

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[4] People using direct payments are referred to as 'direct payment users'. I also use the terms 'employer' or 'direct employer' to refer to people who use direct payments to employ their own personal assistant.

comparable employment. Yet as I will show in chapter 3 this comparison of direct and non-direct employment of support workers is missing from UK literature. I felt it was essential that research should investigate this relationship and my PhD study has grown and developed from that interest.

The impetus for the development of cash payment systems both in the UK and other developed countries has a number of important strands. Changes in demographic trends, where increased longevity together with decreasing birthrates, means there are increasing numbers of very old people needing care with comparatively fewer younger people available to deliver it. Coupled with greater labour market participation of women, and changes in family structure resulting in a reduced pool of working aged women willing and able to provide informal care, has caused governments in the developed world to seek ways to contain the cost of social care, without the need to initiate tax raising measures (Ungerson and Yeandle 2007). User-controlled support such as direct payments is seen by some, as a cheaper way of delivering care without a reduction in the quality of the support (Netton et al 2005; Wanless Review Team 2005), although as I will argue in chapter 9 this assumption is by no means certain.

Alongside demographic changes powerful groups of disabled adults, promoting ideas of independent living based on 'cash for care schemes' and the use of personal assistance, exerted sustained pressure for the right to receive direct payments. The feminist debate on informal care which argued decades ago that women should receive payment from the state for the unpaid work many perform in supporting their families (Oakley 1972, 1974), and the carers' movement in its campaign for improved state support and

public recognition for informal carers (Bytheway and Johnson 1998) can all be seen as components in the development of direct payments. New payment systems for care emerged throughout the 1990's in countries in the European Union (EU), Canada, Australia and parts of the US (Ungerson and Yeandle 2007).

In terms of UK social policy trends, the shift towards marketisation of social care within the last fifteen to twenty years, which brought about the introduction of quasi markets, the contract culture and large scale privatisation has been argued to be the beginning of a move towards the direct purchase of support by users. Indeed Ungerson (2003) suggests that once the market system was in place then direct payments for users was almost a natural progression. Certainly as I will show in chapter 9, the present Labour government has demonstrated on-going commitment to direct payments placing continued pressure on local authorities to significantly raise the numbers of people using them: 'The government expects to see a substantial increase in the numbers of direct payment recipients and will be monitoring local council's progress in achieving this goal' (DoH 2003:5). Strategy and policy proposals such as: 'Improving the Life Chances of Disabled People' (Prime Minister's Strategy Unit 2005) and the White Paper 'Our health, our care, our say: a new direction for community services' (DoH 2006:6), have continued this trend focussing strongly on the development of individualised budgets[5] in social care. In a speech at the National Conference on Direct

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[5] An individualised budget is an umbrella term, which covers three ways of delivering services. Under government proposals an individual would have control of the resources a local authority has allocated to meet their needs, in the same way as a bank account. Resources can be taken as a combination of cash (direct payment); services brokered by an advisor; or commissioned by a local authority (Rankin 2005)

Payments in May 2007 Ivan Lewis, the Parliamentary Under-Secretary of State for Care said that: 'Direct payments are not yet mainstream, but they are the future of social care'.[6]

Radical increases in the numbers of people using direct payments to purchase support is likely to result in the direct employment of many more people as personal assistants, and this gives greater motivation for research that examines this employment relationship. As yet, welfare policy appears to have paid little heed to the position of people employed by direct payment users. Indeed care workers generally are 'a curiously under examined feature of the policy changes and debates' (Cameron and Moss 2001:8). The direct employment of workers by disabled adults raises many important issues. For example, at the time of writing there is no requirement for employees of direct payment users to register with the General Social Care Council, which contrasts sharply with the move towards a more regulated and skilled care labour force in other contexts. Employment by a single individual as opposed to an organisation, such as a local authority, may result in fewer training opportunities, less support and protection for employees, a lack of access to formal qualifications and fewer employment rights. Direct employment of support workers may provide an environment where both employers and employees are at risk of abuse. With all of these issues in mind, I wrestled to develop a research question, which changed many times to eventually become: 'How does the opportunity for disabled adults to employ their own workers affect the support relationship?' The title of the thesis was based on a

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[6] This is a quote from a speech by Ivan Lewis spoken at the National Conference for Direct Payments: *Direct Payments: A Route to 21st Century Social Care,* organised by the Department of Health, which I attended in Manchester on 21st May 2007.

comment made by one of the respondents in the study: 'I'm the piper, I pay the money'. It reflects the ability of disabled adults to have the money and pay their own workers, and for me this symbolises the whole debate about cash payments.

The research is timely and forms a significant contribution towards the debate in social welfare about cash payments. The direct employment relationship is clearly of interest, and yet in this thesis I will argue that it is poorly understood, with research focusing on the interests of disabled adults whilst ignoring the workers providing support. The study provides the important comparison between direct and non-direct employment, by comparing the relationship of eight direct payment users and their directly employed personal assistants, with that of eight homecare users and their workers, who are employed by Staffordshire social services. To enable respondents to speak in their own words the research applies a grounded theory approach, using in-depth interviews with respondents. Two questionnaires relating to job satisfaction and stress provide further methods of exploring the relationships in greater detail, and three disabled researchers served as a panel of experts to guide the research design.

1.1 Clarification of Terms

To avoid confusion, it is helpful at this point to clarify some of the terms used in the thesis. The expression 'care' has itself been hotly debated in the literature on informal care (Finch and Groves 1980; Graham 1983; Ungerson 1983; Begum 1990; Brechin et al 1998), with a distinction being made between the acts of caring *for* rather than caring *about* (Ungerson 1983). In the feminist perspective it is argued that caring is the: 'unpaid responsibility

that women have for the welfare of their families' (Graham 1993:126), whilst disabled activists reject this concept of 'care' arguing in favour of the term 'support'. The notion of support moves away from ideas of dependence by indicating that a person is active in receiving help. Disabled activists define support as: 'help from another person with all the activities of day-to-day life' (Hasler et al 1999:14).

In this thesis, rather than indicating an acceptance of the superiority of either perspective by the use of one or other term, I have used both care and support interchangeably. This is intended to suggest recognition of the validity of the arguments of both perspectives, and also that there needs to be a greater sense of balance between the interests of disabled adults and the women who predominately provide their care (either paid or unpaid). The terms 'care relationship' or 'support relationship' are used to describe the relationship between a disabled adult and the person providing their social care, this may be a homecare worker, family or friends providing informal unpaid care or a personal assistant employed via a direct payment.

Another area where clarification is useful is the meaning of the terms 'social care' and 'health care', as their ambiguity is well documented (Glendinning et al 2000a, 2006; Lewis 2002; Glasby et al 2004; Henwood 2006). Definitions of health care have altered over the last fifty years with a sizeable reduction in the scope of National Health Service (NHS) responsibilities, especially those relating to the long-term nursing of disabled adults. Many tasks previously considered to be the domain of nursing staff are now routinely undertaken by homecare workers, with a general shift of responsibilities from the NHS towards local authorities (Taylor 2000). To make matters even more confusing

there are considerable local and regional variation in practice, with definitions of what is or is not health care, subject to legal challenge (Glendinning 2006).

One of the main differences between health and social care is the financial element, as care that is defined as the responsibility of the NHS is free at the point of use, whilst social care funded by the local authority can be subject to charges (Lewis 2002). In general, health care can be taken to mean care of the body, that requires the skills of a nurse or medical doctor, such as surgical intervention, gastric feeding, care of pressure areas, and is the responsibility of the NHS (DoH 2005a). Social care meanwhile: 'deals with those aspects of the patient that medicine leaves out, or prefers to assign to other lesser professionals, typically aspects relating to practical needs or social or psychological functioning' (Twigg 2006:120). Social care covers a wide range of provision, designed to support disabled adults in their daily lives, for instance help with washing, dressing, socialising, help to the toilet and to obtain meals (Taylor 2006).

1.2 The Structure of the Thesis

The thesis is divided into nine chapters with each chapter further sub-divided into numbered sections. The history and policy contexts of cash payments are explored in chapter 2, starting with an explanation of their legislative base and take up in the UK. The chapter goes on to provide a profile of direct payments in Staffordshire, the local authority in which the research took place, and discusses social support in Britain, including the shift to a market economy in social welfare. This chapter explores the role of women, the feminist debate of care, the carers' movement, the campaign by disabled activists for the right to have cash payments and New Labour's position on direct payments.

In chapter 3 there is a review and critique of existing literature which provides the opportunity for continued exploration of key perspectives identified in the previous chapter: neo-liberalism and market economy; the feminist perspective of care, and the social justice and rights perspective. The chapter examines concepts relating to the research question such as: paying for care; notions of power; independence; autonomy; and boundaries in the care relationship. It explores the importance of reciprocity in the relationship, concluding with a critique of the literature on stress and job satisfaction. The ontological and epistemological basis for the study is discussed in chapter 4, as is the involvement of disabled researchers in the research process. The chapter compares research methodologies and explains the choice of the grounded theory approach for the study. It details procedures to ensure ethical practice and explains how the study was undertaken, including the process of data analysis.

The next three chapters report the findings of the research, examining differences and similarities between the direct and non-direct employment arrangements, demonstrating the complex nature of care relationships. Chapter 5 'The blurring of the boundaries' explains how respondents perceive the relationships and considers boundary setting, conflicts of interest and feelings of obligation. In chapter 6, 'Autonomy, independence and power' the findings centre on meanings of independence, differences in disabled adults ability to reciprocate in the relationship and the power dynamics. The chapter goes on to look at notions of power by exploring the status of care work and perceptions of domestic service. Chapter 7 'Investigating stress and job satisfaction: positive and negative aspects of the support relationship'

reports the results of the job satisfaction and stress questionnaires, and these are considered together with interview data. The chapter looks at respondents' views about methods of working and the impact these have on satisfaction and levels of stress. It considers areas such as the employment of family by disabled adults and finally the extrinsic elements of work such as pay and conditions of employment.

The penultimate chapter provides a discussion of the findings presented in the previous three chapters. It draws together all the main threads of the research and situates the study within existing literature. The chapter demonstrates the contribution the study has made to the literature and the debate about cash payments. In chapter 9, the conclusion to the thesis, the research is placed in the wider context of policy, together with a consideration of the implications of the work. In the final sections of this chapter recommendations for practice and for future research are made.

Chapter 2 Cash Payments: History and Policy Context

The introduction to this thesis has established the aim of this research, which is to consider how the opportunity for disabled adults to employ their own workers using cash payments affects the support relationship. In this chapter I provide background to the provision of social support and consider three perspectives important in explanations of cash payments: the market economy perspective including neo-liberalism, the feminist ethic of care and the social justice and rights perspective. To place this study in context I start by explaining direct payments, moving on to consider their legislative base, how they can be used and their take-up both nationally, and in the county of Staffordshire, where the research was undertaken.

2.1 Direct Payments Explained: Legislation and Take-Up

A direct payment is a cash payment made by a local authority to a person assessed as needing certain services such as a community care service (Appendix 1), so that they can buy services for themselves. An individual uses the payment to meet their assessed needs, instead of the local authority providing or buying services on their behalf. This may involve people buying special equipment, spending time away from home, eating out at a restaurant, going to a gym, employing a personal assistant to help with everyday tasks and so forth. People can receive mixed packages of support with a direct payment and some directly provided services, although at the time of writing direct payments cannot be used to buy services provided by a local authority, for permanent residential care (DoH 2003), nor for services that are the responsibility of the NHS (**www.dh.gov.uk**). Direct payments are intended to:

'Promote independence, choice and inclusion...to give recipients control over their own life by providing an alternative to social care services provided by a local authority' (DoH 2003:3-4)

To allow local authorities to make payments directly to disabled people in England, Wales and Scotland, the Community Care (Direct Payments) Act 1996 was implemented on 1st April 1997. This Act gave local authorities the power (but not the duty) to make cash payments to disabled people, aged less than 65 years, to enable them to purchase care. Prior to this legislation it had been illegal for local authorities to give money directly to service users for the purchase of their support, although a few local authorities got around this by using third party or indirect payments (Evans and Hasler 1996). On 1st February 2000 the legislation was amended to include older people, so that they too could receive a direct payment. The 1st April 2001 saw the implementation of the Carers and Disabled Children Act (2000). This extended the powers of local authorities still further to expand direct payment schemes to include people with parental responsibility for a disabled child, disabled young people aged 16/17 years and carers of people aged 18 years and over. On the 8th April 2003 the Health and Social Care Act (2001) Section 57 placed a mandatory responsibility upon local authorities in England and Wales to make direct payments to users who meet the criteria.

In Scotland the Community Care and Health (Scotland) Act 2002 made direct payments mandatory in June 2003 and allowed parents of disabled children to have a direct payment, although unlike England and Wales it excluded people providing care to adults (Pearson 2006a). The Act differed from legislation governing England and Wales, as it initially contained proposals to enable

local authorities in Scotland to make direct payments not only to disabled adults, but to all people assessed as having community care needs, including people fleeing domestic violence, refugees, homeless people and people recovering from drug or alcohol dependency. These proposals were due to take effect from 2004, but amid concern that local authorities would be unable to cope, the proposals for the additional user groups were withdrawn (Pearson 2006b).

Systems of cash payments for disabled and older people exist throughout Europe, Australia, Canada and the United States. In North America there is a much longer history of cash funding than the UK (Lord and Hutchison 2003). Cash schemes vary in the way they are funded, some are financed in the same way as the UK from central taxation, and others such as in Holland and Germany from long term care insurance (Leece 2004b; Ungerson and Yeandle 2007). Schemes also differ in the amounts of money paid and the way they operate which can make comparisons between countries difficult. For example, in Austria the 'Pflegegeld' system can be used to pay for permanent residential provision as well as support at home. When people in this system choose a residential home the cash is paid to the institution rather than the individual, which would not be defined as a direct payment in the UK (Osterle 2003).

In England and Wales local authorities have some discretion about the operation of direct payments, for example it is up to each authority to decide on the amount of direct payment as long as it meets the 'reasonable cost of securing the provision of the service involved' (DoH 2003:22) resulting in differences between schemes. However many features are constant between

local authorities, due to the comprehensive guidance for direct payments issued by the government (DoH 2003). To obtain a direct payment a disabled adult first needs to undergo a community care assessment by the local authority under the NHS and Community Care Act (1990). Individuals also need to meet the individual eligibility criteria set by local authorities following the government's Fair Access to Care Guidance (DoH 2001a). Following this if a person has community care needs they should be offered the choice of a direct payment or local authority arranged support such as homecare, although in practice research shows that many people are not being given the option of direct payments. For example, in 2005-06 only 17 per cent of local authorities were offering direct payments in all assessments (Commission for Social Care Inspection 2005-06), and this will be explored later in this section. When a direct payment has been agreed an amount will be paid into the individual's bank or building society account each month, and this must be used by them to meet their assessed needs. Local authorities have a responsibility to review individuals' needs and monitor that the direct payment is being used to meet these needs (D0H 2003).

Statistics indicate that take-up of direct payments in England was initially slow and from a low base increased steadily. For example, Table 1 shows that from September 2002 to March 2005 the numbers of people using direct payments trebled to just under twenty-five thousand users. Scotland, Northern Ireland and Wales have around half the number of direct payment users there are in England relative to population (Riddell et al 2005). Direct payments currently form a small proportion of social care, for example in 2002-2003 (when my study was conducted) there were an estimated 1.68 million people

receiving a social care service and direct payments made up just over 0.75

per cent of the total (DoH 2005a).

Table 1	Numbers of people using direct payments in England				
	30/9/2001	30/9/2002	30/9/2003	30/9/2004	3/3/2005
Total number of Recipients	5,423	7,882	12,585	21,912	24,744
Older people (65+)	537	1,032	1,899	4,365	5,493
People with learning disabilities	353	736	1,337	2,354	3,142
People with physical disabilities	4,274	5,459	6,944	9,733	11,376
People with sensory disabilities	100	159	207	*	*
People with mental health needs	61	132	229	520	830
Young carers	3	3	12	*	*
Carers of disabled children	66	228	875	*	*
Disabled children (16-17 years	8	38	125	*	*
Carers (for carers services)	21	95	957	2,327	2,327
People with HIV/Aids	*	*	*	*	253
Drugs and Alcohol Misuse	*	*	*	*	15

(Sources: Council's Delivery and Improvement Statements 2001-2003, Cited in Commission for Social Care Inspection 2004 and 2005a)
*Data unavailable

The take up around the country has been variable with generally the north of

England reporting a lower take up than the south (Hasler and Stewart 2004),

which may be related to local authorities' 'ideological positions' (Pearson

2001). For example, research found that there was resistance to

implementing direct payments in a local authority where senior policy planners

saw them as part of a wider drive to privatise social care services (Pearson

2000). In other local authorities such as Hampshire, which at the time of

writing has the second largest number of people using direct payments in the UK (see Appendix 2), there has been a greater eagerness to develop the social care market combined with a long tradition of involvement with local disability groups (Pearson 2004). Riddell et al (2005:80), drawing on data from an ESRC funded project about direct payments, argue that: 'in general, Labour controlled local authorities have failed to develop direct payments, whereas in Conservative controlled local authorities particularly where there is a strong user-led support organization the numbers of direct payment recipients has increased markedly'.

The statistics in Table 1 indicate there are imbalances in take up rates between groups of disabled people. For example, despite being the largest single group of people using community care services, older people make up less than one sixth of the total number of people accessing cash payments, whilst people with physical disabilities form the largest single group. There are a number of possible explanations for this. The disabled people's campaign for the right to receive cash payments (which will be discussed later in this chapter) tends to be associated by local authorities with younger people who have a physical disability and it is likely that the idea of direct payments has become linked with this group of people (Leece and Leece 2005). This focus on younger people may result in fewer older people being offered direct payments by social workers or care managers and may form one of the barriers to older people's take up. Some studies have suggested that social workers are failing to offer direct payments to older people, because they believe that older people will not want the responsibility associated with managing the payments (Hasler et al 1999; Clark et al 2004; Lomas 2006).

Table I shows that fewer people with learning disabilities access direct payments in comparison with people with a physical disability. Williams and Holman (2006) argue that one of the major stumbling blocks for people with a cognitive disability is the issue of 'consent and manage'. Local authorities can make a direct payment only if they are satisfied that a person is able to manage them either alone or with help and has consented to receiving them (Appendix 1). Williams and Holman consider that many local authorities apply these criteria too stringently, leading to the wholesale exclusion from direct payments in many areas, of people with learning disabilities.

Research in Scotland found that direct payments are rarely offered to people with mental health needs often because of concerns by professionals about how people will manage the money when they become unwell (Ridley and Jones 2002). Social workers in this study were worried about giving cash payments to people whose judgment may be impaired either temporarily or permanently. Professionals also raised concerns that giving people the money, instead of providing them with a service, could result in services provided by the local authority being lost. A more recent study found that many people with mental health needs said they had not been told about direct payments by their social worker and that social workers involved with them had a poor understanding of direct payments (Newbigging and Lowe 2005).

2.2. A Profile of Direct Payments in Staffordshire

The research was undertaken with a group of people receiving either direct payments or homecare from Staffordshire social services and the workers employed to provide their support. Staffordshire is a large, rural county

stretching from the Staffordshire Moorlands in the north, through Cannock Chase down to Kinver in the south of the county. With a population of just over 800,000, Staffordshire is the seventh largest shire county in England (Staffordshire County Council 2003). Located in the industrial heartland of Britain positioned between Manchester and Birmingham, with Shropshire to the west and Derbyshire to the east, the county consists of eight districts and several large towns and cities. In April 1997 the city of Stoke on Trent separated from the county in terms of its administration, to become a unitary authority.

In common with the rest of Britain, Staffordshire has an ageing population with twenty-one per cent of its population being over the age of sixty, and a forty-five per cent increase in the population aged over eighty-five from 1993-2003 (Staffordshire County Council 2003). Staffordshire has a slightly higher percentage of people with a long-term illness than nationally and more people providing informal unpaid care. There is a lower black and minority ethnic (BME) community than the rest of the Country, at just under two and a half per cent, opposed to nine per cent on average nationally (Census 2001). At the time the study took place only one person from the BME community was using direct payments.

Staffordshire social services has offered direct payments since starting a pilot project in 1998, for disabled people including those with learning disabilities, aged under sixty-five years. When the pilot project was evaluated (Leece 2000) there were only ten people in receipt of a cash payment with a further six in the process of arranging one. Following the evaluation, the scheme was extended to the whole county in September 2000 and also made available to

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older people. In November 2001, parents of disabled children, disabled young people and young carers were also included in the scheme. Staffordshire was one of the few local authorities to provide direct payments to parents of disabled children at this time (Social Services Inspectorate 2003). Since 1998 social services has contracted with the Rowan, which is an organization representing disabled adults, to provide a support service to direct payment users. The Rowan provides information about direct payments and employment law, helps people to recruit personal assistants and operates a payroll service for users (**www.therowan.org**).

When the fieldwork for the study started in October 2003, there were ninety-four disabled adults using direct payments in Staffordshire. Compared to the national picture, Staffordshire was a long way behind some authorities such as Essex, Hampshire and West Sussex, but well ahead of many others (North Tyneside, Slough, York), which were reporting low numbers of users. Hampshire for example had over six hundred and fifty direct payment users at this stage whilst York had only two (Appendix 2). Appendix 3 indicates that compared with other similar local authorities in the Performance Indicator Comparator group (**www.audit-commission.gov.uk**) Staffordshire is slightly below average in terms of take up of direct payments. Table 2 shows that take up of direct payments for user groups in Staffordshire has a similar imbalance to the national picture, as the largest group using direct payments in Staffordshire were people with a physical disability, whilst people with learning disabilities, mental health needs and older people typically had a lower take up rate.

Table 2	
Numbers of people using direct payments in Staffordshire (October 2003)	
Total number of Recipients	94
Older people (65+)	18
People with learning disabilities	15
People with physical disabilities	58
People with sensory disabilities	Not recorded
People with mental health needs	3
Young carers	0
Carers of disabled children	20
Disabled children (16-17 years)	0
Carers (for carers services)	0

Staffordshire has been described as having the historical legacy of a traditional labour authority with regard to many of its practices (Henwood and Waddington 2002). It has not embraced the market approach to social care as vigorously as some local authorities. For instance, in 2002, social services was providing sixty per cent of its homecare provision in-house unlike some other local authorities, which contract with independent sector agencies for all of their homecare provision (Knapp et al 2001, Henwood and Waddington 2002). The approach to direct payments also appears to reflect this political legacy resembling the slower development of the north of the country.

The chapter now moves back in time to explore the history and policy context of cash payments to discover how direct payments came into being.

2.3 Social Support in Britain: Neo-liberalism and the Market Economy Perspective

Cash payments for the provision of social welfare are not new. The origins of social welfare in twenty-first century Britain are rooted in nineteenth-century philanthropy and the charitable organisations, which distributed money to 'the deserving poor'- those people considered unable to work due to age, disability

or lack of suitable employment. In 1814 overseers at Chepstow paid 1s 6d 'for shaving Charles Fisher for six weeks' (cited in Borsay 2005:187). Whilst for the 'undeserving poor', people whom it was felt could work (but apparently chose not to), the Poor Law provided outdoor relief in the form of cash, clothes and food (for a history of the Poor Laws see Slack 1995).

From 1750-1850 Britain experienced a growing trend towards industrialisation, with large movements of the population from agricultural areas into rapidly expanding towns. This move towards an industrialised society brought about a change in the nature of work with many women working outside the home in factories, resulting in a loosening of family ties and obligations, which placed enormous strain on the poor relief system in operation at the time (Dexter and Harbert 1983; Borsay 2005). To counter this, the Poor Law Amendment Act (1834) was passed by Parliament, to reduce the scope of poor relief. People who were destitute were not given state support in their own homes; their only option was the workhouse; an institution greatly feared by the general population, for its stigmatising, unpleasant and frugal conditions (Means and Smith 1998).

The thinking behind the Poor Law Amendment Act was that to provide practical or financial help to people in need would reward the 'the feckless and the thriftless' (Glasby and Littlechild 2002:4) and create dependency upon the help provided. It would also reduce individual responsibility, so undermining family life and the nation's moral fibre, subsidise employers, thus keeping wages at an artificially low level and damage trade and industry by diverting profits to help poor people (Hunt 1970). The distinction between the deserving

and undeserving poor has run through the history of social policy and is still current in much social welfare thinking today (Means and Smith 1998).

There were many amongst the richer classes who were aware of the extent of poverty and by the 1850's it had become fashionable for wealthy ladies to undertake charitable work. A number of charities offering support to disadvantaged people, such as the Charity Organisation Society and the Jewish Board of Guardians started around this time. Alongside poverty there was a widespread general ignorance regarding health hazards and personal hygiene. Poor sanitation, contaminated water supplies, badly constructed houses and overcrowding, contributed to recurring epidemics and high rates of infant mortality. As a response charitable organisations began to extend into provision of nursing care for poor people in their own homes and a network of voluntary and municipal hospitals and medical missions developed (Marks 1996). Training schools for nurses were set up and by 1887 the concept of district nursing had spread across the country, with almost 500 branches formed by 1902 (Dexter and Harbert 1983; Rose 1988). These early district nurses completed many domestic tasks, such as helping people to wash and dress in their own homes, which would later be considered legitimate work for the homecare service.

Social researchers such as Charles Booth and Seebohm Rowntree completed surveys of poor areas showing statistically the full extent of health and social deprivation in Britain. These studies demonstrated the lack of health and fitness of army recruits, infant and child death rates, and disadvantages of children from poor families in terms of their weight, height and general health (Rowntree 1901). It became apparent that the arguments for lack of state

involvement in family life were not acceptable in the new industrialised way of life. Attention focused on maternity and midwifery services owing to the high rates of neo-natal, infant mortality and the poor physical condition of children. The Maternity and Child Welfare Act (1918) empowered local authorities, for the first time, to provide domestic help in the home for pregnant women, these powers were continued by the Local Government Act (1929) and the Public Health Act (1936). By 1939 around half of all local authorities were providing a home help service (later known as homecare) for home confinements (Welshman 2000b; Borsay 2005).

The Second World War created an enormous impact on family life with increasing numbers of women working in factories, on the land and in the armed forces, leaving fewer women at home to care for family members. In 1944 new powers to establish domestic support services were given to local authorities, under the Defence Regulations. These new powers enabled local authorities for the first time to provide home helps to people other than pregnant and nursing mothers. Help could now be provided to elderly infirm people, children whose mother was ill, in hospital, or called away to care for their father in hospital, and families with several members who were ill. It is interesting to note that the legislation clearly assumed that women had responsibility for providing care and support to their families. Means and Smith (1998) argue that the main drive behind this change in policy was to prevent sick and older people from having to enter hospital or residential care and to keep up service and civilian morale. There were attempts to increase home help provision at this time, although these met problems with recruitment of staff. By 1945 about 65 per cent of all local authorities had

home help schemes in place often jointly run with the Women's Voluntary Service, which later became the WRVS (Hunt 1970).

The welfare state, which developed during and after the Second World War, was the result of a great change in social policy. It brought the bulk of health, social care and welfare benefits into central government responsibility and control. Other services such as education and subsidised housing although provided by local authorities, came to be dependent on central financing and policy oversight (Loney et al 1987). The National Health Service Act (1946) established a health service available to the whole community and section 29 enabled local authorities to provide domestic help to households requiring support. The home help service had always been associated with children and maternity, developing around a housework model that traditionally stopped short of intimate care tasks. Home helps would undertake work such as cleaning, fire lighting, washing and ironing clothes, making beds, shopping, help with dressing and care for children (Sinclair et al 2000). Home help provision for older people was mainly accorded to people without family or those on low income (Borsay 2005). At this stage there was no mandatory responsibility for local authorities to provide a home help service, but by 1957 all were providing a scheme in some form (Dexter and Harbert 1983; Welshman 2000a). Local authorities were able to charge service users for the home help services they provided, and this formed an important distinction between social care for which there was a charge, and health care, which since the development of the welfare state was free at the point of delivery. The payment by users for social care is discussed in more depth in section 3.2.

The creation of the welfare state with its system of social security benefits and the abolition of the Poor Law in 1948 brought about an end to social workers in England and Wales making cash payments to people in need. This had previously been allowed under Poor Law legislation. The National Assistance Act of 1948 made direct payments by local authorities illegal. In Scotland the situation differed slightly in that the Social Work (Scotland) Act 1968 allowed social workers to make cash payments in exceptional circumstances, although this provision was rarely used (Witcher et al 2000). The removal of the ability to make cash payments to help people in need highlighted a change in social policy where certain provision by the state, such as education and health was expanded, although there was still a presumption that most welfare needs would be satisfied by either the family or by people purchasing support privately (Cochrane and Clarke 1993).

The expansion of the British welfare regime continued up to the mid 1970's fuelled by the international post war economic boom (Cochrane and Clark 1993). Demographic trends, a combination of a baby boom and growing numbers of older people, increased the demand for welfare services alongside growing prosperity and technological advances, which encouraged greater expectations of care provision. Together with this, a critique of support provided in institutions had been developing, since Townsend's (1962) study provided evidence of poor conditions in residential homes for older people (see Johnson et al 2007 for a longitudinal follow up to this research). This was compounded by a series of scandals about malpractice, low standards and ill treatment of patients in long stay hospitals and nursing homes, such as the

inquiry at Ely in Cardiff (Butler and Drakeford 2005). Long-term institutional care was also seen as ineffective and costly.

This critique combined with a view of the desirability of people living independently in the community with support provided by a network of care, expected to be mainly female relatives (Cochraine and Clarke 1993). Many academics argued that this was a cynical attempt to shift the provision of support from the public purse onto the unpaid labour of women (Finch and Groves 1980; Stacey 1981; Graham 1983; Means and Smith 1985, 1998; Dalley 1988; Finch 1990) and this will be discussed further in the next section of this chapter.

Despite government pressure for support in the community, care in residential and nursing homes remained constant, between around 3-5 per cent of people over sixty-five, throughout the 1960's and early 1970's (Victor 1991). However in the domestic home there were enormous regional differences in the amount of home help support offered by local authorities caused by the permissive nature of the legislation (Means and Smith 1998). In 1960 some local authorities were providing as many as 2 home helps per 1000 population whilst others as few as 0.07 per 1000 (Borsay 2005:190). A study by Townsend (1957) had shown the home help service to be totally inadequate with many people who were in need not getting a service. In response to this, and also to the Seebohm Report (1968), which argued that local authority services should be community based, provision of a home help service was made a mandatory responsibility for local authorities, by the Health Services and Public Health Act (1968). This responsibility was further reinforced in 1970 by the Chronically Sick and Disabled Persons Act (Welshman 2000b).

The 1970's brought political uncertainty, disillusionment and a heightening of social and political conflicts. The Keynesian view of the economic responsibilities of government, and the way economic policy was managed came increasingly under attack, with fears that the welfare system could not be sustained in the form in which it had been developed (Loney et al 1987). There were concerns about the spiralling cost of residential care for older people, despite the push to greater support in the community, and the fear of unsustainable demographic and expenditure trends. Higher and higher wage demands by trades unions, together with rising unemployment and escalating inflation. There were increasing claims made on the government in the form of state welfare and questions about whether the state should actually assume the major responsibility for the provision of support (Johnson 1987; Loney et al 1987; Means and Smith 1994, 1998).

In 1974 the Labour party was elected on the promise of a 'social contract', an agreement between government and the unions to: 'preserve welfare services in return for restraining demands for wage increases' (Cochrane and Clarke 1993:46). In the two years following Labour's return to power real wages fell as the unions complied with the social contract and inflation soared. In an attempt to stem the nation's economic deterioration, the government was obliged to seek help in the form of a loan from the International Monetary Fund. The terms of this loan required a cut in public expenditure on welfare, causing widespread protest and provoking union action in what became known as 'the winter of discontent' (Cochrane and Clarke 1993). The social democratic consensus of support for the welfare state began breaking down and a neo-liberal critique of the welfare state started to emerge (Johnson

1987; Loney et al 1987; Cochrane and Clarke 1993; Means and Smith 1994, 1998).

This critique argued that state welfare contributed to deindustrialisation, and created disincentives and demoralisation (Cochrane et al 2001). Deindustrialisation, it was argued, was caused by the growth of the public sector, which was unfavourable to the national economic performance (higher taxes to pay for it) and leading to the decline of Britain's manufacturing base. Spending on the public sector, it was claimed, brought disincentives in two different ways. Firstly by high levels of personal and business taxation inhibiting enterprise and risk taking, as people did not 'reap the rewards of their endeavours' and secondly by social security benefits, which provide a cushion from unemployment (Clarke et al 2000). As well as these economic arguments against state welfare, criticisms were directed at its effect on social and cultural areas. Demoralisation referred to 'the sapping of a once vital national culture through people's expectations that the state would provide' (Cochrane et al 2001:75).

In Neo-liberal economics public sector provision is seen as highly bureaucratic, unresponsive, inefficient and controlled by professional interests, as well as operating as a monopoly rather than being controlled by market forces (Cochrane et al 2001). Private provision on the other hand is considered to free market forces to operate competitively, so encouraging new alternative sources of welfare to develop, which in turn would lead to more efficient services and greater consumer choice: or what became known as the 'three E's'- efficiency, economy and effectiveness (Cochrane et al 2001). In this perspective there is emphasis on individual behaviour where

individuals, when left to their own devices, are active, innovative, responsible, rational people who are the best judge of their own interests and seek to provide for themselves and their families (Barry 1999; Clarke 2004). Individuals are thus transformed from being passive subjects of welfare, provided by a benevolent state, into active consumers able to make their own choices and decisions (Le Grand 1997). This view of welfare advocated an enhanced role for market forces with a 'rolling back' of state intervention in both industry and welfare, with the state being the organising force to co-ordinate rather than the main provider of services (Flynn 1989).

With the election in 1979 of Margaret Thatcher as prime minister policies based on ideas of neo-liberalism came to dominate the 1980's and 1990's. This philosophy became known as the New Right and can be seen in various government publications of the time, such as the White Paper 'Growing Older' (DoH 1981) and the Audit Commission's report 'Making a Reality of Community Care' (1986). Sir Roy Griffiths, the Prime Minister's personal advisor on health service matters, was asked to lead an enquiry into community care focusing on the social security system of funding residential and nursing homes. This system had already been criticised by the Audit Commission (1986) for creating a perverse incentive for certain people to go into residential care rather than be supported at home (Wistow et al 1994; Rao 2000). The report by Sir Roy Griffiths 'Community Care: Agenda for Action' (1988) had a number of key objectives reflecting market ideology. For example, he argued that local authorities should promote the development of a flourishing independent sector alongside public services, services to enable people to remain living at home, such as homecare should be developed and

informal carers should be provided with practical support to ensure they could continue to support their relatives. The report formed the basis of the government White Paper 'Caring for People: Community Care in the Next Decade and Beyond' (DoH 1989) and later the NHS and Community Care Act (1990), which put the ideas of the market discourse into practice in social care.

The implementation of the Act in 1993 required enormous changes in the social care market and especially homecare. Local authorities in England and Wales, whilst retaining the responsibility to assess an individual's needs, were required to separate the function of service purchasing from that of service provision, and to spend 85 per cent of their new funding for community care in the independent sector, rather than on their own services. The intention was to develop a 'mixed economy of social care' or 'quasi-market' - 'internal trading systems within public sector organisations that are intended to mimic the behaviour of real markets by creating internal trading between different sections' (the private, public, voluntary and the informal sector) (Cochrane et al 2001:87). Prior to these reforms, as we have already seen in this chapter, homecare was mainly provided by local authorities, but the new legislation brought significant changes to this. There was a shift away from in-house provision and a dramatic increase in the amount of homecare purchased by local authorities in England from the independent sector; 2 per cent in 1992 to 33 per cent in 1997, 56 per cent in 2000 and 73 per cent in 2005 (Ford et al 1998; Mickelborough 2002; Commission for Social Care Inspection 2006). The independent sector homecare market that developed has been described as a 'cottage industry' dominated by small providers, some of whom are

inexperienced in running their own business (Wistow and Hardy 1999; Commission for Social Care Inspection 2006). However, Laing and Buisson (2005) argue that the market is beginning to stabilise, with larger providers increasingly winning contracts from local authorities and acquiring some of the smaller businesses.

There have been criticisms about applying the market economy perspective to social care based on the difference between conventional markets, where providers seek to maximise profits (Page and Silburn 1999) and social care markets where many providers (voluntary, not-for-profit) do not. For instance, competition in the social care market may not work effectively because some providers are operating as a monopoly, or purchasers (care managers) may not know consumers' best interests, and if they do there is no guarantee they will act upon them. Other arguments are that individual purchasers may not have a good awareness of availability in the market; quality in social care is difficult to monitor, because if it is defined by purchasers; providers may favour cheaper or 'less troublesome' users (cream skimming); users with learning disabilities or mental ill health may not be able to make the rational choices needed, and some services provided by local authorities are compulsory so that users cannot make choices (Knapp et al 2001; Le Grand 1992; Le Grand and Bartlett 1993).

The development of the market economy perspective with its focus on the individual rational decision-maker who knows his or her own needs and then meets them, signalled the shift away from provision by the state and increased the likelihood of the reintroduction of cash payments for social support. Cash payments to individuals are clearly compatible with New Right

thinking, because of the emphasis on the individual and market forces. So whilst it was still illegal for local authorities to make direct payments at this stage the philosophy of the New Right had placed possibility of direct payments in social welfare squarely back on the agenda.

The community care reforms were radical and required local authorities to move away from a bureaucratic, professional regime to a more managerial system 'tightly controlled by the centralized state, but organizationally dispersed through the creation of the three M's- markets, managers and mixed economies' (Williams 1999:670). Indeed the 1990's saw a growth of organisations for regulation, inspection and audit, with new roles for existing agencies such as the Social Services Inspectorate (SSI) and the Audit Commission (Clarke et al 2000). Local authorities had to rethink the way services were allocated to save money and to enable people to remain living in the community rather than in residential care. To do this they increasingly targeted services on highly dependent people who were likely to need residential care, to enable them to remain at home. There was a move away from providing small amounts of homecare for large numbers of people, to arranging large packages of care for small numbers of people with high dependency. In 1992 the average hours of care received per person was 3.2 and by 1996 this had increased to 5.6 hours whilst over the same period the number of households served had fallen by 11% (Government Statistical Service 1998). By 2005 this had increased still further to 10.1 hours (Commission for Social Care Inspection 2006).

The change to large complex care packages for very disabled adults required a different type of support, with homecare evolving from a predominantly

domestic cleaning service to the provision of personal care (helping people to use the toilet, to wash and dress), which had implications for the skills and training required by homecare workers. At the same time homecare work became more clearly defined and task-based in an attempt to increase efficiency and reduce costs (Taylor 2000). Homecare workers had to adapt to changes in the way they provided support, with time spent with users becoming more accountable. Local authorities increasingly purchased and provided support in 'time periods' with a specified list of tasks to be undertaken by the worker (Johansson and Moss 2004). For example, at the time my study was undertaken Staffordshire social services, in common with other local authorities, required homecare workers to complete fifteen minute 'toilet visits', where they were expected to assist a user to the toilet and then move on quickly to their next appointment. There is anecdotal evidence that this method of working is unpopular with workers giving them little time to form meaningful relationships with service users.

The history and social policy detailed in this section has shown that whilst cash payments are not new in social welfare their use has waxed and waned depending on the circumstances, ideology and social policy prevalent at the time. In the next section I continue to examine the history and policy of social care by looking at women's role in greater detail.

2.4 Community Care and Women: Informal Care and the Feminist Perspective of Care

Informal care is the unpaid support provided by family, friends and neighbours to disabled and older people (Borsay 2005), and whilst there are many men providing support, especially to their wives and partners, women are more

likely to be informal carers than men (DoH 1999; Census 2001). In this chapter I have shown that the thinking behind social welfare in Britain has been heavily associated with ideas of the family and particularly women's role in providing this informal support for their relatives. The White Paper 'Growing Older' for example, promoted care as a routine 'family function' arguing that the state's role should be limited (DoH 1981 cited in Forbat 2005:18). Indeed a statement by Margaret Thatcher whilst Leader of the Opposition in 1978 clearly outlines policy intentions:

Once you give people the idea that all this (care) can be done by the state and that it is somehow second best or even degrading to leave it to private people....then you will begin to deprive human beings of one of the essential ingredients of humanity- personal moral responsibility (Quoted in Morris 1993:6)

The debate about the impact of informal care on women has been influenced enormously by feminist research in the 1980's (Finch and Groves 1980; Stacey 1981; Graham 1983; Dalley 1988; Finch 1989). At much the same time as the neo-liberal critique of the welfare state began to gain momentum in the 1970's, the international wages for housework began to campaign for women to receive state payment for the unpaid domestic tasks they perform for their family (Oakley 1972, 1974, 1979, 2005; Malos 1980). As well as wider issues, such as the effect of patriarchy and women's unequal position in society, feminist research emphasised the negative impact upon women of undertaking care for their family, in terms of their ability to participate equally in the labour force. For example, interrupted employment and pension records, lower rates of pay and part-time working (Arber and Ginn 1991;

Thomas 1993). Providing informal care can cause financial disadvantages for women throughout their lives and especially in old age, and may also cause or increase women's financial dependence upon men (Arber and Ginn 1991). Feminist research focused on the so-called 'burden of care' and questioned the idea prevalent in social policy that providing care was somehow 'natural' for women.

Feminist scholars are critical of the expanded role expected of informal carers by the community care reforms of the 1990's (discussed in section 2.3). They argue that the state was effectively transferring its responsibilities for care onto the shoulders of women, care by the community rather than care in the community (Phillips 1995), and that the policy was regressive and patriarchal (Baldwin and Twigg 1991; Arber and Ginn 1991). Indeed Forbat (2005:23) argues that 'the informal carer became explicitly integral to the provision of care in the community'. There was a rejection of community care policies by some feminists and a case made for collectivist non-community based policies and institutional care for disabled adults, to enable able-bodied women to participate equally in the work force (Finch 1989,1990; Dalley 1988).

The proliferation of research into caring was mirrored in the political arena by the emergence of organisations for informal carers, which began to agitate for better state support for informal carers. The term carer was developed over the last forty to fifty years 'through the interplay between individual experience and various interest groups- policy makers, researchers and pressure groups' (Bytheway and Johnson 1998:241). The National Council for the Single Woman and Her Dependents was formed in the 1950's to represent the views

of single women, many of whom were caring for elderly relatives whilst trying to earn a living themselves. The significance of the focus by this organisation on the interests of single women can be seen by the introduction of Invalid Care Allowance (ICA) in 1975, a social security benefit paid to people providing certain levels of support. This highlights an important change in welfare policy, as ICA was a cash benefit paid by the state, to individuals for the care they provided. Initially ICA could be claimed only by single women and was intended to 'protect the current incomes and future retirement pensions of members of the labour market whose full-time employment was prematurely terminated by the care of elderly relatives' (Glendinning 1988:131). It was assumed by the then government that married or cohabiting women would be at home and available to provide care without payment (Forbat 2005).

The Association of Carers was formed in 1981 during the campaign to extend ICA, and in 1986 after a long struggle this benefit was made available to married women and men. The Association of Carers merged with the newly named National Council for Carers and Their Elderly Dependents in 1986 to form the Carers National Association (Bytheway and Johnson 1998). The carers' lobby suggested they were being exploited as family members, and argued for improved support through central taxation, social security, health and welfare systems and public recognition of the unpaid work performed by carers (Fine and Glendinning 2005). A number of pieces of legislation followed which highlight the importance of informal care, emphasising the priority of family care over that provided by paid workers and making attempts to help informal carers continue looking after their relatives. For example,

'Caring for Carers: National Strategy for Carers' (DoH 1999), the Carers Recognition and Services Act 1995 (DoH 1995), and the Carers (Equal Opportunities) Act 2004 (DoH 2004).

The lobbying by carers' organisations and the work of feminist academics did much to raise awareness of informal carers' experience and bring about an increased emphasis on the roles and rights of carers (Forbat 2005). It has emphasised the many disadvantages faced by women who provide care and raised the notion of payment for the unpaid care these women provide. The feminist analysis of care and the carers' movement though, have been heavily criticised for the emphasis they have placed on female carers' experiences, whilst failing to take disabled people's experiences of care into account (Morris 1991). For example, Bytheway and Johnson (1998) argue that to achieve their aims it has been necessary for the carers' movement to keep quiet about the experience of people receiving care.

2.5 Independence and Control: Disabled People's Perspective

Disabled academics and activists have strongly challenged the ideas of the feminist ethic of care. They argue that its focus on the oppression of able-bodied women coping with the 'burden of care' for their families, fails to acknowledge the contributions of disabled adults in providing care (Morris 1991, 1993; Arber and Ginn 1997), and also the contributions made by men caring for their partners (Fisher 1994,1997). The disabled people's movement suggests that feminist research ignores the rights of disabled adults to go to work and be economically independent, to live independently within the community, to have children and care for them, in the way that able-bodied people may do (Morris 1989, 1997a,b,c; Cooper 1993; Lloyd 2001). At the

same time caring for family may be the site of many women's oppression, but it can provide others with their greatest satisfaction (Morris 1989). In addition it is argued that many qualitative research studies (Ungerson 1987; Lewis and Meredith 1988; Hicks 1988), which claim to explore the care relationship, provide only a one-sided view, as they fail to involve the person receiving support. It can be argued that the idea that there is no place in the community for people with disabilities is insulting, and as a woman born with spina bifida argues:

If we claim liberation for ourselves at the expense of someone else we merely create a new system of oppressors and oppressed, which is the trap I think the mainstream women's movement has fallen into… liberation becomes an end in itself, and it means that women become in turn oppressors of a still more vulnerable group (Davis 1987:277)

Organisations set up and run by disabled people in Britain, inspired by the Independent Living Movement in the United States, began to campaign in the 1980's for the right to live independently at home, rather than in residential care. Independent living refers to the control and choice over where and how to live, choice about who provides assistance and control over how, when and what they do (Hasler et al 1999). The Union of the Physically Impaired Against Segregation stated in its constitution that their aim was:

To have all segregated facilities for physically impaired people replaced by arrangements for us to participate fully in society. These arrangements must include the necessary financial, medical, technical, educational and other help required from the state to enable us to gain the maximum possible

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independence in daily living activities, to achieve mobility, undertake

productive work and to live where we choose with full control over our lives

(Disability Challenge 1980:1)

There was a focus on notions of independence with disabled activists rejecting the commonly held view in society that achieving independence requires the ability to be self-reliant, and redefining it as control over the decision-making processes in a person's life (Barnes 1991; Wood 1991). The disabled people's movement argued for control over the way their support is provided with the right to receive the cash to purchase it themselves, rather than support being provided or purchased on their behalf by local authorities. There was increasing dissatisfaction amongst many disabled people about the lack of control, unreliability and inflexibility of services directly provided to disabled people (Zarb and Nadash 1994).

The disabled people's movement tried (and are still trying) to create a human rights discourse based upon citizenship, which rejects the segregation and exclusion from society of disabled people (Campbell and Oliver 1996). There was also a denial of the 'medical model' of disability, where disability is seen as a personal tragedy needing medical correction (Oliver 1990). Disability was reclaimed as 'a complex and pernicious form of institutional discrimination that is rooted in history and culture' (Borsay 2005:x). In the social model, disability is not caused by an individual's impairment, but by the organisation of society, which takes little or no account of people with impairments thus excluding them from full participation in society (Oliver 1990). There have been criticisms made of the social model of disability for its failure to include explanations of multiple oppressions such as class, race, ageing, gender and

sexuality (Morris 1991, 1993; Shakespeare 1996; Vernon 1996; Shakespeare and Watson 2002). It has also been criticised for disregarding the experiences of some disabled people of pain and illness, which would continue even if the disabling barriers erected by society were removed (Morris 1991; French 1993).

In 1971 to encourage a move away from institutional care towards greater levels of care at home the government introduced a non-means tested social security benefit Attendance Allowance (AA). This was paid to disabled and older people needing assistance with daily living to help them remain in the community. Mobility Allowance followed this in 1976 for disabled children and adults between the ages of 5-65, and by Disability Living Allowance (DLA) in 1990. DLA combining the two allowances into a single benefit for people under the age of sixty-six with older people being eligible to claim AA only. These benefits are significant, in that they are cash amounts paid directly to disabled adults (or parents of disabled children) by the social security system to help them meet the cost of support needed in relation to their impairment, although the amounts paid have never been enough to provide any substantial amount of support (Borsay 2005).

In 1986 following sustained pressure from the disabled people's movement the government launched a means tested benefit, the Independent Living Fund (ILF) paid via social security. This was the first large scale provision of substantial cash payments in recent times, paid directly to disabled adults to meet their support needs, and in this context can be seen as the fore-runner of direct payments. The government was concerned that loss of the domestic assistance payment (paid through supplementary benefit), which had been

removed by the Social Security Act (1986), would result in some disabled adults having to go into residential care (Kestenbaum 1993; Pearson 2001). The scheme was more popular than had been anticipated (Glasby and Littlechild 2002) with over 3,000 people in receipt of an award, ranging from £5-£100 per week, by 1989 (Stainton 1994). In 1993 the government, worried about the financial implications, changed the system to exclude new claimants over the age of sixty-five and the payment became a top-up for younger people receiving large support packages from local authorities (see Kestenbaum 1993,1996, 2001 for a history of the ILF).

In the mid 1980's a few local authorities, sympathetic to the independent living philosophy, set up independent living schemes, as a way of making third party cash payments to disabled people, via disability groups or voluntary organisations (Evans and Hasler 1996), as direct payments by local authorities in England and Wales were at this stage still illegal. The campaign to change the legislation to enable local authorities to make direct payments was started in 1989 by two organisations representing disabled people in the UK, the British Council of Disabled People (BCODP) together with the Spinal Injuries Association (Evans and Hasler 1996). The campaign involved lobbying MP's by a parliamentary officer, awareness raising, briefing meetings, publicity and dissemination of information. A Conservative MP Andrew Rowe became a supporter and introduced a Private Member's Bill on direct payments twice in three years, although both of these failed. Support for the change in legislation was growing and the Association of Directors of Social Services passed a motion at their annual conference supporting the need for direct payments (Evans and Hasler 1996).

To further the campaign the BCODP commissioned research to produce evidence about the cost implications and effectiveness of direct payments. This was funded by the Rowntree Foundation and undertaken by the Policy Studies Institute. The research looked at the cost and benefits of direct payments for personal assistance and how this compared with traditionally provided services. It found that direct payments would offer a higher degree of choice, reliability, control and service user satisfaction than service provision and would be 30-40 per cent cheaper than equivalent service-based support:

The findings on the comparative costs have shown that payment schemes are not only a cost-effective means of meeting disabled people's practical support needs, but often represent considerably better value for money than direct service provision (Zarb and Nadash 1994:144)

These research findings were to prove crucial in the campaign for direct payments. Whilst the arguments for cash payments by disabled activists were born from a desire for greater control and independence the research evidence of their cost effectiveness were enormously important, and in 1997 the Community Care (Direct Payments) Act 1996 was implemented by the then Conservative government making cash payments by local authorities legal.

The long campaign by the disabled people's movement for independent living and the right to control their support by receiving cash payments was essentially about disabled adult's civil rights, argued from a social justice and rights discourse. While direct payments can rightly be seen as a victory for the disability movement it is also important to consider them as part of wider social policy and a change in the ideology of welfare provision. The

introduction of direct payments also fits with the philosophy of neo-liberalism and the market economy perspective of reducing state responsibility for welfare and increasing consumer power and responsibility. The market perspective and the social justice and rights discourse have been described as competing perspectives, yet both clearly have a number of common threads and the philosophy behind direct payments is compatible with both discourses (Pearson 2000; Stainton 2002; Spandler 2004; Leece 2004a). I have argued elsewhere that this compatibility and support from proponents of both perspectives has aided direct payments to become part of social policy (Leece 2004a).

The direct payment legislation was in place and its implementation just starting when in 1997 a new government was elected into office bringing with it a New Labour philosophy- 'the Third Way'. The next section briefly explores what this meant for direct payments.

2.6 New Labour and Direct Payments

In 1997 a Labour government came to power declaring in its election manifesto: 'We will be the party of welfare reform' (Labour Party 1997:5). This brought a new perspective to social policy, which had clear continuities with Thatcher's conservatism, combining both 'Old Labour' and the New Right to become known as 'the 'Third Way' (Clarke 2004). The Third Way built on the 1980's legacy of neo-liberalism, fusing the individualistic focus on independence with notions of responsibility, a strong work ethic and conditionality of welfare benefits (Jordan 2005). It sanctioned values of autonomy and choice rather than collectivism, as a basis for public services, with local authorities expected to adopt a style based on commercial

enterprise. The managerial agenda of a business orientated social care system was already well underway, following the community care reforms and New Labour embraced the public sector management agenda (Cutler and Waine 2001). Many of the welfare reforms made by preceding Conservative governments were left in place, and the early years of the new government saw a number of policy proposals that were underpinned by a discourse of modernisation: performance measures; targets; improving standards and efficiency; best value and star ratings for local authorities are all indications of this trend.

A central theme of the modernising agenda for social care was the concept of promoting independence linked to a requirement for services to be more responsive to the needs of people using them, and on the aim of reducing dependency on service provision through rehabilitation and prevention (Lewis and Glennerster 1996). The concept of independence has been a constant thread in social welfare policy and underpinned much of the thinking behind direct payments. This will be discussed in greater depth in the next chapter and chapter 6. The modernising agenda continued to focus on greater regulation, inspection and audit, which became a feature of social care following the community care reforms. New standards and targets were introduced and a culmination of this thinking brought the Care Standards Act (2000) (DoH 2000a) to reform the regulatory system for care services in England and Wales. This legislation was based on several White Papers, the main one being 'Modernising Social Services: Promoting Independence, Improving Protection, Raising Standards' (DoH 1998) and made a number of changes to the regulation of care and the way homecare is provided. It

established a new independent regulatory body in England for health and social care called the National Care Standards Commission, which later became the Commission for Social Care Inspection. Organisations providing personal care (local authorities, the independent sector, NHS) were required to register and undergo inspection to ensure they meet the minimum care standards (DoH 2002a), bringing homecare within the regulatory framework for the first time.

New Labour's philosophy of a welfare state based on rights, duties and responsibilities (Blair 1998) with consumers of social care as creative negotiators rather than passive recipients of services (O'Brien 2001) is compatible with the direct payment focus on independence, choice and individual control (Beresford 2002; Spandler 2004). There are though some apparent contradictions between the direct payment system and New Labour agenda of increasing regulation and central control. At the time of writing, social care services such as homecare are subject to increased regulation, inspection and workforce training under the Care Standards Act, however the employees of direct payment users are exempt from this Act (DoH 2002a). It is though possible to understand this within New Labour's approach to autonomy, responsibility and changing ideas of risk (Scourfield 2005). It may also be in response to pressure from disabled activists for direct payment users to have control over their employees, rather than them subject to outside regulation (www.ncil.org.uk; Desborough 2005).

At the time the research was undertaken in 2003 direct payments had thus become an established part of social welfare thinking and policy, although as shown earlier in section 2.1 slow to take off in practice. The philosophy behind

direct payments was compatible with the disabled people's movement, the market economy perspective and with New Labour.

2.7. Conclusion

The examination of the history and policy of social welfare in Britain shows that cash payments are part of that history. Their prevalence and usage has fluctuated depending on circumstances in society such as: demographic movements, changing female working patterns and prevailing ideology. Cash payments then have been a feature of social welfare policy and are part of an evolving process.

The impetus for their recent reintroduction, via the Community Care (Direct Payments) Act 1996, was fuelled partly by the strong campaign for independent living and human rights by the disabled people's movement and partly by a change in welfare ideology that resulted in successive governments' determination to create a market economy in social care. Three perspectives are important in their explanations of cash payments: the market economy perspective, the feminist ethic of care and the perspective of disabled people.

Chapter 3 The Care Relationship: A Review of the Literature

In this chapter I review and critique existing literature[1], which provides the key perspectives and concepts for explanations of the research question: 'How does the opportunity for disabled adults to employ their own workers affect the support relationship?' Underpinning much of the research discussed in this chapter are the three perspectives, identified in chapter 2, which I suggested are important for understanding cash payments: the market economy perspective, the disability or social justice and rights perspective, both of which have been influential in the recent reintroduction of cash payments, and the feminist ethic of care, which highlights the crucial role of women in care provision. In order to explore these perspectives a number of concepts are considered: power, independence and autonomy, reciprocity, interdependence, boundaries, stress and job satisfaction. These concepts and related issues form the basis of the organisation of discussion in this chapter.

I will argue that the literature relating to each of these areas is unhelpful when explaining the impact of money and direct employment on the care relationship. Research has tended to focus upon just one party in these relationships, yet concepts such as boundaries, power and autonomy all involve behaviours, dynamics, understandings, possible conflicts and contradictions requiring a more complete view that involves both parties. In addition, the crucial comparison of direct and non-direct employment is missing. Consequently I will argue that previous research has conceptual and empirical gaps, which the research in this thesis seeks to address.

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[1] Details of how the relevant literature was located can be found in Appendix 4.

3.1 Researching Direct Payments

There are many studies that explore direct payments, but almost all of this literature focuses on the perspective of users without consideration of the position of workers (Zarb and Nadash 1994; Dawson 2000; Leece 2000; 2001; Pearson 2000; 2001, Carmichael and Brown 2002; McMullen 2003; Lord and Hutchison 2003; Clark et al 2004; Stainton and Boyce 2004; Commission for Social Care Inspection 2004). This reflects, I would suggest, the powerful voice of the disability lobby, as discussed in the previous chapter. At the time of writing, only four studies in the UK (Ungerson 1999, 2004; Glendinning et al 2000a; Flynn 2005) involve personal assistants in their research. This is an important omission, for to understand the dynamics of a relationship, we need to understand the experiences of both parties in that relationship. In other countries the situation is similar with only five studies that I could locate include personal assistants: United States (Eustis and Fischer 1991; Rivas 2003; Benjamin and Matthias 2004; Dale et al 2005), Norway (Askheim 2003). Brief details of these studies are included in Appendix 5.

Another crucial gap in the literature is the failure to include a comparison between non-direct employment and the direct employment of personal assistants. I would suggest that to investigate the impact of the direct employment on the support relationship we need to compare this relationship with non-direct employment, such as support provided by homecare services where workers are employed by the local authority, rather than directly by disabled adults. There are currently no studies in the UK that provide this important comparison and only one in another country (Dale et al 2005).

However, in this study whilst personal assistants are included in the methodology, direct employers are not. Therefore there are no existing research studies involving both users and workers that compare the direct and non-direct employment relationship. The research in this thesis seeks to rectify this situation.

The four UK studies above are of relevance, yet aspects of their methodology are unhelpful in terms of investigating the research in this thesis. Both of the Ungerson studies are important because of their focus on direct employees. The earlier study (1999) reports findings from a pilot study of in-depth interviews with seven personal assistants, whilst the later (2004) is a cross-national study of five European countries (Austria, France, Italy, Netherlands, UK). The studies examine the shifting boundaries between formal and informal care, and the impact of direct payments on these. This is of interest, as we will see in section 3.5, but the research has a misconception, which makes it less compelling. For example, Ungerson (2004:190) incorrectly states that the British scheme of direct payments: *'expressly forbids the payment of relatives'*. However, whilst the employment of relatives has been restricted by the direct payment legislation, their employment, other than for relatives living in a user's home, has always been allowed when approved by a local authority (DoH 2000b; DoH 2003). Correspondingly, none of the personal assistants in Ungerson's UK sample are relatives of their employer, yet many cash payment users employ people related to them (Lakey 1994; Dawson 2000; Kestenbaum 2001). The potential for employment of relatives is an important difference between direct and non-direct employment, and is an area of interest for this research.

There are other difficulties, the first of Ungerson's studies (1999) looks at the relationship from only the perspective of personal assistants, as disabled adults are not interviewed, whilst in the second study all of the direct payment users are older people, as this is the focus of her research. However this makes the study less representative of direct payment users generally, as younger disabled people form the largest group of people using direct payments (Commission for Social Care Inspection 2005b), and older direct payment users may not share the same views of the care relationship as younger users. In her work on ageing and intimate relationships, Jerrome (1993) argues that members of different cohort groups may not have a lot in common, because they are socialised at distinct times in history, which can result in dissimilar expectations of care provision.

Turning to the Glendinning study, which again is of interest because of its' focus on the interests of workers, there are two aspects of this research that are unhelpful. Firstly, the study uses focus groups to gather data from personal assistants, acknowledging that discussions in these groups were 'aimed to avoid topics which would have compromised confidentiality about individual employers' (Glendinning et al 2000a:23). Restricting discussion topics in this way, and not interviewing respondents privately in-depth, may have resulted in less rich and revealing data. Secondly the study has what appears to be an unusual sample of personal assistants, as the majority (ten) worked previously as nurses, or had nursing training. This is uncommon, as other studies report that personal assistants generally have no formal qualifications, with employers preferring to employ untrained friends and relatives or to train workers themselves (Morris 1993; Clark et al 2004;

Stainton and Boyce 2004). This may have influenced the results, as we will see in section 3.5.

The only other UK study to include personal assistants was undertaken for the Skills for Care Council (Flynn 2005). This research attempts to define current expectations of the personal assistance role and its future, but places its focus on users and the training needs of their personal assistants. It is thus limited in its ability to explore the possible effects of direct employment. Research from other countries is interesting and helps to raise important issues. However we need to view these findings with caution, as cash payment schemes vary from country to country (Leece 2004b; Ungerson 2004), as do social attitudes across cultures (Giddens 1989), which can influence people's views, making the findings less applicable to the UK. The findings from the direct payment literature are considered further in the relevant sections throughout the rest of this chapter.

3.2 Paying for Intimate Care

Chapter 2 identified the feminist perspective and the disability debate as two important streams of research and theory in social welfare, that have adopted separate positions in their explanations of care, by placing the locus of emphasis differently (Davies 1998; Lloyd 2001; Fine and Glendinning 2005; Hughes et al 2005). Generally for feminist academics the main focus of interest is on the person giving care, whereas for disabled activists it is on the person receiving care. This difference is significant, as it results in both perspectives tending to ignore the interests of the other and failing to examine both sides of the relationship.

The disability perspective redefines care as 'help', 'support' or 'personal assistance' with disabled people being in control of their support, by the use of cash payments to employ the services of a personal assistant. A disabled person is then 'master of his (sic) own destiny with a personal assistant at his command' (Hughes et al 2005), rather than being the dependent recipient of care in the feminist perspective. This idea of independent living based on directly paid personal assistance advocated by the disability movement (Morris 1993; Oliver 1993), transforms care from a provision by local authorities, into a contractural relationship between an employer and an employee. The transformation of the care user into an employer introduces new dimensions into the care relationship that need to be explored further.

Ungerson (1999) discusses the delivery of care to people in their home, where there is some form of financial assistance, referring to it as the 'commodification of care', that is the treating of care as a good to be bought and sold in the market. She argues that treating care as a commodity is leading to the breaking down of the boundaries between paid and unpaid care, whilst Glendinning et al (2000a) suggest there is now a spectrum of complex relationships between money and care. At one end there is informal support given by families and friends, where often no payment is made, only a token payment, or deferred payment via inheritance. At the other end is professional care funded by the state from redistributed tax contributions, and in the middle are arrangements containing a mixture of both formal and informal support. These may be: family care paid for by state benefits, token payments made to volunteers by local authorities, or money paid directly to disabled adults to purchase care (Glendinning et al 2000a).

While these distinctions aid clarity, neither of these studies adequately addresses the importance of money in the support relationship in terms of providing an empirical comparison with care provided by non-directly employed care workers. The way care is paid, by whom and the form of payment is significant and likely to affect that relationship. Direct payments are not simply a transfer of money to individuals, they represent purchasing power and this power can change the dynamics between disabled adults and the workers employed to provide their support (Roeher Institute 1993). The market perspective suggests that the use of cash payments increases users' power, because it transforms them into consumers with the choice of buying support such as personal assistants from a range of suppliers. Rivas (2003) argues for example that when people pay for care they gain entitlements or rights and may feel that they can tell workers to do all kinds of tasks not specified in their conditions of employment.

Treating care as a commodity on the other hand can be argued to be nothing new, as affluent people have always been able to pay workers to provide their support and to care for their children (Hochschild 2003). Indeed Britain has a long history of domestic service and 'nannying' (Gathorne-Hardy 1972; Waerness 1984), and whilst there was a decline in these roles following the Second World War there appears to be a resurgence of this type of employment in recent years (Ehrenreich and Hochschild 2003). General household expenditure on domestic service (domestic help and childcare) has risen from around £2 billion in 1987 to just over £4 billion in 1997 (www.statistics.gov.uk). The numbers of disabled adults opting to pay privately for care has also increased from 670,000 in 2001 (Deeming and

Keen 2002) to around 723,000 in 2002 (Mickelborough 2002), which may be linked to the decrease in funded care provision following the community care reforms discussed in section 2.3. And as Bornat suggests:

Names might change yet employments do continue. Though domestic service has lost many of its descriptors and much of its operational language, the roles remain embodied in posts such as butlers, chauffeurs, au pairs, cleaning ladies and nannies (2006:8).

Zelizer (2005:56) argues that whilst there is a general view in society that involving money in intimate relations is in some way corrupting, intimate relations are fundamentally intertwined with economic transactions: 'All of us use economic activity (cash, equivalence or reciprocity), to create, maintain and renegotiate important ties-especially intimate ties to other people'. She writes from a US perspective, but suggests this is equally applicable to other countries such as the UK. Zelizer considers that although there are heated debates about payment for certain areas such as surrogacy arrangements, blood and human organs, these debates fail to recognise how frequently intimate social relations coexist with financial transactions. For example, divorced spouses pay maintenance, parents subsidise university education for their children, friends lend each other money, victims' relatives are paid compensation for their loss (Zelizer 2005).

Zelizer's argument is relevant to local authorities' practice of charging disabled adults for services, which they have done for many years, as this is clearly an area where money is involved in intimate relations. Fairer Charging legislation allows local authorities to financially assess users and make charges based on their perceived ability to pay. Local authorities recoup

around 11 per cent of their expenditure on homecare through these charges, although this varies from one local authority to another (Commission for Social Care Inspection 2006). Users are assessed on their income, including social security benefits and savings, with some not having to make a contribution (DoH 2002b). Thus whilst homecare users do not pay workers' wages directly, many will do so indirectly through their financial contribution for services they receive. However, I suspect that whilst economic transactions may be intrinsically involved in the care relationship, as argued by Zelizer, direct payments make this more noticeable, and this may have implications for the relationship.

The explicit cash transaction between disabled adults and workers has the potential to change the nature of the care relationship and the balance of power within that relationship. I would argue that this has not been adequately addressed by existing research and empirical research is needed to examine the effect it has upon the support relationship.

3.3 Power in the Care Relationship

Power is of fundamental importance in understanding the care relationship indeed it is a pervasive part of all human relationships (Giddens 1989). As we saw in the previous chapter the disability lobby, in their quest for independent living and the right to receive direct payments, placed the issue of power at the forefront of their arguments. Power has many forms: physical power, where one person may use their physical strength against another, financial power, where a person may use their wealth to gain advantage, intellectual power, legal power, and so forth. Power can be defined as the 'ability of

individuals or groups to make their own concerns or interests count, even where others resist' (Giddens 1989:52).

In the literature about power and intimate care it is Foucault (1973, 1977, 1979) who can be argued to have made the most significant single contribution to our understanding. Foucault (1977:122) argues that power is flowing all around and within us operating on 'the basis of other power networks that invest the body, sexuality, the family, kinship, knowledge, technology and so forth'. He goes on to suggest that power 'is neither given, nor exchanged, nor recovered but rather exercised and that it only exists in action' (1977:89).

Foucault proposes that to understand power we need to appreciate how it is exercised and the mechanisms involved. Clearly for Foucault an understanding of the power dynamics within a relationship requires us to have a thorough grasp of what is happening within that relationship, and I would suggest that in existing studies, whilst there is much that is helpful, there is only a limited consideration of the notion of power in the direct employment relationship.

In the support relationship there is a tendency for the literature on care to assume that power lies with the person providing support, yet the exercise of power between disabled adults and the people providing their support is more complex than this. In her highly relevant work on care of the body and bathing Twigg (1997, 2000, 2004, 2006) highlights this complexity arguing that to be naked in the presence of others who are clothed is to be at a disadvantage. She cites the process of interrogation where prisoners are kept without clothes to undermine them and create vulnerability. When being bathed by a

worker disabled adults are in this vulnerable position. Intimate care by relatives and spouses too can make people feel at a disadvantage. Researchers have identified that many disabled adults prefer to be supported by a care worker, rather than a relative, because their perceived loss of status can affect their relationship with kin (Twigg and Atkin 1994; Parker and Seymour 1998; Twigg 2000). Touch is also associated with hierarchy, with powerful people touching the less powerful, so that touch and physical intimacy can alter the balance of power in the support relationship. Twigg (2000) suggests that some care workers are aware of the power bodily exposure gives them, and use it to exert control over the person they are supporting.

On the other hand, occupations dealing directly with the body are often regarded as low status with care workers tending to occupy a relatively powerless position in society (Twigg 2000, 2006). Care work is gendered with the majority of workers being women who have family commitments and few qualifications, resulting in their occupying a weak position in the labour market (Aronson and Neysmith 1996; Ungerson 2000; Twigg 2000, 2006). Performing intimate bodily tasks then places workers in an ambivalent position, as in one sense it provides the worker with opportunity to achieve power and a reversal of status, but in another it places workers in a humble position, similar to that of a servant.

In the previous section I mentioned Britain's history of domestic service, and to aid understanding of the power dynamics in support relationships, it is helpful to revisit this form of direct employment in more depth. Domestic and support work remains deeply embedded in status relationships with

employers having power over workers especially if they are unable to find alternative employment easily (Anderson 2003). Twigg (2000) argues that care workers struggle to reject the notion that their role is one of a servant, because this subordinate position conflicts with modern western ideas of autonomy and individualism. Twigg (2000:189) considers that this rejection of the role of a servant 'lies at the heart of the power struggle of care'. In her later work Twigg (2006:141) goes on to suggest that the position of direct employees is comparable to that of servants, because they are chosen by disabled people and expected to work directly under their orders, rather than being as homecare workers are: 'agents of professional control'.

In her work on paid and unpaid work, Ungerson (1997a+c) takes a similar position arguing that there are similarities in the direct employment of personal assistants with the employment of domestic servants, because of the weak labour market position held by personal assistants, and the power of employers to 'hire and fire'. She later modifies her position to argue that the servant analogy is too simplistic, as disabled employers are no longer protected by social deference in the same way nineteenth century employers of servants were, and that disabled adults' physical vulnerability is likely to reduce their power (Ungerson 1999). A more recent study of older direct payment users also argues that 'the days of domestic service are long gone' with relationships being friendly instead of dictatorial (Clark et al 2004:18). However, this provides an incomplete picture, as a friendly relationship does not necessarily preclude workers being treated or feeling like servants. Indeed Shakespeare argues there is a danger that cash payments may mark a return to the age of personal service, because 'legally personal assistants employed

to work in the home are classed as domestic servants' (Shakespeare 2000:68). The master and servant analogy is clearly unresolved in the literature suggesting the need for further investigation.

Rivas (2003) discusses 'invisible support' where workers provide help as inconspicuously as possible (comparable to the way servants have traditionally worked) and how this can transfer power to users. She suggests that workers need to 'create an illusion of invisibility' by transferring control of the tasks they perform from themselves to disabled adults (Rivas 2003:76). This is echoed in a study of homecare workers in the UK, Sweden and Spain, which argues that: 'brilliant social care is completely invisible' (Johansson and Moss 2004:14). Other studies consider worker invisibility, in relation to disabled adults being able to maintain their personal space in the support relationship. Both Pearson (2001) who interviewed forty-nine direct payment users and Kestenbaum (1999) in her study of ILF users, identified difficulties for employers in achieving personal space (or invisible support). Another employer, with 24-hour live-in support, said she found it difficult to ask her personal assistant to leave the room when she wished to be alone with her partner:

If the (PA's) are not sensitive and remove themselves from the room the only private time I would get with (a lover) would be when I was in bed with him (cited in Morris1993:141)

Bailey (2002), a direct payment user, said her method of getting the help she needs and the space to be alone with friends, was to ignore her personal assistant when in social situations, unless help was required, concluding that what she really wants is a personal assistant who is like a 'broomstick'.

However, these studies look at this issue from the users' point of view only, failing to explain the experience of providing invisible support from the perspective of the worker and whether it is different in some way for employees of direct payment users. For instance, current available literature does not address whether personal assistants are more likely to be invisible than workers employed by a local authority, and again my research seeks to address this omission.

Twigg (2000) draws on material from a manager who had taken over responsibility for a personal assistant. The manager describes how the personal assistant was expected to sit in a bedroom until summoned by a bell to provide support. She argues that this type of subordination could be undermining for workers, because of its association with domestic service. Rivas (2003) concurs with this suggesting that 'being invisible' is humiliating for workers, as it does not give them credit for the work that they do, nor does it recognise their efforts. One direct employer also agreed with this saying: 'It's somewhat demeaning to expect someone to just sit in a corner and not think for themselves.... I don't believe you give anyone a sense of value if you say right go back to your chair and pick up your magazine' (ILF user in Kestenbaum 1999:50). Ideas about invisible support appear to be contested in the literature depending on whose perspective takes precedence and need further examination to develop a clearer understanding of the direct employment relationship, such as who appears to gain most from workers providing support invisibly.

Many studies argue that power is an important element of the support relationship (Silvers 1995; Kittay 1999; Twigg 2000, 2006; Forbat 2005), and it

has been suggested that a system of direct payments 'effectively reverses the balance of power between 'carer and 'cared for', because paying for care gives users more control (Hughes et al 2005:263). This could have a big impact upon workers who may, for example, be placed under pressure to perform tasks associated with risk. Manual lifting is an area identified as risky for workers (Taylor 2000) and Unison, the public sector union, recommends that hoists be used for lifting and moving users (Unison 2000). The legislation relating to manual lifting is contained within the Health and Safety at Work Act (1974), the Management of Health and Safety at Work Regulations (1992) and the Manual Handling Operations Regulations (1992), none of which applies to direct employees in a private home. Thus if direct payment users prefer to be lifted manually, they may insist this is done even though it puts workers at risk, and workers have no legal protection, unlike workers employed by a local authority who are protected by the legislation.

The provision of intimate care is vulnerable to the exercise of power (Foucault 1977), and a place where conflict is likely to occur: 'Clients struggle to resist the domination of workers and to maintain a fragile sense of self in the face of the erosion of disability and age. Workers strive to establish control over their work and to extract from it sources of esteem and status' (Twigg 2000:179). The literature has emphasised the importance of understanding the dynamics of power within care relationships and I have argued that whilst existing studies are helpful in setting the parameters of this debate, there is only a limited consideration of power in the direct employment relationship. The impact of money and direct employment on the power dynamics of this relationship are poorly understood, as is the effect that a possible shift in

power between users and workers will have on that relationship. Ideas of master and servant or invisible support in the relationship are unresolved in the literature.

3.4 Independence, Autonomy, Interdependence and Reciprocity

Notions of independence have provided a major focus for the disability movement in their fight for greater control over their lives, and researchers too have explored ideas of independence in an effort to gain understanding of the care relationship. However, the term independence lacks clarity, and in the following section I review the literature and argue that autonomy is a more useful concept in aiding our understanding of the direct employment support relationship.

3.4.1 Independence and Autonomy

In the literature on care, independence tends to be defined in terms of the extent to which dependence is absent, with a focus on a person's ability to function unaided, stemming from the ideology of self-reliance prevalent in both Britain and the US (Secker et al 2003). Social care professionals and service providers too have a tendency to define independence in relation to disabled adults' ability to perform self-care tasks (Morris 1993; Reindell 1999; Goble 2004). The disabled people's movement on the other hand rejects notions of independence based on self-reliance, arguing that this results in disabled adults who need support, being defined as needy or dependent (Brisenden 1986, 1989; Oliver 1993). Disabled activists argue that independence does not mean doing everything for yourself, but instead refers to: 'Someone who has taken control of their life and is choosing how that life

is led' (Brisenden 1986:4), thus having the ability to make and effect decisions.

The meaning of the term independence is thus contested in the literature leading to a lack of clarity about what is meant when the term is used in research. When respondents talk about being independent does it refer to their ability to control the decision-making process or to the ability to self-care? This ambiguity causes problems for our understanding of what is happening in the care relationship, and to overcome this both workers and users need to be given the opportunity to specifically discuss what the term means to them.

In her study, which examines whether older people and their workers are made independent or empowered by cash payments, Ungerson (2004:196) does not define what she means by the term independence for users, but for workers adopts a broad definition where independence and empowerment at work are taken to mean: 'that their [the workers] position is broadly as they would prefer, and that they perceive themselves as recognised and/or adequately remunerated for the work they do'. Using this definition Ungerson argues that direct employees' independence was not enhanced, as they were open to exploitation based on emotional blackmail. Yet a definition of independence imposed by the researcher removes the freedom to allow respondents to describe in their own words what independence means to them, and this may have influenced the results.

Glendinning et al (2000a) consider whether independent living for disabled adults can be enhanced through direct payments, by extending the payments to cover a wider range of health related support, so increasing the integration

of health and social care. To do this the study looks at areas such as the tasks personal assistants perform, the training they receive and the boundaries of the relationship. The research explains ideas of independent living developed by disabled activists, (the choice over where and how to live, and who provides assistance), but does not go on to explore notions of independence specifically, either for disabled adults or workers.

In section 3.1 I highlighted that almost all of the literature relating to direct payments concentrates on the views and interests of disabled adults. Much of this literature reports the benefits of cash payments for users including greater independence (Morris, 1993; Lakey 1994; Zarb and Naidash 1994; Kestenbaum 1996; Dawson 2000; Leece 2000, 2001; Carmichael and Brown 2002; McMullen 2003; Lord and Hutchison 2003; Clark et al 2004; Stainton and Boyce 2004; Commission for Social Care Inspection 2004). It is significant that the definition of independence developed by disabled activists focuses on the needs of disabled adults; this definition does not attempt to capture the experience of workers providing support. Disabled activists definition of independence is thus not helpful in assisting us to understand independence in relation to workers.

As well as being contested in the literature the notion of independence is problematic in the way it is used by disabled activists. In reading through the literature it seems that when activists talk about independence they are referring instead to the concept of autonomy. There is a helpful distinction made between the two terms in the psychology literature. For instance, self-determination theory defines an individual as autonomous when their behaviour is willingly undertaken, with their actions and values fully endorsed

by that individual. Independence on the other hand is considered to involve being self sufficient for support, guidance and needed supplies (Ryan and Lynch 1989). In this theory the opposite of independence is dependence (relying on others for guidance, support and supplies) rather than being non-autonomous, which occurs when a person's actions are controlled by outside forces, and they are forced to behave in a way regardless of their interests or values (Chirkov et al 2003). A person can thus be autonomously dependent on another, such as in the case of a disabled adult willingly relying on care from a support worker, and I would suggest this is what the disabled people's movement are referring to by their definition of independence. We should thus look to notions of autonomy in the care relationship to aid our understanding of that relationship. It is also particularly helpful to have a term that can be applied to both users and workers.

The concept of autonomy, in the modern sense, is based on the work of Immanuel Kant who argues that humans are rational beings able to have a will based on reasoning. In this *rational model* autonomy consists of reflection and reasoned decision-making (Reindal 1999). There are other models of autonomy, which are critical of this stance (Stainton 1994), as people with cognitive disabilities who lack the ability to reason or be rational will be defined as non-autonomous. Another approach in a different tradition advancing a *voluntarist* view of autonomy is usually attributed to thinkers such as Mill and Hulme, and in this view autonomy is to be found in the unrestricted expression of the will and the desires (Reindal 1999). A *rational-voluntarist model* combines the two perspectives to present a model of autonomy where: the autonomous self is located in the will and desire that is discovered,

shaped and to an extent ordered and corrected by reflection and reason'
(Aviram 1995:63). The rational-voluntarist view has been described as 'control
in principle' (Reindal 1999) and its explanation of autonomy encompasses
people with cognitive disabilities who rely on the judgement of others to make
decisions.

Peace et al (1997) apply a rational-voluntarist view of autonomy based on the
work of the US writer B. J. Collopy to their study of residential care for older
people (see Table 3). Collopy (1988:10) defines autonomy as: 'a cluster of
notions including self-determination, freedom, independence, liberty of choice
and action. In its most general terms autonomy signifies control or decision-
making and other activity by the individual. It refers to human agency free of
outside intervention and interference'. This model helps us to understand and
unpack the complexity of the notion of autonomy, as it distinguishes various
states of autonomy such as 'autonomy of execution', which is the ability to
implement, act upon and operationalise choices (Collopy 1995:10), and
'decisional autonomy'. This is the ability to make decisions, to have personal
preferences and values, even though one may not be able to act on them
independently or accomplish them without assistance (Collopy 1988:12).

Table 3	Model of Autonomy
Decisional autonomy	The ability and freedom to make decisions without external restraint.
Executional Autonomy	The ability and freedom to act on decisional autonomy.
Authentic Autonomy	Choices and behaviour that are deeply in character.
Delegated Autonomy	Decisions and activities supplied for people by others, based on authentic autonomy

Based on Peace et al (1997:55)

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The notion of independence defined by disabled activists as the ability to control the decision-making fits neatly into Collopy's definition of *decisional autonomy*, whilst *executional autonomy* encompasses the idea of independence as self reliance. The model also provides a view of autonomy that embraces a person's whole life, their past, their future hopes and the context in which they live, rather than being a series of isolated decisions. For example, *authentic autonomy* refers to choices, action or decisions that are in character with a person's life history. In this way decisions made by people with intellectual disabilities such as dementia (or by an advocate on their behalf) can be defined as autonomous. This model of autonomy then is comprehensive and I have used it later in this thesis to guide the discussion of the findings.

Unlike the notion of independence the concept of autonomy can be used in relation to the workers' perspective in the relationship such as any conflicts of interests that may occur. The potential for conflict between users and workers in this relationship is of interest for my research, and has been highlighted in the literature. As we saw in the preceding section Twigg (2000:188) emphasises the 'struggle for dominance' between care workers and users and the rejection by workers of the subordinate servant role. The nursing literature too has argued that changes in nursing practice, to ensure shared decision-making such as patients' *right to know,* has led to conflict between the exercise of professional and individual patient autonomy (McCormack 2001:418).

Conflict in the relationship is discussed by Clement (1996:59) in her work on informal care, where she argues that care workers are expected to 'renounce their autonomy', because carework is essentially about following the instructions of others. These instructions can be either from the user, or the 'experts' by whom the care worker is employed. Bland (1999) considers the notion of personal service in her study of residential care for old people. She compares two methods of delivering residential care the 'service approach' based on the type of service provided by hotels (in a residential home owned by former hoteliers) and a 'social care approach' provided in a local authority residential home. She argues that the crucial differences between the methods is that in the service approach residents are considered to be experts about their needs, whilst in the social care approach it is professionals who define residents needs. Bland found that in the service approach residents' power and autonomy was greater. This is of interest, as the service approach relates to provision where users pay for the services they receive (a hotel), yet it is not truly comparable to the direct payment scenario, as hotel workers are not directly employed by users.

The literature about independence is then unclear and contested concentrating on the needs and interests of users, whilst generally ignoring the workers providing support. To aid our understanding of the support relationship the research uses the concept of autonomy, guided by the model developed by Collopy (1988), which can be used to explore the perspective of workers as well as disabled adults.

3.4.2 Interdependence and Reciprocity

In their attempts to redefine notions of independence disabled activists argue for an understanding that moves away from notions of individualism, requiring people to make decisions and carry them out, and instead for a focus on interdependence (Oliver 1993; Morris 1993). Oliver, a key commentator in the disabled people's movement, argues that: 'No one in a modern industrial society is completely independent, for we live in a state of mutual interdependence', and that dependence on personal support should be seen as an integral part of human existence rather than a personal tragedy (Oliver 1993:50). Notions of interdependence have also been explored in the feminist literature. Indeed Forbat (2005) in her work on informal care suggests that the convergence of ideas of interdependence helps to bridge the gap between the feminist and disability perspectives. She argues that a 'reliance on others can be understood as an exchange of assistance across the life span' (Forbat 2005:27).

Reciprocity where people are able to 'give something back' links with notions of interdependence, and is seen as an important element of retaining independence within a relationship (Johnson 1993; Forbat 2005). This notion has been developed from social exchange theory, which argues that relationships are only entered into and sustained, if they are satisfactory in terms of the rewards and costs involved (Blau 1964). The literature on friendship (Allan 1979; Adams and Allan 1998) also stresses the significance of reciprocity in maintaining an equal relationship. Thus where parties in a relationship are able to reciprocate the relationship is likely to be one that has greater degrees of interdependence and equality than where reciprocity does

not occur. Indeed Fine and Glendinning (2005) argue that the presence of reciprocity is seen as an indication of interdependence within a relationship.

The care literature shows us that the ability to reciprocate is clearly important to people, with many disabled adults trying to 'return the caring' to workers providing their support (Baldock and Ungerson 1994; Balloch et al 1999; Clark et al 2004). Piercy (2000) found in a study of home health aides, that some older people reciprocated by giving gifts, advice, food and opportunities to watch television. However, the literature tells us little about reciprocity and interdependence in the direct employment relationship. It does not, for example, show whether direct employment enables disabled employers to be more or less reciprocal in the relationship, or whether the direct employment relationship is more interdependent than the non-direct employment relationship.

In the literature relating to direct payments there are few specific references to notions of reciprocity or interdependence. Clark et al (2004), in her study of older direct payment users, and Dawson (2000) in her evaluation of a direct payment pilot project in Norfolk, both mention reciprocity by users briefly to suggest the relationships contain some instances of reciprocal acts. Another study reported that several users 'were glad to be giving something back to people who had provided care in the past' (Stainton and Boyce 2004:449). However none of these studies involved personal assistants, and I would argue it is less meaningful to discuss the concept of reciprocity, which requires the input of both parties, when only one party has been researched.

Ungerson's (2004) study of older direct payment users and their personal assistants finds elements of reciprocity. Both the Austrian and Italian schemes

differ from the UK in that cash paid to users for support can be assimilated into their household budget, rather than paid to workers in the form of wages. Some older people were using the payment in this way, whilst also giving 'tips of money' to relatives and friends supporting them. Ungerson argues that carers saw these tips, as users reciprocating for the help given. In the UK sample Ungerson suggests that 'care workers had constructed an occupation for themselves that they found congenial' (2004:204). Interpretation of this is unclear, as it could imply that employers were being reciprocal by providing a flexible working environment, or on the other hand that workers were able to 'take advantage' of employers by doing as they pleased. Another study comparing directly employed workers with agency workers in the US did not discuss reciprocity, and only reported that agency workers had more 'fringe benefits' than directly employed workers (Dale et al 2005).

In chapter two I discussed neo-liberalism and the market economy perspective. In this perspective reciprocity in the support relationship can be explained as employers striving to create a good working environment, so that workers will be satisfied with their job and not seek alternative work. In times of high employment where workers are scarce, employers will have greater incentive to provide good working conditions, than when there is high unemployment and workers are plentiful (Barry 1999). This suggests that the extent of reciprocity and interdependence may fluctuate in direct employment relationships, depending on the availability of workers. However, I would suggest this explanation is too simplistic, as it fails to encompass the richness and complexity of human relationships. For example, personal assistants may choose to stay with an employer, because of a sense of obligation or

affection, even though there are other employment opportunities. Also the market economy perspective does not explain whether the ability to be reciprocal is increased by direct employment. Hence the literature indicates the importance of these concepts in the support relationship, but is inadequate in explaining whether reciprocity and interdependence are affected by the direct employment relationship.

3.5 Boundaries in the Care Relationship

The literature about boundaries in the care relationship suggests that they are complex, unclear and difficult to define. For instance, as discussed in chapter 1, the boundary between health and social care has itself been subject to considerable ongoing debate and ambiguity. Existing research indicates that in many care relationships the boundaries are blurred, so that it is difficult to distinguish where the lines of the relationship start and finish. Direct employment appears to exacerbate this. Researchers have speculated that this lack of clarity of boundaries may lead to problems for direct employees in terms of greater obligations towards their employers. However I will show in this section that although current research is valuable in raising areas of possible concern, it is problematic and does not provide in-depth explanations of the impact of direct employment.

There are many types of boundary in society: political and religious boundaries; hierarchical and structural boundaries; boundaries of nation; estate, or class; or between groups (Douglas 1966, 1970). For anthropologists and sociologists cultural boundaries are cognitive, relating to social and interpersonal relationships, rather than natural phenomena such as those used to distinguish countries from each other. Cultural boundaries are formed

through common practice, social relations and the allocation of valued social goods (Fuller 2003). Southerton (2002:173) suggests that 'boundaries are the point where group similarities end and difference begins' whilst Cohen (1985:12) explains that:

By definition the boundary marks the beginning and the end of a community...a boundary encapsulates the identity of the community and like the identity of an individual is called into being by the exigencies of social interaction. Boundaries are marked because communities interact in some way or other with entities from which they are, or wish to be distinguished.

Boundaries are often the site of ongoing negotiation and struggle, because there is rarely a consensus about their meaning, as boundary making is about the creation of difference- 'us' and 'them' (Joseph 1997). They are not fixed or constant across cultures, class or gender and can be in a state of constant change (Fuller 2003). An example of this is the boundary between NHS responsibilities (health care) and local authority provision (social care), with the farce of the 'medical bath' or 'social bath' being well known by health and social care professionals. The Royal College of Nursing (1988) argues that the line between nursing or non-nursing care has altered so much that it is difficult for managers to achieve a general acceptance of where the boundaries in nursing lie. To confuse matters further the nursing literature suggests that the boundaries between nurses and patients tend to be different when care is provided in a patient's own home rather than in a hospital setting (Cox and Cox 2000; Carr 2001; McGarry 2003), with nurses reporting closer relationships when supporting people in their own homes (McGarry 2003).

McGarry (2003:426) goes on to argue that nursing care at home can result in the 'medicalisation of the home' where home becomes like a hospital, because of medical equipment and routines. This was also noted by Willcocks et al (1987) and Peace (1998) in their work on residential care and care in the home: 'The home as a place of informal care provided to family members is not a regulated setting, but if used as a place of paid care it may be subject to regulation and inspection' (Peace 1998:242). This suggests that when care is provided in a person's home the boundaries of the relationship can be less clear than when it is provided in an institution, and illustrates the difficulty of defining limits in the care relationship.

The literature on work-life balance indicates a trend of unclear boundaries between home and work, with many people working much harder, feeling under pressure to work longer hours at work and taking work home with them (Hochschild, 1989, 1993, 1997; Hochschild, and Machung 1997; Taylor 2002; Bunting 2004). The advent of technologies, such as the personal computer, fax and telephone have made home working more likely. Mallett (2004), in her critical review of the literature about the meaning of home, argues that the division between the private and the public realms has never been as clear as the literature has previously implied, because women have always worked, both paid or unpaid, within the home. Many men too have engaged in labour in or from the home. Twigg (2000) makes the distinction between boundaries of the public arena outside the home and the private sphere of the home in her work on bathing. She argues that the provision of care at home represents not just the crossing of this boundary, but an intrusion into the private world of home.

Research suggests that the boundaries between paid and informal care are also breaking down (Ungerson 1997a,b, 1999; Twigg 2000; Forbat 2005). Heaton (1999) in her analysis of the discourse of informal care argues that there has been a change in the meaning of being a carer, resulting in a gentle, but persistent fusion of the informal carer into a professional. The idea that family carers are increasingly undertaking professional care roles has been discussed by Twigg and Atkin (1994), whilst the National Strategy for Carers (DoH 1999) treated informal carers as: 'family members, co-workers and commodities' (cited in Forbat 2005:24). To help us to identify broad differences between formal and informal care Table 4 outlines work by Finch (1989), Ungerson (1990) and Qureshi (1990), which details some of the characteristics of informal and formal care.

Table 4	Characteristics of Informal and Formal Support
Characteristics of Informal Support (Provided by family and friends)	**Characteristics of Formal Support (Provided or purchased by social services)**
Support is delivered by virtue of the social relationship	Support is delivered to service users who have met social services eligibility criteria
The carer usually has a strong attachment to the cared for person	There is no strong attachment
The support provided has continuity	Support is often provided by different workers with no continuity
The carer mainly provides support for one person	Care workers provide care for a number of people
The involvement and desired outcomes are not clearly specified	Involvement and outcomes are clearly defined
The cared for person has no formal method of complaint if they are dissatisfied	Formal complaints procedure
Tasks are often undefined and wide (gardening, repairs, cleaning, transport, shopping, healthcare, car maintenance etc)	Tasks are clearly defined and narrow (often personal care only)
Carers may feel a personal responsibility or obligation towards the supported person	No personal responsibility
Carers may feel guilty if they do not provide care	No guilty feelings- care provision is the responsibility of social services
The carer may visit the person socially	No social visiting
The relationship would continue if the support provision ceased	Relationship would cease if support ceased.
The carer may be 'on-call' most of the day and night	Individual carers are not on call. Overall responsibility rests with social services.
Support often lacks constraints regarding time and place where support is provided	Constraints in terms of time and place support is provided
Substitution of the carer may be difficult	Substitution of the carer is usually easy

Table devised using work by Finch (1989), Ungerson (1990) and Qureshi (1990)

This table is not an actual representation of care provision, but rather a generalised picture to aid clarity in this thesis. It shows that in general terms informal support provided by family and friends, often has undefined tasks, a

relationship involving an attachment with support being provided because of the relationship. In contrast formal support such as that by homecare workers requires no attachment, no previous social relationship and usually has a defined and narrow list of tasks. But what does research tell us about direct employment by disabled adults, and its impact on the boundaries of the support relationship? Studies involving only disabled employers describe the development of friendly relationships with confused limits, where workers perform a wide range of tasks similar to the support provided by family members (Kestenbaum and Cava 1998; Pearson 2001; McMullen 2003; Clark et al 2004; Stainton and Boyce 2004). Much of the research focuses on the positive aspects of this for disabled adults in terms of a greater breadth of support.

The small number of studies involving personal assistants, both in the UK and abroad, also indicate that direct employment relationships are characterised by unclear boundaries showing many of the features of informal support (Eustis and Fischer 1991; Ungerson 1999, 2004; Glendinning et al 2000a; Rivas 2003; Askheim 2003; Benjamin and Matthias 2004; Dale et al 2005; Flynn 2005). One study, which examines the role direct payments can play in overcoming divisions between health and social care, found that some personal assistants lacked clear job descriptions, specified working hours and leave entitlement (Glendinning et al 2000a). In this study, workers providing live-in support experienced problems in establishing rights to some free time, and there were examples of personal assistants reluctantly undertaking tasks associated with healthcare such as: giving injections, helping with physiotherapy exercises, bladder and bowel management. However as I

argued in section 3.1, Glendinning's study appears to have an unusual sample of personal assistants, as most had previously worked as nurses unlike the majority of personal assistants who are unqualified (Lakey 1994; Dawson 2000; Kestenbaum 2001). This could have distorted the results of the research, as it is possible personal assistants in this study had nursing tasks delegated to them precisely because of their nursing skills, and would not have done so if they were unqualified.

Some research suggests that blurred boundaries and close family-like relationships can be an area of concern for personal assistants. Both Ungerson (1999, 2004) and Glendinning et al (2000a) argue that these relationships can bring all the associated obligations of a 'real' family member. Anderson (2003) goes on to suggest that being part of the family benefits employers rather than employees, as employers will feel able to encroach on workers off-duty periods, whilst workers are unlikely to be given the unconditional love associated with kin relationships. Personal assistants may be vulnerable to emotional blackmail, because they are 'frequently working alone with no colleagues and operating in a segment of the labour market which credentialism has barely touched' (Ungerson 2004:204). In another form of direct employment, that of nannying, Gregson and Lowe (1994) argue that these 'false kinship' relationships develop, because of the sense of obligation that mothers rather than workers feel, because the nannies enable them to achieve 'working motherhood'. Alternatively Ehrenreich and Hochschild (2003) suggest that nannies develop a strong sense of commitment to the children they care for often, because they are separated

from their own children, and channel their caring impulses into their relationship with their charges. The literature is thus inconclusive on this point.

Moving on to look at research about boundaries in other countries, one study in the US involved disabled users (including employers), homecare workers and personal assistants, and as such has the potential to make a comparison between direct and non-direct employment (Eustis and Fischer 1991). In terms of the boundaries in the relationship the authors observed four 'patterns of relationships' in their study: the personal, the formal, the asymmetric and the collegial, and these are reproduced in Table 5. This research found that older users who were not direct employers were more prone to having a formal relationship, suggesting that the boundaries in non-direct employment situations are clearer than in direct employment relationships.

Table 5	Patterns of Relationships
1. Personal Relationship	User views worker as a friend or like family. Behaviour is friend-like Workers and users share and discuss problems Worker and users do activities together outside work
2. Formal Relationship	User views worker in contractural terms No confiding or socializing with each other
3. Asymmetric Relationship	User thinks of worker as a friend or like family No mutual confiding, only user confides
4. Collegial Relationship	Relationship is contractural (user thinks of the helper as a worker) Some mutual confiding and socializing with each other

(Eustis and Fischer 1991)

This research initially appears interesting, however despite the inclusion of workers, this study places greater emphasis on the views of users. For example, questions about the relationship were asked only of users, with their responses used by the authors, to develop 'patterns of relationships', even though workers perceptions of the relationship were missing, and may have been different to those of users.

In another study from the US, Benjamin and Matthias (2004) argue that the boundaries are more confused in the direct-hire relationship, because of the closeness which can develop, causing difficulties in boundary setting. This paper also discusses the employment of family members as personal assistants suggesting that because they are related they encounter even greater problems in setting limits in the relationship. In this study related workers were more likely to help with a large range of tasks and provide unpaid support than non-related personal assistants. This aspect of the research is of consequence, as it highlights the potentially difficult position faced by directly employed relatives.

The literature thus indicates that blurred boundaries, despite definite characteristics, appear common in many care relationships, and are intensified by the direct employment of workers. Researchers suggest that unclear boundaries can cause difficulties for personal assistants, especially those who are related to their employer. However as I have argued, whilst current research is beneficial in highlighting issues of possible concern, it is problematic in that it lacks the involvement of both parties in the relationship, and the comparison between direct and non-direct employment. The research

in this thesis seeks to create a different way of looking at the boundaries of the direct employment relationship by filling these gaps.

3.6 Job Satisfaction and Stress

Job satisfaction and stress are important elements of people's experiences of their job. Work related stress is a serious problem with up to 5 million people in the UK reporting that they are 'very' stressed by their work, and about half a million people experiencing work related stress at a level they believe is making them ill (Health and Safety Executive 2005). The Health and Safety Executive (HSE) (2004) define stress as: 'The adverse reaction people have to excessive pressure or other types of demand placed upon them'. Whilst job satisfaction is defined as: 'An expression of the complex interplay between the various facets of a person's work such as pay, prestige, relations with staff, working conditions and so on' (Sibbald and Young (2001:6).

A number of studies have now established links between stress and a whole range of medical conditions such as an increased risk of heart attack and strokes (Landsberis 2003), inability to relax, (Sutherland and Cooper 1999) a lower immune system, indigestion and ulcers (Smith et al 2000). Stress and job satisfaction are linked. For example, feeling stressed can influence a person's satisfaction with their jobs in terms of their morale, well-being, work attendance and productivity (Mclean 1999; Cameron and Moss 2002). Jobs have two main dimensions to them, the extrinsic (material rewards, pay, promotion prospects, job security) and the intrinsic (level of autonomy, nature of work, hours of work).

In terms of employment generally, a number of studies indicate that people's satisfaction with their job is declining, because employment has become more stressful, due to the increased number of hours they are expected to work and the amount of work they need to accomplish (Oswald and Gardiner 2001;Taylor 2002). Bunting (2004) refers to this as 'work intensification' and argues that the public sector has been particularly affected over the last ten years, as 50,000 jobs have been lost whilst work responsibilities have become greater. For homecare workers, most research suggests that they appear to gain greatest satisfaction from the intrinsic elements of their job, such as their relationship with users (Balloch et al 1999; Sinclair et al 2000; Henwood and Waddington 2002), and least satisfaction with the extrinsic elements of their work, the rate of pay, lack of status and lack of appropriate training (TOPSS 2003; Johansson and Moss 2004).

There have been few studies that investigate stress and job satisfaction for employees of social services and those that have tend to focus on social workers (Mclean and Andrew 2000). Other research reports findings from studies with combined groups of workers making it difficult to determine the experiences of a particular group (Cameron and Moss 2002; TOPSS 2003; Coffey et al 2004; Johansson and Moss 2004). Research into stress and job satisfaction for personal assistants employed by direct payment users is even sparser, and there is currently no research in the UK that specifically examines these areas. For users too there are no studies that measure levels of stress for people using direct payments. Yet this is an area that can help us understand the impact of direct employment on the support relationship. For example, whether direct employment results in workers being more or less

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stressed or satisfied at work. And whether being an employer causes users to have greater or lower levels of stress.

The literature suggests that workers providing support to disabled adults may become stressed, because of the emotional nature of their work. Balloch et al (1999) used the General Health Questionnaire to measure stress levels in homecare workers. This study reported that their main source of stress was coping with homecare users' distress and feeling overwhelmed by users' problems. The concept of 'emotional labour' was developed by Hochschild (1983) and used to described work where people are required to use their emotional skills to do their job. It is a vital component of most service work with face-to-face contact between workers and clients. Emotional labour involves a worker paying close attention to another person, interpreting and reacting to their needs. It requires the worker to control their own feelings and 'give something of themselves', rather than just giving trite responses (Twigg 2000:161). The literature about nursing recognises the dangers for employees of emotional labour (McMahon and Pearson 1998), and in her work on hospices James (1989) argues that emotional labour is usually a hidden part of a job, implicit but not acknowledged, often regarded as unskilled work that female workers are expected to know how to do simply because of their qualities as women. Nevertheless this work can be very demanding, indeed Hochschild suggests it is potentially damaging to workers, because their feelings are taken out of their control and managed by their employer.

There is remarkably little data on job satisfaction and stress in the direct employment relationship. None of the UK studies on direct payments address these issues specifically, although some researchers mention situations,

which could be stressful both for workers and users. For instance, as we saw in the preceding section Rivas (2003) talks about how workers may feel upset when their efforts are ignored or they are made to feel invisible, whilst Glendinning et al (2000a) found that some personal assistants were worried about undertaking healthcare duties in case something went wrong. In reporting her cross-national study, Ungerson (2006) argues that many personal assistants work in conditions that are unsatisfactory, although she makes the point that this does not mean that the work itself is unsatisfactory. She also highlights the lack of job opportunities for some personal assistants, so that if they feel stressed they have few alternatives: 'Even if I don't like it, what can I do? It is a stressful job, not easy work. Here the only work that one can do is to care for old people. What I did in my own country [nursing training] is not recognised here' (Peruvian personal assistant in Milan in Ungerson 2006: 224).

Two studies in the US (Benjamin and Matthias 2004; Dale et al 2005) do focus on stress and job satisfaction. Both of these studies also provide a comparison between directly employed workers and agency employees, although users are not involved in this research. Almost seven hundred care workers in each study were asked a series of questions, either by telephone interview or short face-to-face interview (20 minutes). Responses were then analysed using statistical tests, such as multiple regression. The studies report few differences between the two groups in terms of 'emotional strain', although they found that direct employees were slightly more likely to worry about their employers' safety when they were not present, and were a little more satisfied when it came to their relationship with users. Both studies also

report that direct employees who were related to their employer faced additional stress in terms of providing unpaid help and undertaking a wide range of tasks. This research is of interest and provides a basis for comparison, though the large sample size, short interview and quantitative analysis removes the probability of any in-depth data enabling a more detailed understanding of the care relationship.

In terms of employers, a number of research studies report the benefits of direct payments for users, including greater levels of satisfaction with the support provided than with traditional services (Morris 1993; Leece 2000; Witcher et al 2000; Stainton and Boyce 2004; Commission for Social Care Inspection 2004; Poll et al 2006). However other user research suggests some negative aspects to being an employer that could cause stress or dissatisfaction, such as having to complete a lot of paperwork, and problems with recruiting or managing staff (Maglajlic et al 2000; Vasey 2000; McMullen 2003). Yet none of these studies directly focuses on or attempts to measure levels of stress in employers, and so consequently provides a limited contribution to the debate.

Moving on to explore satisfaction with the extrinsic elements of work chapter 2 explains that following the implementation of the NHS and Community Care Act in 1993, local authorities were required to change from being providers of social care to purchasers of care. This was achieved by a reduction of in-house provision, such as homecare by local authorities, and a corresponding increase in care services purchased from the independent sector (Means et al 2002). Many local authorities transferred in-house services, such as residential homes, into the independent sector around this time, and workers

in these establishments found themselves suddenly employed by private companies or not for profit organisations often on much poorer terms and conditions (Leece 1995). The shift from local authority provided services resulted in workers losing jobs in the public sector, where they had pension provision, union representation and safe working environments for jobs in the independent sector with less beneficial terms, creating a new low paid, casualised social care workforce (Carpenter 1994; Ford et al 1998; Wistow and Hardy 1999; Eborall and Gameson 2001).

Relating this to the direct employment of personal assistants, there have been suggestions in the literature that the move to direct payments is a continuation of this trend, and will disadvantage women who provide most of the support for disabled adults (Ungerson 1997a, 2000; National Union Research 1998). The new labour market for personal assistants has been described as a 'flea market', which will bring together 'poor purchasers and poor vendors who sell goods of limited and contested utility' (Ungerson 1997c: 50). Unison (2004:2), the public sector union, has also expressed concern over the impact of direct payments for employees in the social care sector stating that: 'direct payments do not allow recipients to offer decent rates of pay to personal assistants'

It is difficult to obtain a clear picture of the terms and conditions of employment for direct employees in the UK, as there is little conformity in the amounts paid to users to employ a personal assistant (McMullen 2003; Ridley and Jones 2003). Although there is evidence that some direct payment users see the money they receive as too low to pay personal assistants a reasonable wage (Pearson 2001; McMullen 2003). Some older direct

payment users too said that they 'either topped up the money themselves or paid their personal assistant peanuts' (Clark et al 2004). There is also a lack of research that tells us about any resulting impact that low pay has on personal assistants' satisfaction with their job. The research in this thesis seeks to address this by comparing personal assistants and homecare workers' job satisfaction, pay and conditions of work.

3.7 Conclusion

In this chapter I have critically reviewed previous literature to consider its relevance to the research question: 'How does the opportunity for disabled adults to employ their own workers affect the support relationship?' Existing research is useful and has raised a number of important issues about the support relationship, such as the possible risks of direct employment, especially for personal assistants who are related to their employer. However, as I have demonstrated, this research is problematic in that there are major empirical and conceptual limitations. The majority of studies focus on the interests of users, failing to include the perspective of workers and this is a significant omission, for to understand the dynamics of a relationship the experiences of both parties in that relationship need to be recognised. Research in the UK has not made the comparison between the direct and the non-direct employment relationship, which would enable the differences and similarities to be examined; neither has it explored the compelling areas of job satisfaction and stress in the relationship.

The literature has only a limited consideration of the notion of power and money in the direct employment relationship, and the concept of independence is ambiguous and contested. The definition of independence,

used by the disabled people's movement, is too narrow and focuses only on the interests of disabled adults. I have suggested that the concept of autonomy should be used, as this enables an understanding of the perspective of both workers and users, such as where conflicts of interest could occur. Economic transactions may be intrinsically entwined with intimate care, yet this can be a hidden part of the social care relationship. Paying of wages directly to workers, as in the case with direct employment, brings the money element out into the open, creating the potential to change the balance of power and the ability of users to reciprocate within that relationship. Explanations about the notion of boundaries or limits in the direct employment relationship are also confused in the literature. These areas have not been adequately addressed by current research, and the research in this thesis sets out to address this.

In chapter one I described the present government's determination to radically extend the numbers of people using direct payments, which will almost certainly result in the direct employment of many more people as personal assistants. Indeed Askheim (2005: 252) argues: 'it increasingly appears to be official policy that direct payments should be the norm rather than the exception'. Consequently there is a need for a far greater understanding of the direct employment relationship than research presently allows, especially as some researchers suggest there are potential risks from direct employment. It is therefore important that empirical research is conducted to examine the direct employment relationship further.

Chapter 4 The Methodology of the Study

In this chapter I discuss the choice of methodology for my research and explain how the study was undertaken. The chapter is divided into three main sections. First I explain the philosophy that has guided the research, broadly locating it within the symbolic interactionist tradition, and evaluate research methods to explain how the methodology was selected. In section two I look at the ethics of the research, following onto the third section in which I explain how the research was undertaken and the data analysed.

4.1 The Research Tradition

When undertaking a study it is important to understand and acknowledge the assumptions that underlie the purpose and how these match the approach to the research (Bryman 2001). Ontological and epistemological persuasions need to be made clear, as does a consideration of methodological questions, so that the process of the research is transparent, coherent, logical and rigorous (Charmaz 2000). The process of research does not take place in isolation it is influenced by the philosophical allegiances held by researchers (Gilbert 1993; Bryman 2001). The formation of research questions occurs from our perception about the nature of reality (ontology), how we regard knowledge and what can be known (epistemology) and how best to discover reality (methodology) (Annells 1996).

In order to clarify the ontological and epistemological thinking in this study I looked at a number of positions and traditions in research. For example, positivist ontology regards the world as 'real and completely separate from human mean-making', where the world is an ordered system made up of

discrete and observable events that have objective reality (Potter 2006:79).

Objectivism is an ontological position reflecting this view suggesting that

phenomena such as organisations or institutions have a reality or existence

that is independent from human's role (Rand 1957; Kelley 2000), Culture and

organisation are thus pre-given and impact on people as realities that they

have no role in altering, so that in this view it is reasonable to conduct

research independently from any consideration of the role people have in

making sense of it (Denzin 1997; Potter 2006). Conversely constructionist

ontology argues that the world is just as people understand it, made up of

meanings represented in the signs and symbols, which they use to think and

communicate (Potter 2006).

Closely related to ontological ideas is the question of what is regarded as

acceptable knowledge in research. Epistemology is the study of the nature of

knowledge and is concerned with what counts as valid knowledge, how we

can gain this and whether knowledge can be certain (Potter 2006). Positivist

epistemology broadly considers that knowledge is gained through the

gathering of facts from systematic, objective observation. In this perspective

theories are used to generate hypotheses, which can be tested

experimentally, and this has generally become associated with scientific study

(Patton 2002). In contrast constructionist epistemology regards knowledge

very differently, arguing that it is constructed rather than being simply

discovered, with people understanding the way their world operates through

interaction with others. For example, the term 'care' is not an absolute entity

but a social construction, as its meaning will vary in both time and place and is

built up during interaction (Devaus 2001; Bryman 2001). Constructionist

epistemology argues that we need to study the world of meanings and interpret or make sense of people's action (Bryman 2001). This perspective draws on postmodern theory to stress the links between knowledge and power arguing that those who create knowledge thereby gain power (Potter 2006) and that knowledge gained by scientists is influenced by what they choose to observe and how they interpret it.

Symbolic interactionism is a social-psychological approach largely associated with Mead (1934) and Blumer (1969), which places great emphasis on meaning and interpretation (Patton 2002). The original work by Mead, which argues that our notion of self emerges through our perception of how others see us, has been extended by Blumer who suggests that there are three main principles fundamental to symbolic interactionism, which I have paraphrased below:

1. People act towards things on the basis of the meanings things have for them.

2. The meaning of things arises out of the social interaction between people.

3. The meaning of things are dealt with and modified by people through a process of interpretation.

Blumer considers that qualitative inquiry is the only real way of understanding how people perceive and interpret their world, as close contact, direct interaction, open-minded inquiry and inductive analysis enable us to understand the world of people being studied. One of the main characteristics of symbolic interactionism is a concern for understanding social processes

and interactions from the individual's point of view (Bryman 1988), and this was an important focus of the research. For example, to understand the impact of direct employment on the relationship there was a need to examine the power distribution in the relationship, the boundaries, also to look at the ability of workers and users to be autonomous within the relationship, and all of these areas required people to explain their views in their own words. Symbolic interactionism focuses on individual agency, yet it also accepts that the structure of society, cultural ideology, historical and environmental circumstances shape individual interpretations and interactions by providing a set of norms and roles which people use to construct their reality (Blumer 1969). I felt that this too was important as it located my research within the wider context of society.

Therefore I decided to reject objectivism and positivism, because my research required an understanding of people's experiences of their relationship, rather than a scientific collection of 'facts'. I decided to broadly locate the study in the symbolic interaction (interpretivist) framework, as the research needed to focus on understanding reality from the individual's perspective. The research needed to discover how users and workers defined their relationship, what the relationship meant to them; to enable them to speak in detail about their world, so that the data generated would give insights and understandings into the nature of that relationship.

4.1.1 Researching Disabled Adults

In choosing the research methodology for the study I became aware of the numerous criticisms made by disability theorists concerning aspects of social research into disability and disabled adults. Central to these criticisms is that social science research has ignored or rejected analyses of disability as a form of oppression (Mercer 2004). Also that it has failed to have any important effect on either disabled adults' quality of life or provision of services, with researchers cast in the role of 'expert' and disabled adults as 'passive research subject' (Abberley 1987; Oliver 1992; Branfield 1998). Indeed Oliver (1992:105) argues that many disabled adults have become alienated from research and view it as:

A violation of their experience, as irrelevant to their needs and as failing to improve their material circumstances and quality of life.

Theorists have been scathing about both positivist and interpretive research traditions, with claims that research into disability has been undertaken in an objective and non-partisan fashion, using empirical methods, which have compounded the oppression faced by disabled adults through:

The misunderstanding of the nature of disability, the [projects'] distortion of the experience of disability, their failure to involve disabled people and the lack of real improvements in the lives of disabled people (Barton 1992:99)

From these ideas, the emancipatory paradigm of disability research has been developed with proponents arguing for a 'radical reversal of the social relations of research production' with researchers 'challenging oppression and facilitating the self-empowerment of disabled people' (Stone and Priestley

1996:703). This model is located within the social model of disability (discussed in chapter 2) and argues that disability research should 'aim to change the world not just describe it' (Carmichael 2004). According to this theory, traditional researcher-researched hierarchy is reversed, with disabled adults having control of the research resources; the research agenda and the processes of research (Zarb 1992, 1997). This involves their determining the research questions, selecting a methodology, designing questionnaires, completing interviews, drawing conclusions and making recommendations (Aspis 2002). Indeed some have argued that non-disabled researchers should be excluded completely from disability research, as: 'they are not where we are and can never be' (Branfield 1998:143).

On the other hand others have argued that rather than putting people into single unitary categories the 'disabled identity' should be seen as fluid and changing, as non-disabled adults may become disabled and vice versa (Duckett 1998). Being a disabled person does not automatically give people empathy with all other disabled adults. Concern has also been raised about the shortage of disabled researchers available to undertake projects (Zarb 1997), whilst Barnes (1992:122) suggests that instead of regarding disability research as the province of disabled adults conducted by disabled adults it should involve:

The systematic demystification of the structures and processes, which create disability and the establishment of a workable dialogue between the research community and disabled people in order to facilitate the latter's empowerment.

The emancipatory paradigm has itself been criticised. Hammersley (1992) argues that focussing on a particular oppressed group might be at variance with the interest of other oppressed groups. Additionally Stone and Priestley (1996), Oliver (1997) and Shakespeare (1997), who broadly support the emancipatory model, raise issues about the practicalities of actually applying it to research, as many disabled adults may not wish to take over the control of research studies. Difficulties of involving people with intellectual impairments have also been raised (Walmsley 2001), and have caused some researchers to move away from emancipatory methods. For example, Shakespeare (1997) argues that he does not care whether his work is rated as emancipatory, and prefers to follow his own individual and ethical standards, rather than attempting to follow orthodoxy.

So where does that leave me, as presently a non-disabled researcher, researching the experiences of disabled people? My eldest son has a physical disability and my mother had Alzheimer's disease before her death. I have witnessed the discrimination and oppression both have faced and feel strongly that research should not add to the oppression of disabled adults. However, I also feel that the aims of the emancipatory paradigm conflicts with the demands of a PhD study, which requires students to submit a thesis of their own independent work (Open University 2004), although I am aware that some PhD students have contested this notion (Clement 2003). Also as half of the sample in the study (the workers employed to provide support), are likely to be non-disabled, should the emancipatory paradigm be used to guide their involvement in the research? I decided to accept the position presented by Shakespeare (1996) that whilst researchers need to strive to equalise the

relationship with participants, give them some control over the research process and represent their voice, a totally equal relationship is impossible. This study therefore involved disabled adults in the research process (a participatory approach- Zarb 1997) rather than being emancipatory. This is discussed later in this chapter in section 4.3.1.

4.1.2 The Research methodology

Grounded theory was developed as a methodology by Glaser and Strauss in 1967 with its origins in the pragmatist Chicago School tradition of symbolic interactionism, and is thus particularly suited to research such as mine, conducted in a symbolic interaction research tradition. It has become the most widely used framework for analysing qualitative data and the most influential model for qualitative research in the social sciences (Denzin 1997). Grounded theory was conceived as a way of generating theory through data rather than testing hypotheses determined in advance of data collection. It is generally associated with inductive reasoning, due to its focus on theory generation from data, but is also an iterative approach, as researchers are required to move between theory and data (Bryman 2001).

Initially grounded theory required researchers to follow a framework from the design of the project right through to the writing up stage, using methods such as: theoretical sampling, theoretical saturation, open coding, axial coding, categorisation and constant comparison (Dey 2004). However the original methodology has evolved over the years and there is now controversy about what grounded theory actually entails (Charmaz 1991). It is no longer a single, clearly defined methodology instead a number of different interpretations exist (Strauss and Corbin 1990, 1998; Kools et al 1996; Dey 2004). Indeed Corbin

and Holt (2005:50) argue that grounded theory is 'a method in flux that has many different meanings to different people'.

Whilst this lack of a clear framework can be seen as a weakness and may be daunting for researchers, it can also be a real advantage, as it allows the researcher flexibility to develop the best methodological strategy for their research study. For as Coffey and Atkinson (1996:10) argue, research 'is not about adhering to any one correct approach or set of right techniques, it is imaginative, artful, flexible and reflexive'.

4.1.3 Developing a Methodology: Studies using Grounded Theory

In this section I look at studies that use grounded theory to research relationships generally, for as I identified in chapter 3, there is no research that compares precisely with the area studied in this thesis. Research in Sweden, which focussed on thirteen disabled children who used the equivalent of direct payments, investigated how they perceived their relationship with their personal assistants. The authors argue they used a grounded theory approach as it led to 'an improved understanding of relationships and interactions between individuals' (Skar and Tamm 2001:921). The study involved a semi-structured interview guide developed from thematic questions based on previous research knowledge. The analysis was carried out in parallel with consideration of other research literature to stimulate theoretical sensitivity, which is the 'ability of the researcher to recognise what is important in the data and give it meaning' (Hareven 1982:377).

Skar and Tamm (2001) argue that because of their small sample it was impossible to know if theoretical saturation had been reached. Theoretical saturation in grounded theory is the idea that sampling continues until a category has been saturated with data. This occurs when no new or relevant data emerges regarding a category; the category is well developed and the relationship among categories is well established (Strauss and Corbin 1998). In a study to investigate the meaning of relationships for owner-managers of small firms with their customers the decision about whether theoretical saturation had been reached was 'partly based on available resources' (Fuller and Lewis (2002:321). Another indication of the difficulty of identifying the point of theoretical saturation is that a number of studies using grounded theory have sample sizes that are in round numbers, for example 5, 10, 15. 20, 25, which may suggest that the number of participants in the sample have been chosen for reasons other than theoretical saturation (Crisp 2000; Haas 2002; Fuller and Lewis 2002; Edwards 2004). Achieving theoretical saturation in my study was a concern given the constraints of time and financial resources of a PhD study, and the restricted availability of direct payment users to take part. However I argue that theoretical saturation was reached and this will be discussed later in this chapter.

A study by Haas (2002) used grounded theory to explore how social support affects the relationship in gay male couples coping with HIV or AIDS. The author used his previous knowledge of research in this area to devise the research question for the study and to inform the analysis: 'throughout the analysis, themes, categories and sub-categories are constantly compared with other data, as well as the researcher's knowledge of pertinent existing

research' (Haas 2002:94). Other researchers using comparable approaches use existing research knowledge in a similar way to this (Skar and Tamm 2001; Marsiglio et al 2001; Edwards 2004).

Nonetheless the original model of grounded theory required researchers to reject the use of existing knowledge and theory as a basis for data analysis. Concepts and categories, it was argued, should be dictated by the data rather than previous research knowledge (Glaser and Strauss 1967). Theoretical sampling, devised as an alternative strategy to the deductive approach of probability sampling for hypothesis testing, also required the researcher to abandon previous knowledge. Theoretical sampling is: 'The process of data collection for generating theory whereby the analyst jointly collects, codes and analyses the data and decides what data to collect next and where to find them in order to develop the theory as it emerges' (Glaser and Strauss 1967:45). There has been much criticism of this notion and it has been argued to be impossible for researchers to undertake projects with a completely open mind and to totally discard previous substantive knowledge (Dey 1999, 2004; Gilgun 2001; Kools et al 1996; Kelle 1997):

Qualitative researchers always bring with them their own lenses and conceptual networks. They cannot drop them, for in this case they would not be able to perceive, observe and describe meaningful events any longer- confronted by chaotic, meaningless and fragmented phenomena (Denzin and Lincoln 1998:4)

Gilgun (2001) argues that although researchers cannot ignore their previous knowledge, what they can do is to be open to what respondents are saying with the role of previous research being to guide researchers and to help

interpret the data. Furthermore Dey (2004) considers that the analysis should build up a picture informed by theory and literature, where theory is not tested, but closely examined in relation to the data for explanations. A number of studies use grounded theory in this way. In a study informed by symbolic interactionism authors said they used their familiarity with relevant theory and knowledge of issues to develop a conceptual framework for their research (Marsiglio et al 2001). Further research looking at how women construct and manage family relationships used a 'set of concerns derived from the literature' and then used existing knowledge to help analyse the data (Edwards 2004:517).

Kvale (1996) argues that without presentation of existing knowledge it is difficult for researchers to know whether the data gathered from their research is new and so contributes to the literature. This is particularly important in a PhD study, which needs to 'show evidence of making a significant contribution to knowledge' (Open University 2000:8). Kvale (1996) considers that before any data collection takes place researchers should develop a conceptual and theoretical understanding of the phenomena to be studied to establish a base to which new knowledge will be added. Knowledge of the study area is required to pose relevant research questions. Coffey and Atkinson (1996:153) argue that we should bring to our data:

The full range of intellectual resources derived from theoretical; perspectives, substantive traditions, research literature and other sources. Research methods do not in themselves substitute for disciplinary knowledge

The arguments for using previous research knowledge and experience to inform and guide the research are persuasive. My previous role as a Commissioning Officer gave me a detailed and extensive knowledge of direct payments, as did my research (Leece 2000, 2001, 2002a+b, 2003a+b, 2004a; Leece et al 2003). I felt it would be impossible to 'unlearn' or ignore this experience and that it would be valuable in enabling me to develop an effective research study. Therefore I used my previous research knowledge to build up a picture and guide the process of the research in this thesis.

Further research by Marsiglio (2004) studied the relationship between stepfathers and their stepchildren. This research followed the symbolic interaction tradition exploring the way men described their relationships with their stepchildren by examining the labels and language they used. My study looked at the language used by respondents to help to understand the meaning the relationship has for individuals. Marsiglio's study highlighted criticism of grounded theory that although the method was conceived as a way of generating theory through research, rather than testing ideas or hypothesis, it is often difficult to determine what theory, in terms of an explanation for a phenomenon, is actually being advanced (Bryman 2001; Dey 1999, 2004). Marsiglio (2004:27) states that 'my aim in this conceptual analysis is more modest than what are typically associated with classic grounded theory: the generation of explicit theory…my principal objective is to use the grounded theory method to generate and sharpen a conceptual lens for exploring how some men experience the relationship with their stepchildren'. My use of grounded theory was similar to Marsiglio's, a method of exploring in detail the relationships of respondents.

Research in Australia that applied a grounded theory approach used disabled adults as expert contributors to the research process (Crisp 2000). This was also the approach adopted in a study by Knox et al (2000) where grounded theory was used to explain the processes by which people manage relationships within their communities. In this study a group of people with learning disabilities formed a panel of experts to collaborate in the research design. For the research in this thesis, I also recruited a number of disabled adults to act as a panel of experts to give a 'disability perspective' to the study, and this will be explained further in section 4.3.1.

4.1.4 Choosing the Method

The two most prominent methods of data collection in qualitative research are interviews and participant observation, with both of these featuring strongly in studies using grounded theory (Denzin 1993). Participant observation is closely linked to ethnography involving researchers immersing themselves in a group for a period of time; becoming a member of the group; observing behaviour; listening to what is said and asking questions. There are a number of advantages with this method: the researcher may come to understand the social reality and culture of the group studied, because of the long involvement; the data will include non-verbal aspects rather than relying on what is said; deviant or hidden activities are more likely to be exposed due to the long interaction.

On the other hand there are a number of disadvantages to participant observation. There are certain situations where it may not be feasible for

researchers to insinuate themselves into the life of research subjects to observe them. The research in this thesis falls into this category, as direct payment users live at home. Many disabled adults receive support of an intimate nature and to observe intimate care between users and workers could be intrusive. There are ethical considerations about informed consent when people are observed without their knowledge, and having an observer present may result in participants altering their behaviour (Potter 2006). I therefore felt that for all these reasons participant observation was not the right method to use in the research and decided to interview all the participants.

Using interviews to gather data helps researchers to understand the respondent's reality from their own perspective (Patton 2002), which I have argued is of particular importance to this research. There are three main types of qualitative interview. Firstly, the informal conversation that relies entirely on the spontaneous generation of questions following the natural flow of conversation. Secondly, the standardised open-ended interview that consists of a set of carefully worded questions, which the interviewer asks each respondent in the same sequence, and thirdly the approach using an interview guide (Bryman 2001; Patton 2002). In this research I used an interview guide (Appendix 6) to provide a structure to the interview, whilst allowing the flexibility to follow up respondent's replies, and to vary the order of the questions depending on responses given. This method allowed interviewees to 'have their say' and correct information that was wrong. It allowed me to find out about those things that cannot be directly observed,

such as feelings, thoughts and intentions (Patton 2002). Kvale (1996:70) argues that the qualitative interview is a:

Uniquely sensitive and powerful method for capturing the experiences and lived meanings of the subjects everyday world. Interviews allow the subject to convey to others their situation from their own perspective and in their own words

Rather than taking verbatim notes of the interviews I decided to record the interviews on audio, to enable me to concentrate on to the dialogue, and maintain eye contact with respondents. Whilst tape recordings do not include visual images of the situation or respondents' facial expressions they are a permanent, verbatim record that can be listened to over and over again to enable researchers to become immersed in their data. Tape recording can help respondents to relax and talk freely as they can ignore the process of the recording, which may be less possible if a researcher is taking notes (Thyer 2001)

4.1.5 Measuring Job Satisfaction and Stress

In chapter 3 I argued that an investigation of job satisfaction and stress in the care relationship was important for understanding the effect of direct employment; it also enables a consideration of positive and negative aspects of the relationship. No UK study examines job satisfaction and stress in the direct payment relationship, so there was a need to consider how these were explored in other research. The literature suggests that measuring stress and job satisfaction is difficult, as an individual's personal situation, such as a happy domestic life, may influence their evaluation of their work. For example,

people who are happy with their life generally may be more inclined to express contentment with their job (Rose 2003). Also the process of interaction between people and their working environment is dynamic (Cox et al 2000). This means that a single method of evaluation is unlikely to discover the whole of respondents' experience and using more than one method is a more effective method of exploring this (Shipley and Orlans 1988; Coffey et al 2004). I therefore decided to use three methods to consider job satisfaction and stress: questions and prompts relating to these areas during the qualitative interview; and two questionnaires, one to measure stress and the other to measure job satisfaction.

The interview guide contained a number prompts concerning job satisfaction and stress:

- Would you describe to me what you like best about your job?

- And what you like least?

- Is there anything in the relationship (or your work) with (supported person or worker) that makes you make you feel stressed?

Asking workers to describe the best and worst things about their job to determine their satisfaction is a method used in research by the Care Work in Europe Programme (Korintus and Moss 2004). To examine job satisfaction I decided to use an instrument developed by Warr et al (1979). This is a schedule containing questions related to: physical working conditions, recognition at work, the freedom to choose methods of working, responsibilities, rates of pay and so forth (see Appendix 7). It measures overall job satisfaction, including extrinsic job satisfaction (features external to the work, for example pay) and intrinsic job satisfaction, features central to the

job itself such as autonomy (Coffey et al 2004). This questionnaire has been used previously in a number of studies with social care and health staff (Wall et al 1997; Willcocks et al 1987; Balloch et al 1999; Oswald and Gardiner 2001; Redfern et al 2002; Coffey et al 2004), suggesting it was the most suitable measure for my study.

To measure the stress levels of all the participants in the study I used the 12-item General Health Questionnaire (GHQ12) (Goldberg and Williams 1988). The GHQ12 was originally developed as a self-administered screening instrument to detect psychiatric illness in the general population. It identifies 'caseness', which is whether an individual would be classified as having a minor psychiatric disorder by a psychiatric assessment, and covers areas such as concentration, depression, confidence, insomnia and happiness. The GHQ12 (Appendix 8) has been used to measure stress in UK workforce studies (Buck et al 1994; Oswald and Gardner 2001), including the social care workforce (Tobin and Carson 1994; Balloch et al 1999; McClean and Andrew 2000; Coffey et al 2004; Huxley et al 2005) It is also used as a stress measure in national studies such as the British Household Panel Survey and has been utilised to measure stress in residents in nursing homes (Redfern et al 2002). It is commonly used to measure stress (Cameron and Moss 2002) and is the best validated instrument of its kind (Wall et all 1997). The GHQ12 is an effective measure for both large samples of people and on an individual basis (Goldberg and Williams1988). Many research studies use the GHQ12 and the job satisfaction questionnaire with large samples, but they are also effective with small samples and for individuals (Johansson and Moss 2004).

I chose both questionnaires for the study because they are easy to administer, tried and tested tools, which are in common usage. They have been utilised in previous studies with social and health care workers allowing comparisons to be made with previous research. It is important to note however that data from these questionnaires has not been analysed using statistical tests, as given the small size of samples of participants within the study, this would be statistically flawed. The data is used to help the interpretation of the interview material and to increase understanding.

4.2 The Ethics of the Research

Ethical issues concerning research can arise at every stage of the development of a research study. Some emerge at the beginning during the formulation of the research question and methodology, whilst others appear as the research is being conducted or at the analysis and reporting of the results stages. This section considers ethical issues and looks at areas such as harm to participants and informed consent. In addition it examines ethical issues for conducting in-depth interviews, the potential for a female researcher to exploit the easy rapport between women and insider research.

4.2.1 Harm to Participants

Research that is likely to harm participants is generally regarded as unacceptable as this can involve physical injury and loss of self-esteem (Bryman 2001). There have been several infamous research studies in the past, which have resulted in real or potential harm to people taking part (Milgram 1963; Humphreys 1970). The Department of Health (DoH 2001b) considers that the dignity, rights, safety and well-being of people taking part in

research must be the primary consideration in any research study and the British Sociological Association (2002) states that researchers should: 'anticipate and guard against consequences for research participants which can be predicted to be harmful' (www.britsoc.org.uk).

As part of undertaking this research, ethical approval was gained from the Open University Human Participants and Materials Ethics Committee (Appendix 9). Furthermore as a qualified social worker registered with the General Social Care Council I have undertaken to abide by the Code of Practice for social workers (www.gscc.org.uk). The British Association of Social Workers (BASW 2002) also has a Code of Ethics, which suggests that researchers should: 'Retain a primary concern for the welfare of research subjects and actively protect them from harm, particularly those who are disadvantaged, vulnerable, oppressed or have exceptional needs.'

Ethical codes for research practice place emphasis on the importance of avoiding harm to participants by ensuring participant confidentiality, so that individuals cannot be identified. This extends to any published findings from the research, and is particularly important now that many journals are available on the Internet, resulting in research being available to a worldwide audience. In the research confidentiality was strictly maintained. Data was stored in a locked cabinet and safeguarded by a password when kept on computer files. Participants' names and addresses were stored separately from their transcripts, and their identity was safeguarded by the use of pseudonyms. Participants were 'rendered anonymous' in publications about the study (Leece 2004a, 2006a) All of these safeguards were clearly stated in the 'Agreement to Participate' form and in a statement read to respondents

prior to the interview (see Appendices 10 and 11). The Agreement to Participate form was based on recommendations by the Oral History Society (www.oralhistory.org.uk).

4.2.2 Informed Consent

There is a responsibility upon the researcher to explain as fully as possible in meaningful terms what the research is about, who is undertaking and financing it, and what the likely effects of participating will be. The use to which any data will be put should be explained as well, to enable people to make an informed choice about whether they wish to take part (May 1993; Thyer 2001; Bryman 2001). The BASW code of ethics states that researchers should:

Ensure that subjects' participation in a programme is based on freely given informed and acknowledged consent, secured through the use of language or other appropriate means of communication readily comprehensible to the research subject, conveying an adequate explanation of the purpose of the research and the procedures to be followed (www.basw.co.uk)

Obtaining informed consent can be difficult and to try and ensure that respondents had the information on which to base their decision I used a number of strategies in my study. A letter was sent to possible respondents inviting them to take part (Appendix 12). The letter explained the study and how the data would be used in easy to understand language. I read a statement to respondents prior to the interview reiterating information from this letter (Appendix 11). The Agreement to Participate form (consent form) mentioned in the previous section, which advised respondents that they could

withdraw their consent at any time, was developed with the help of disabled researchers. I asked respondents to sign this form *after* their interview had taken place, so that the consent was meaningful, as it was given in the full knowledge of the interview. This form also advised respondents whom to contact should they, for example, wish to make a complaint about any aspect of the study.

I tried hard to ensure that all respondents had enough information to enable them to give their informed consent nonetheless I accept that achieving this is difficult, and that the methods used had limitations. Although I tried to explain the study, some respondents may not have understood exactly how I would be using the data, or some of the terms such as PhD. The methods would have been inappropriate if the sample included people with cognitive impairments. However I decided not involve people with dementia or learning disabilities in the study, because the nature of the research and methodology required that people were able to speak in-depth about their world. This does not imply that people with cognitive impairments are any less important, but that within the scope of this study it was not possible for me to include them.

4.2.3 The Ethics of In-Depth Interviews

Interviews have the potential to bring out strong feelings in participants, as they involve asking people to share personal details, and this can be problematic for both respondents and researchers. Researchers can experience difficulties in maintaining their role and avoiding becoming embroiled in participants' problems (May 1993; DeVaus 2001). Oakley (1981) highlights potential difficulties for researchers based on her own experiences of interviewing women for research on motherhood. She agues that there is a

is a crucial balance for interviewers to achieve to avoid being 'too friendly', while still being able to give something of themselves, as there is *'no intimacy without reciprocity'* (1981:49). Oakley stresses the contradiction that researchers face in having the need to develop a positive rapport whilst: 'interviewing necessitates the manipulation of interviewees as objects of study/sources of data' (1981:33*)*.

Following on from this Finch (1993) suggests there is potential for female respondents to be exploited by female researchers, because of the easily established trust that women often experience. As I am a female researcher, and the majority of the respondents in the study were female then this was of concern. Finch argues it is possible for female researchers to obtain information from other women with great ease. Dunscombe and Jessop (2002:108) refer to this as researchers 'doing rapport' by 'faking friendship'. They suggest that if respondents are persuaded to participate in the interview by a researcher's show of empathy and friendship, then consent given at the outset is not fully informed for any disclosures given during the interview. To try to avoid this happening all of the respondents in my study were asked to give consent after the interview had taken place, so that they were aware of all disclosures they had made.

Finch (1993) also suggests that to avoid a betrayal of trust researchers should make certain that the data is not used against the collective interest of women. The interviews in my study with both male and female respondents often included sensitive, intimate material. To ensure that the research from this study is not used against the interests of any of the respondents, copies of published articles have been circulated to them all prior to publication for

their comments. Hopefully whilst individual and collective interests are not always the same, my research will not betray the interests of women (or men) generally.

4.2.4 The Ethics of Being an Insider Researcher

At the time the research took place I was an employee of Staffordshire social services, and accessed respondents via this organisation. Undertaking the research meant I needed to decide how to separate my professional work role from my researcher role. For example, research may reveal practices, such as abusive situations, that would otherwise remain hidden, and I would have to decide on a course of action. Gambrill (1997: 51) discusses this in terms of the legal position for social workers and indeed other professionals where respondents threaten or commit a criminal act. She argues that in these cases the courts have found that professionals have a 'duty to warn'. Aware that in such situations, as an employee I needed to abide by social services' adult abuse procedure I avoided giving unrealistic assurances about confidentiality to participants. The Agreement to Participate form accordingly contained a statement saying: 1 understand that the researcher may need to disclose certain information if it is revealed that a person is at risk of serious harm'.

It was important to consider the issue of divided loyalties, as my research could be compromised if my employers influenced it. Insider researchers can have pressure put upon them to research certain areas or feel they cannot report negative findings (May 1999). For this reason I was careful not to accept funding towards my PhD study from my employer. The Director gave his agreement for the study to take place, but there was no involvement in the research by social services. I was fortunate in that Staffordshire social

services is open to research and constructive criticism, such as having negative findings published (Leece et al 2003). Bell and Nut (2002) discuss divided loyalties for practitioner researchers who may have responsibilities towards their employers, and colleagues, as well as respondents in their study, suggesting these roles need to be kept separate. I was helped in this because my role as a Commissioning Officer was not an operational role, with no general involvement with service users, direct payment users or homecare workers. Nevertheless my insider status was not hidden from respondents, as I felt this would be dishonest. It was stated on the letter inviting people to take part and the statement read to all respondents before the interview.

Another area of concern for insider researchers is that respondents may not tell them everything, because they think the researcher already knows the answer, or that insider researchers do not ask certain questions, as they believe they already know the answers (Bartunek and Louis 1996). This was of real concern to me, especially when I interviewed homecare workers who may have seen me as 'an expert from headquarters'. Homecare workers could also have avoided telling me things, which may compromise them, such as if they had broken any rules. To try to avoid this I assured respondents that the research was confidential, I tried to focus respondents on my role as a researcher rather than as an employee by the use of Open University letter headed paper; using my home contact details and my Open University identity card to identify myself. I also asked respondents questions about areas of which I am already knowledgeable.

It is worth stressing that whilst being an insider researcher can bring problems it also has many advantages such as having easy and direct access to a

relevant sample, knowing and understanding the 'system', and respondents feeling safer about inviting an employee into their home. Research by practitioners is also likely to be rooted in practice, as practitioners are aware of the real problems confronting service users (Fuller and Petch 1995).

4.3 Undertaking the Research

This section details the involvement of disabled researchers, how the study was piloted (developmental study) and samples of respondents obtained, the interviewing process, transcribing of tapes and the methods of data analysis.

4.3.1 Involving Disabled Researchers

To develop the research study with the involvement of disabled adults, I decided to link with the 'Consumers as Researchers Programme' at Staffordshire University. This programme teaches research methods to disabled adults. It is a ten-week course, generally with eight to ten students. The sessions include designing research studies, devising questionnaires, interviewing skills, collecting data, compiling results and completing research studies. I have connections with this University through my work for them as a freelance practice teacher and I am an Honorary Research Fellow. I contacted the Centre for Health Policy and Practice and it was agreed that a letter would be sent from me to students who had completed the latest course. The letter explained my research and invited consumer researchers to contact me regarding the development and design of my study (Appendix 13).

Three disabled/consumer researchers responded and agreed to assist in developing methodology for the study. I met each of the researchers at a venue of their choice to explain my study and benefit from their advice. We

also exchanged numerous emails as well as letters and 'phone calls. The value of involving user researchers was enormous they provided an opportunity to discuss the appropriateness of the research question, the methods and the interview schedule. They commented on the Agreement to Participate form, and gave advice on research strategies from their position as disabled researchers. The consumer researchers were able to suggest topics for enquiry that I had not considered, such as looking at gift giving in the relationships. I made changes to the interview schedule to reflect this and to take account of the practical comments they made, such as wording of the Agreement to Participate form.

One important issue that the consumer researchers highlighted and helped me to resolve was whether to make 'thank you' payments to respondents. Disabled adults are often paid for taking part in consultation meetings with social services, and this recognises the contribution that they make as well as enabling people to participate on a more equal basis. One consumer researcher, when making initial contact, asked if any payment would be made for his time. He agreed to help with my research, even though at that stage I said involvement was purely voluntary. I discussed this with him at some length with the result that I offered a £10 thank you payment (cash or shopping vouchers) to all consumer researchers and respondents to the study funded by myself.

The literature about making thank you payments is mixed and is mainly concerned with inducements to take part in medical experiments. The arguments against making payments centre on whether they undermine voluntary decision-making and encourage people to take part in research that

may cause them harm (McNeill 1997). Wilkinson and Moore (1997) consider that this is comparable to paying people wages to work in risky occupations. It has also been argued that incentive payments may cause a 'deteriorating quality of response' as people are taking part 'for the wrong reasons' (the money), although research into responses to postal surveys did not find this to be the case (Singer et al 1998:157).

Paying people to take part is likely to increase not only the numbers, but also the diversity of people who respond. For example, offering payment will mean that those people who require payment will come forward, as well as people who do not require payment, and after all research should not just involve altruistic individuals. There is no indication in the literature that offering payment results in some people, who would have responded altruistically, deciding against it, because of the payment. Indeed two of the respondents in my study agreed to take part, but declined to accept payment.

It can be argued that payment may make people feel obligated and unable to withdraw from research. To counter this, the payment offered was small, so that respondents should feel valued but not coerced. The Agreement to Participate form stated clearly that people could withdraw at any stage. Payment was given to respondents before the interview, so that they could withdraw at any stage and keep it. Carmichael (2004) considers that it is now accepted practice to acknowledge the value of the participation of disabled adults by offering a nominal payment. Involving disabled researchers also reflects the BASW Code of Ethics for research (www.basw.co.uk), which encourages practitioners to involve users in the research process.

There were some negative aspects to the Consumer Researchers' involvement which involved practicalities, such as the time consuming process of making initial contact, arranging to meet and the time spent meeting, also the financial cost (payment and travel costs). The downside however, was outweighed by the considerable benefits to the research of the participation of disabled researchers, who provided a very valuable disability perspective to the study.

4.3.2 Developing the interview Guide

An interview guide can take a number of forms, it can consist of a detailed sequence of carefully worded questions, a list of memory prompts, or just rough topics to be covered. It is important though that the language used is easily understandable to research subjects and that the topics result in data that will help to answer the research questions (Kvale1996). The way that questions are posed can influence the responses made, so that asking direct or leading questions may influence the data. However, direct questions are often necessary parts of interviews, to gain essential information, to check the reliability of the respondent's answers and to verify the interviewer's interpretations (Kvale 1996). Direct questions may not reduce the reliability of the data, but instead enhance it. I decided to use a number of direct questions in order to be sure that all the points I needed to cover for my research were included. This was particularly important, as my research was a comparative study, so it was necessary that I should be able to compare responses.

After developing two draft guides (disabled adults and workers) I shared them with the disabled researchers and my supervisors to obtain their views. Following this, a number of changes were made, both guides were also

amended again after the developmental study, detailed in the next section. I divided them into sections of issues with a series of detailed prompts (Appendix 6). The prompts were designed to ease my nerves and give me confidence during the interview. If my mind went blank, as it sometimes does, I could then refer to the guide and would not forget any areas I wished to cover. This method meant that the interview was fairly flexible in its structure and allowed me to follow interesting avenues raised by respondents: I could thus go with the flow of the conversation and not be too rigid.

4.3.3 The Developmental Study

The developmental study was conducted using a sample of homecare users and their homecare workers in order to preserve the small sample of direct payment users. At the time the study was undertaken there were only thirty-nine disabled adults (without a cognitive disability) in Staffordshire using direct payments to employ a personal assistant. Oppenheim (1992) suggests that where the available population for a study is small they should not be 'used up' in a developmental study; instead an alternative sample that is comparable in their ways of thinking should be used. Subsequently I asked homecare managers to identify twelve disabled adults using Staffordshire social services homecare service, and sent a letter inviting them to take part (Appendix 14). Three disabled adults responded and the first two were interviewed. They were asked to identify one of their regular homecare workers who was then asked to take part. Homecare workers were also offered a £10 thank you payment.

I interviewed four people for the developmental study, two homecare users and two homecare workers supporting them. The interviews were tape-recorded and later transcribed by me. Following the first interview after listening to the tape I was surprised that the interview felt different to how it had felt at the time. I appeared to be quite controlling during the interview and often interrupted the respondent, spoiling their flow. In retrospect I think my social work interviewing skills, which I had assumed would be of benefit to me, impeded me in obtaining an in-depth interview. Social workers need to obtain certain information quickly and tend to focus service users' responses, which is unhelpful for gaining in-depth information. My training in counselling skills however was useful in reflecting information back to respondents to check its accuracy.

Following this I looked at oral history interview techniques, which suggested that to hear women's perspectives accurately you need to get at: 'the web of feelings, attitudes and values that give meanings to activities to events rather than accepting comments at face value' (Gluck and Patai 1991). The researcher needs to explore what people have said rather than moving on to the next question, to ask people to explain what they mean by certain words and phrases and listen carefully to what they say. In the second interview I put these techniques into practice, which improved the quality of the interview and data. I made revisions to the interview schedule after the developmental study, to make it less interrogative and to encourage more in-depth response rather than one word replies.

The GHQ12 (measure of stress) was completed at the end of each developmental interview and proved easy to administer. All of the

respondents were able to complete it. It was scored using the method suggested by Goldberg and Williams (1988), which is simple to do. The scores are detailed in Table 6 with details of the questionnaire and the method of scoring explained in section 7.3.

Table 6		Job satisfaction and stress scores	
Pseudonym		GHQ score	Job satisfaction score
Stewart	Homecare user	2	
Martin	Homecare user	1	
Jennifer	Homecare worker	0	59
Debbie	Homecare worker	0	70

The job satisfaction questionnaire was administered only to the homecare workers as part of the interview schedule. For the first interview it was administered early in the discussion, but this seemed to 'break up the flow of the conversation', so in the next interview it was completed at the end, and this worked much more effectively. The responses to the job satisfaction questionnaire were scored using the system developed by Warr et al (1979) and again this was easy to do. Scoring this questionnaire is explained in detail in section 7.2. Following the developmental study I changed the format of the job satisfaction questionnaire from a series of spoken questions during the interview, to a similar written questionnaire format to the GHQ12. This made the two questionnaires consistent, saved on transcribing time/costs and made analysis easier, as the data was in a more accessible format.

My social work training and practice created an awareness of the need to consider personal safety issues during the study. This is particularly important when researchers conduct lone interviews in people's homes as I did. To maximise my safety in the study I adopted the procedures used by social

services: ensuring someone (my husband) had the details of where I was going, the time I should return and what to do if I failed to return. I also carried a mobile phone on my person during the interview. The developmental study was very useful for checking whether methods chosen for the study were effective. It demonstrated that the GHQ12 and job satisfaction scale were easy to use. It highlighted areas that required improvement or change, for example my interview technique and the wording of the interview guide. Having carried out my developmental study I was now ready to draw my sample of respondents

4.3.4 Obtaining a Sample for the Study

Methods of sample selection vary depending on the type of study to be undertaken. As I have already explained, the study required a sample of people using direct payments and people using homecare, including the workers employed to provide their support. Obtaining these types of samples can be problematic, because social services may not agree to researchers having access.. The study uses convenience sampling, which is the use of a sample that is available to researchers by virtue of its accessibility (Patton 2002). The samples were not representative of the population or randomly selected, although direct payment users were chosen on a first come basis.

I discussed earlier in this chapter the difficulty of determining the point that theoretical saturation of a category is reached, especially under the constraints of a PhD study. In discussion with my supervisors it was decided that I should use a realistically 'doable' sample to generate the required data and to enable theoretical saturation to be achieved. The sample size in a study needs to be large enough to enable the researcher to find out what they

need to know (Kvale 1996). A sample that is too small may not provide enough data whilst a sample that is too large would be impossible to manage. After looking at sample sizes in other similar studies where theoretical saturation had been reached I decided that it should consist of: eight direct payment users, eight personal assistants, eight homecare workers and eight homecare users: a total sample of thirty-two people.

The study involved a comparison of two types of employment relationship where support is provided by different options. In order that differences in the relationships of the two groups could be attributed in part to these options then the characteristics of the two groups, in terms of gender, type of disability, age, ethnic origin, needed to be as similar as possible (Bryman 2001). For example, if members of one group were younger and the others all older people then differences in the relationships may be explained by age, rather than the employment relationship. The two samples therefore needed to be 'matched' to have similar characteristics.

4.3.5 The Direct Payment Sample

A letter of invitation to take part in the study was sent to the thirty-nine people in Staffordshire categorised by social services as older people, people with a physical disability or with mental health needs, who used direct payments to employ a personal assistant (Appendix 12). The letter briefly described the study and my involvement with social services. It stressed that the interview would not affect any services or direct payment that people received. The letter said that I would like to interview direct payment users and the person they employed to provide their support. I was unable to write to personal assistants directly, as they are the employees of direct payment users and I

had no way of knowing their contact details. I could therefore only access personal assistants via their employer

Thirteen direct payment users responded, although two of these later dropped out, one through ill health and the other changed their mind (prior to interview). Respondents were chosen for interview on a first come basis. The direct payment users sample contained five women and three men. Six of the personal assistants were women and two were men. The two male personal assistants both supported male direct payment users. All described their ethnic origin as 'white British'. In chapter 2 I explained that Staffordshire has a lower percentage of people from the black and minority ethnic community than nationally, and only one person from this community was using direct payments. Unfortunately she did not respond to the invitation. The ages of the direct payment users ranged from 22-84 years. Their average age was 52 years. The personal assistants ranged between 25-68 years with an average age of 47 years 3 months. The sample members were all given a pseudonym as is detailed in Table 7.

Table 7			Details of direct payment sample		
Direct Payment User			**Personal Assistant**		
Karen	Female	41 years	Joy	Female	36 years
Linda	Female	60 years	Sue	Female	39 years
Gemma	Female	46 years	Mim	Female	52 years
James	Male	44 years	Dot	Female	66 years
Freda	Female	84 years	Liz	Female	53 years
Wanda	Female	63 years	Win	Female	68 years
Harry	Male	22 years	Tom	Male	25 years
Peter	Male	56 years	Ian	Male	39 years
Average age		52 years	Average age		47 years

4.3.6 The Homecare Sample

In chapter 2 I described the trend away from local authority provided services, following the community care reforms of the 1990's, towards the purchase of services by local authorities from the independent sector. Indeed by the year 2000 the independent sector was providing 56 per cent of local authority homecare hours (Mickelborough 2002), although in 2001 in Staffordshire 60 per cent of homecare was still being provided in-house in 2002 (Henwood and Waddington 2002).

In chapter 3 I argued that this move has resulted in workers losing jobs in the public sector for work in the independent sector on worse terms and conditions. There have been suggestions in the literature that direct payments is a continuation of this trend, and I wanted to examine this in the study by comparing the experiences and terms of directly employed workers with local authority employed homecare workers, rather than workers employed in the independent sector. For this reason the homecare sample was recruited from people using Staffordshire social services in-house homecare service.

Following the completion of the interviews with the direct payment respondents, I met with the Principal Officer for homecare in Staffordshire and homecare managers to explain the study. These managers then provided me with names and addresses of people receiving homecare who were broadly similar to the direct payment sample in terms of age, gender, ethnic origin, and disability. I tried to equalise the two samples in terms of the gender of the worker (there were two male personal assistants in the direct payment sample). However managers identified only one male homecare worker and none of the service users receiving support from this worker responded to my

invitation to take part in the study. Initially I also hoped to match the samples in terms of the numbers of workers providing support, but this also proved to be elusive. People using the home care service generally had regular workers, but they could see up to twenty different workers at certain times (peak holiday periods, times of high sickness rates), whilst direct payment users in the sample had their support provided by between just 1-4 workers.

A letter of invitation to take part in the study was sent to fifty-six people receiving homecare from social services (Appendix 12), who were similar to the direct payment sample. Nineteen people responded and were matched with the direct payment group. The two samples were matched by age, gender, ethnic origin and category of disability. There were problems, for example finding a young male homecare user was difficult, as only two males under thirty years had been identified and neither replied to the invitation. Follow-up calls to both of them were made and one agreed to take part, but then changed his mind prior to the interview, due to family illness. The youngest male respondent was thirty-six and he was matched with the twenty-two year old male in the direct payment sample. Table 8 shows the homecare sample, all of whom were given a pseudonym.

Table 8	Details of homecare sample			
Home Care User			**Home Care Worker**	
1. Brenda female 43 years			Jane female 48 years	
2. Jackie female 55 years			Tess female 50 years	
3. Rachel female 45 years			Jill female 41 years	
4. Trevor male 44 years			Beth female 33 years	
5. Jeanne female 76 years			June female 32 years	
6. Sandra female 57 years			Lucy female 57 years	
7. Daniel male 36 years			Anne female 57 years	
8. Mathew male 67 years			Jess female 48 years	
9. Average age 52.8 years			Average age 45.7 years	

4.3.7 The Matched Samples

The match of the two samples is good in terms of disability, age and ethnic origin, as can be seen below in Table 9. The gender of the homecare users and direct payment users matches, but as already discussed it was unfortunately not possible to match the two male personal assistants with male homecare workers. This is a problem found in other studies (Piercy 2000), due to the low percentage of men working as homecare workers (Twigg 2000).

The average age of the homecare workers sample is almost identical to the personal assistants (45.7 years and 47 years respectively). This was a 'lucky accident' as the method of obtaining the homecare workers sample was to ask the homecare user, during their interview to nominate a regular worker. These workers were then invited to take part and all agreed to do so. I therefore had no control over this aspect of the sampling, and did not know the worker's age until their interview took place. Asking disabled adults to choose a worker to take part does have implications, as they may have chosen workers with whom they had a good relationship. The possible effect of this is discussed further in chapter 8. A 'pen picture' giving brief details of each of the respondents in the study, can be seen in Appendix 15.

Table 9	Comparing the samples
The direct payment sample	**The home care sample**
The direct payment users range in age from 22-84 years	The homecare users range in age from 36-76 years
Direct payment users average age is 52 years	Homecare users average age is 52.8 years
There are 5 female and 3 male direct payment users	There are 5 female and 3 male homecare users
The personal assistants range between 25-68 years	The homecare workers age range is 32-57 years
Personal assistants average age is 47 years	Homecare workers average age is 45.7 years
There are 6 female and two male personal assistants	There are 8 female home care workers
All the sample describe their ethnic origin as 'white British' and have a physical disability	All the sample describe their ethnic origin as 'white British' and have a physical disability

In terms of how representative these samples are of people using Staffordshire social services, Table 2 in chapter 2 shows than most people accessing direct payments are younger disabled people (under 65 years), and this corresponds with my sample. For people using the homecare service the majority are over 65 years (personal communication with homecare manager), which differs from this research, but this was unavoidable, as the sample was chosen to correspond with the characteristics of the direct payment group. For personal assistants I was unable at the time of sampling, to gain any information about their characteristics, as they are the employees of direct payment users. Homecare workers in Staffordshire are almost

exclusively female and most are in the age range of 35-55 years (personal communication with homecare manager), which again corresponds with the sample in my study.

4.3.8 Interviewing Respondents and Transcribing the Tapes

The interviews with direct payment users and their personal assistants took place during October-December 2003. All of the direct payment users opted to be interviewed at home, and all but one of the personal assistants were interviewed during the same visit (in their employers' home), usually after the direct payment user. I interviewed everyone in a room on his or her own. One personal assistant (Liz) was interviewed in her own home a few days after her employer, as she was unavailable at the original visit. Direct payment users generally preferred their personal assistants to be interviewed at the same visit and this dictated the pattern of interviewing. I would have preferred to interview people on separate visits, as consecutive interviewing was demanding. Interviewing personal assistants on their own territory (their own home) might also have produced some different results and is discussed further in chapter 8.

The homecare sample was interviewed during February and March 2004. Homecare users all opted to see me at home and three had their spouses present during the interview. Two of the spouses made some responses during the interview. As noted earlier, I asked users to identify one of their homecare workers to be interviewed and I approached these workers to ask them to take part. They were offered an interview either in their own home or my home with five opting for their home and three choosing mine. This differed from the developmental study where I interviewed workers at a social

services area office. I felt this had made the interview too 'formal' and so I decided to provide a more homely, relaxed setting. It also more closely reflected the interviews of the direct payment sample.

The interviews each took between one hour and two and a half hours. The average was approximately two hours. An interview schedule was used and this ensured that although the interviews often followed a different structure depending on the respondent, all the main areas for discussion were covered during each interview. Respondents all signed the Agreement to Participate form and completed the GHQ12 schedule after the interview. All of the workers completed the GHQ12 themselves. Six disabled adults completed this themselves and ten by verbal response. Workers also completed the job satisfaction scale and a form detailing their conditions of employment (Appendix 16). After the interview, thank you letters were sent to respondents (Appendix 17) and letters of thanks to those people who volunteered, but did not form part of the sample (Appendix 18).

The interviews were all tape recorded and transcribed soon after the interview. Two of the direct payment users had unclear speech (Linda, Gemma). During these two interviews I wrote down what they said almost verbatim, as well as tape recording the interview to ensure the tapes were transcribed accurately. My supervisors advised me to transcribe some of the tapes myself as part of the learning process. Due to time constraints I transcribed ten interviews (five from each sample) and paid for the rest to be professionally transcribed by the secretary for Applied Social Studies at Keele University, who is a trained professional in transcription. Following this I replayed the tapes to check the transcripts for accuracy and to start the

analysis process by immersing myself in the data to become aware of emerging themes. I made notes of these themes to help in the analysis process.

This process is seen to be acceptable in the literature for whilst a number of authors stress that it is worth transcribing at least some of the tapes yourself (Kvale 1996; Gilbert 1998; Bryman 2001), a literature search of BIDS for the words 'transcription', 'transcribing', 'transcription + methodology' unearthed no evidence that transcribing all the tapes yourself is more effective. Indeed McLellan et al (2003:72) considers that the optimum strategy is where 'each audio tape interview is transcribed by a single professional transcriber and proofread by the interviewer'. This was the method I adopted. I also found that my ability to absorb information from the tape was enhanced when freed from the arduous task of switching the tape on and off to achieve an accurate transcription. I feel this aided my ability to become immersed in the data and start the process of analysis.

4.3.9 The Analysis of the Data

The initial analysis of the data started during the interview stage of the study when talking with respondents. I listened to what they said to make myself aware of any common issues and themes that were emerging. This process continued when listening to the tapes during transcription and checking the transcriptions for errors. By doing this I began to immerse myself in the data and to note further issues. Through rereading all the transcriptions again I began to code the data. Coding of research data is one of the central processes in grounded theory and both open and selective coding are present in its original formulation (Bryman 2001). Open coding is defined as:

'The process of breaking down, examining, comparing, conceptualizing and categorizing data' (Strauss and Corbin 1990: 125).

There are three phases of the analysis in grounded theory categorising the data (open coding), connecting categories (axial coding), and focusing on a core category (selective coding) (Dey 1999). Strauss (1987) advocates a line-by-line consideration of the data to identify the codes and categories on which the analysis begins to build. Other researchers argue that themes or categories can be identified from a more holistic approach based on a general comprehension of the data as a whole rather than a line-by-line analysis (Jones1985). Dey (1999) considers that most data analysis falls in the middle of these two positions where broad preliminary distinctions are drawn from within the data and then analysis moves towards more refined distinctions.

Seidel and Kelle (1995) argue that coding the data helps the researcher to make sense of the material and build meaningful patterns of facts by looking for structure in the data to find differences and similarities. Grounded theory thus offers researchers a tool for organising the enormous amount of data that can be generated by qualitative research, as it provides a data management strategy (Lee et al 1996). Gilgun (2001) suggests that grounded theory is particularly suited to research undertaken by social work practitioners, because of their focus on the complex social and personal forces that affect people's lives, they are already using many of the skills associated with grounded theory. As a social worker I found this most reassuring.

I decided to code the data line-by-line to ensure that important issues and categories were not missed. I coded by scrutinising the transcripts comparing similarities and differences in the data. Coding involves marking the text in order to label particular segments. This can be done using a specialist computer programme, or as I did, by marking them physically with coloured pens and writing code words onto the transcripts. I was undecided for some time whether or not to use a computer programme to code the data, as there is some controversy in the literature about this. A number of qualitative researchers have argued that the use of computers in the analysis of data can alienate the researcher from their data and cause them to use analysis strategies contrary to the methodological and theoretical direction of qualitative research (Bryman 2001; Seidel and Kelle 1995; Coffey 1996). However, purely practical concerns finally forced my decision. Computers may be faster, but using marker pens meant I could work on the transcripts wherever I was, rather than only when I had access to the computer. For a part time PhD student with work and childcare responsibilities this was invaluable, as I could undertake the coding in a variety of places (back seat of the car whilst traveling, lunch breaks at work, play areas whilst my little boy played).

I found that undertaking the coding process in this way meant it occupied an almost continuous part of my life for a long time, rather than it being compartmentalised into small sections when I was able to use the computer. I feel sure this reinforced my thorough grounding in the data. Coding was quite difficult initially, as I was afraid of making mistakes and failing to 'do justice' to the data, also the sheer amount of data was daunting. In section 4.1.3 I

discussed my intention to use previous research knowledge to guide this study, and my reading of the literature yielded some broad themes (boundaries, stress and satisfaction, power and independence/autonomy), which I used as headings. I organised categories and concepts resulting from the data coding under these headings (see below). By the end of the coding process the data became repetitive in that no new material emerged which revealed that theoretical saturation had been reached.

Boundaries

Description of relationship
Unpaid work
Family and friends
Feelings of obligation
Limits
Rules and regulations
Always on call
Presents/money
Type of work

Stress and Satisfaction

Rushing about
Like about job
Dislike about job
Support or lack of it- colleagues and managers
Sharing worries
Keeping worries to yourself
Perks of the Job
Leaving/staying
Terms and conditions at work

Power

Decisions
Taking control
Powerlessness
Master and servant roles
Invisibility
Broomstick in the cupboard
Infantilising language

Independence and Autonomy

Doing everything yourself
Decision-making
Language used
Reciprocating

I later entered all the transcriptions onto an advanced computer program designed to undertake qualitative data analysis, SR NVivo (N6). Using this computer program I developed the analysis further by searching all the transcriptions for words related to emerging categories. For example, one category revolved around the issue of the boundaries in the relationships, consequently the transcriptions were searched for the words used by many of the respondents when they spoke about their relationships: boundary, boundaries, line, limit/s, rules and so on. Ryan and Bernard (2000) consider that word searches or counts are helpful for discovering patterns of ideas within bodies of text and I found it useful in providing a check to the manual process of marking the transcripts with coloured pens. It was extremely quick and easy to do. To make the findings from the searches manageable and

more helpful tables were constructed onto which the findings were entered (see Appendices 19, 20, 21). This provided a concise and easily accessible record of the computer analysis.

4.4 Conclusion

The aim of the study is to consider how the opportunity to employ workers using cash payments affects the support relationship. To do this the research required an in-depth understanding of both the direct employment relationship and the traditional service delivery relationship of homecare for comparison. In this chapter I have explained the philosophy that guided my research and located the study broadly within the symbolic interactionist tradition. I have evaluated research methods and argued that the research question was best explored using a grounded theory approach, which informed by theory, literature and the data, would build up a comprehensive picture of people's experience of the support relationships.

I discussed the multi-method approach used in the research: a qualitative in-depth interview based on a topic guide, plus two widely accepted questionnaires to develop greater understanding of the relationship. The data from the questionnaires aided the interpretation of the interview generated data rather than being used in a statistical sense. The emancipatory paradigm of social research was explored and I highlighted the difficulties of adopting this approach, especially within the confines of a PhD study. The research instead used a participatory approach through the involvement of trained disabled researchers who acted as a panel of experts for the study and to provide a disability perspective.

Ethical considerations have been considered as well as a detailed discussion of methods and strategies used to ensure that ethical procedures were undertaken in the research. Finally I went on to describe in detail how the research study was conducted and the process of analysis. The categories or themes that emerged during the analysis are examined in the following three chapters which discuss these findings: Chapter 5 looks at the blurring of the boundaries, chapter 6 autonomy, independence and power and chapter 7 job satisfaction and stress.

Chapter 5 The Blurring of the Boundaries

The following three chapters report and analyse the data from the study. In this chapter I detail findings from interviews where direct payment users, personal assistants, homecare workers and homecare users discussed their experiences of the support relationship. In the first two sections I explore the term boundaries and discuss respondents' description of their relationships, looking at possible explanations for the way these have developed. The chapter continues by exploring types of boundaries, charting areas of differences and similarities between the direct payment and homecare relationships, then moving on to consider the effect that blurred boundaries can have on the relationship.

5.1 The Boundaries of the Relationship

The literature suggests that blurred boundaries are common in many care relationships with unpaid family and friends often undertaking tasks and responsibilities that are wide-ranging or undefined. Support provided formally, by non-direct employees such as homecare workers, is more likely to be clearly defined with a narrow remit of requirements and tasks (see Table 4, page 84). As noted in chapter 3, some studies suggest that the division between formal and informal (paid and unpaid) care is breaking down as a result of the increased commodification of care, and that the relationship between direct payment users and their personal assistants has come to resemble the support provided by informal carers. Researchers have highlighted the negative implications of this for both personal assistants and

their employers (Ungerson 1997a,b, c 1999; Glendinning et al 2000a; Morris 1993; Vasey 2000; Pearson 2000; Marquis and Jackson 2000).

The boundaries in the support relationship are clearly an important area for consideration when looking at the impact of the direct employment of workers by the use of cash payments; they may be a place of conflict or a site of change and uncertainty.

5.2 The Language of Boundaries

During the interview I asked all the respondents to describe their relationship with the person who supported them or they were supporting. Most of the respondents defined it in terms of either being friendly, professional or using familial terms, although some described their relationship in other ways such as 'good' or 'close' (Brenda, Jackie, Rachel, Beth, Jane, Win, Liz). In order to make this clearer and to enable comparison between the groups, people who described it in this way were asked to clarify whether the relationship was friendly, like family or professional, and the results are contained in Tables 10 and 11.

Table 10	Non-direct employment sample: details of relationship			
Homecare User	**Homecare Worker Providing Support**	**Length of Time Known Each Other**	**Number of Other Workers Involved**	**Weekly hours of Paid support by worker**
Brenda (friendly)	Jane (professional and friendly)	8 months	About 20	2 ½
Daniel (close friend)	Anne (professional relationship	8-9 years	Up to 14	3 ¾
Sandra (like family)	Lucy (friendly)	Many years	15-16	3 ¾
Jeanne (friendly)	June (professional relationship)	About 6 years	About 10	4
Rachel (friendly)	Jill (professional relationship)	2 ½ months	5-6	4
Mathew (friendly)	Jess (professional relationship)	1 ½-2 years	About 15	8 ¼
Trevor (professional and friendly)	Beth (professional and friendly)	3 years	5-6	5
Jackie (friendly)	Tess (professional and friendly)	10 years	About 6	5

These tables also show other information gained from the interviews such as the length of time respondents have known each other, the hours of support provided and the numbers of other workers involved. This information is incorporated into the discussion later in this chapter. The tables show that homecare workers described their relationship with homecare users formally with four (Jess, June, Jill, Anne) saying it was a purely professional working relationship:

Jess: Just purely professional, you know, I go in there, I do my job, I leave and that is it (HCW).

Anne: It is a working relationship really. I suppose it is like the relationship if you were in an office and it was somebody you were working with but you had got to help them, that sort of relationship (HCW)

A further three homecare workers (Jane, Beth, Tess) said that the relationship was 'professional and friendly' with only one (Lucy) describing it as purely friendly. The term professional is generally used to refer to a specialist skill or a job subject to codes of conduct laid down by central bodies or associations, such as doctors, nurses, electricians and plumbers (Giddens 1989). Homecare until recently has not been subject to external regulation (see chapter 2), although many local authorities have applied their own codes of conduct to staff, as did Staffordshire social services. For instance, the 'Good Practice, Policy and Procedures Manual' (Staffordshire County Council 2001a) sets out guidelines for workers' relationships with users, such as maintaining confidentiality and not sharing personal information. These Guidelines talk about 'personal and professional boundaries' and maintaining a professional image'. Forbat (2005:22) argues that the way care is discussed in documents (such as the Guidelines) influences the way people talk about their relationship, particularly where it is 'seen to indicate how things are, that is, reflecting a realist understanding of care, since it implies moral imperatives guiding what care should be'. In describing the relationship with users in professional terms, homecare workers are reflecting these Guidelines. They may also have been saying what they thought they should say, especially to

an insider researcher. Later in this chapter to gain a more in-depth picture, I examine how workers described their actions and how they behave in the relationship.

Another element of professional care is argued to be care that is undertaken by workers who have had formal training (Davies 1998). In chapter 7 I look at formal qualifications held by workers in the study, which reveals that personal assistants had fewer qualifications than homecare workers (see Table 18). Personal assistants may have been less likely to describe the relationship in professional terms, because they lacked formal qualifications, and this may result in their having less autonomy in the relationship. Notions of power and autonomy in the support relationship are developed further in the next chapter.

Homecare users described their relationship with workers in rather closer terms than did the workers, with one (Sandra) saying that the relationships was like family:

Sandra: I've got a carer (HCW) who I think a great deal of because to me if you've got a good care worker and I feel I have, especially as I say with Lucy (HCW), she is part of my family. (HC User)

Another homecare user (Daniel) said that he and his worker were close friends, with a further five homecare users (Mathew, Jeanne, Rachel, Brenda, Jackie) describing the relationship as friendly:

Mathew: ...they are friends, that they are an essential part of our life, without them we wouldn't cope (HC User)

It is interesting that both parties within the homecare relationship appeared to perceive it differently, as all but one of the homecare users described the relationship in friendlier terms than did the homecare workers supporting them. Four homecare workers (Anne, June, Jill and Jess) said that the relationship was a working relationship, whilst the people they supported (Daniel, Jeanne, Rachel and Mathew) said it was friendly. Only one homecare user (Trevor) talked about the relationship in the same way, as the worker providing his support (friendly and professional). A study in Sweden also reported differences in the way homecare users and workers described their relationship, although in the Swedish study it was workers who were more likely to report the relationship as close, whilst users described it as friendly (Olsson and Ingvad 2001). The authors argue that this reflects workers' desire to feel needed and that their work was valued. This study does not mention whether there were any instruction to workers to maintain professional boundaries with users, and so they may have felt able to form (or describe) closer bonds.

We can see in Table 11 below, that in contrast to the formal definitions of the relationship by homecare workers, almost all personal assistants explained their relationship with direct payment users in much closer terms, with four of the personal assistants (Ian, Liz, Tom, Joy) describing it as being 'like family and one (Mim) as 'almost like family':

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Liz: Probably more like family, cause family you get irritated with each other sometimes don't you? Yes more like family (PA)

Ian: Well I think, from my point of view I would say after a while you feel like a family...........how else could you live in the same building? (PA)

Table 11		Direct employment sample- details of relationship		
Direct Payment User	**Personal Assistant Providing Support**	**Length of Time Known Each Other**	**Number of other workers Involved**	**Weekly hours of Paid support by PA**
Peter (like family)	Ian (like family)	Many years	1	144 Live in
Freda (like family)	Liz (like family)	18 years	2	15
Harry (like family)	Tom (like family)	2 ½ years	0	16
Karen (like family)	Joy (like family)	Many years	0	22
Wanda (friendly)	Win (friendly)	14 months	2	15
Gemma professional and friendly)	Mim (almost like family)	5 years	3	26 + 2 sleep-ins
Linda (professional and friendly)	Sue (professional and friendly)	Many years	3	6
James (professional and friendly)	Dot (friendly)	All James' life	0	13

Two personal assistants (Dot, Win) described their relationship with their employer as a friendly relationship, and friendship can be defined as a meaningful, mutual, personal connection (Williams 2001). Only one personal assistant (Sue) talked about it in formal terms saying that her relationship was friendly and professional. Sue previously worked as a homecare worker for an agency and was working part-time in the evenings for social services. Sue's experience of formal employment for social services would almost certainly

have influenced her views about the way the relationship should be conducted. Personal assistants on the other hand were not subject to the local authority Guidelines and were unlikely to have even seen them. Four direct payment users (Peter, Harry, Freda and Karen)' explained that their relationship with their personal assistant was 'like family' and this corresponded exactly with the way it was described by their personal assistants:

Peter: Oh yes very much, we're very much like family and both our families interact with us and with each other, as if we were a married couple if you like but without the sex (DP User)

One direct payment user (Wanda) said that her relationship was friendly rather than like family and again this matched the way her personal assistant talked about the relationship. Two direct payment users described the relationship in terms of being professional and friendly (Gemma and Linda). For Linda this was the same way her personal assistant talked about the relationship, but for Gemma it differed as Gemma's personal assistant (Mim) described their relationship as 'almost like family'. Linda also talked about her reasons for choosing to employ a number of personal assistants, so that they would be able to cover for each other, but also so that the relationship would be more distant and formal:

Linda: It was my choice to have a lot of care workers rather than one, I mean I could have got away with only two, one for the morning and one for the evening, but then if something happened you fall into a trap and you're a bit stuck. This way having four care workers if one is ill then another can cover

for her and it keeps that bit of distance between you and them. Because you have to keep that boundary, have to keep, you know keep it, if you let it get out of hand then you would have extreme difficulty if something did go wrong, you would have extreme difficulty in correcting that and before you knew where you were you could have a major problem on your hands.

Another discrepancy in the way the relationship was experienced occurred with James who, despite being related to his personal assistant (nephew), described the relationship in terms of 'just a job' or friendly and professional whereas his personal assistant saw it as friendly:

The findings show that the way in which the respondents described the relationship differed depending on whether they were in the 'direct payment sample' or the 'homecare sample'. Most homecare workers said that they had either a professional and friendly or a purely working relationship with homecare users, although the majority of the homecare users said that the relationship was friendly. Conversely most direct payment users and personal assistants explained their relationship in family terms with the remainder saying it was a friendly relationship. The local authority Guidelines for Good Practice are likely to have influenced homecare workers description of methods of working although there are other possible explanations why these differences should occur.

For example, Tables 10 and 11 show that whilst it is difficult to calculate the exact amount of time respondents had known each other, as some gave an estimate such as 'many years', direct payment users and personal assistants generally appear to have known each other longer than homecare workers

and users. Six direct payment users said they had known their personal assistants for five years or more, whilst only four homecare users have done so. Indeed four personal assistants knew their employer and were friends before their employment started (Ian, Liz, Tom, Joy) and one (Dot) is the aunt of her employer. The other two personal assistants were recruited via advertisement. Direct payment users are able to choose whom they employ (DoH 2003) and many decide to recruit friends and family (Lakey 1994). In these circumstances the relationship is likely to be close even before the employment starts. The power of employers to choose their workers and to thus shape the type of relationship that develops is discussed further in section 6. 2.

The literature on friendship identified that people tend to become friends from choice rather than by chance, and that friendship is often based on homogeneity of age, gender, race and social class (Hess 1972; Adams and Blieszner 1994; Harrison 1998). The pre-existing relationship and the ability to choose a compatible person in the direct employment situation would almost certainly make the development of a close relationship more likely than with the homecare relationship, where users have little choice about who provides their support (Adams 1985-86). Furthermore, in the direct payment sample seven of the relationships consisted of people of the same gender, and so could be expected to be closer than the homecare sample which had only five, although the sample size is small.

Social class can also be important in the support relationship. For example, Twigg (2000) found that homecare users who shared a similar background with their workers in terms of social class were more likely to consider them to be part of the family. The meaning and definition of social class is complex (Weber 1948; Marx 1970; Wright 1978; Parkin 1979), but broadly social class can be said to be: 'A large-scale group of people who share common economic resources which strongly influence the type of life style they are able to lead' (Giddens 1989:209). The social class of all disabled adults in the study is detailed below in Table 12. However deriving measures of social class for disabled adults is problematic, as it is typically based on an individual's or their partner's last occupation (Standard Occupation Classification 2000). Many disabled adults have never undertaken paid employment, or may have not worked for a considerable time. This is further compounded by differences in the stage of life that people become disabled. For instance, some disabled adults may have been denied access to job opportunities, or had to give up work when they became disabled, whilst others may have had long periods of employment. Thus social class can only be a crude indicator.

Table 12	Occupation and social class of respondents	
Direct Payment User	**Occupation (present or previous)**	**Social class (based on Standard Occupation Classification 2000)**
Peter	Management consultant/ Barrister	1
Freda	Counsellor	2
Harry	Student	unclassified
Karen	Catering company owner	2
Wanda	Publican	2
Gemma	Clerical assistant	3
Linda	Panel member for tribunal	2
James	Scaffolding company owner	2
Homecare User		
Brenda	Police officer	3
Daniel	Quality control –steel industry	5
Sandra	Book keeper	3
Jeanne	Waitress	7
Rachel	Pottery worker	6
Mathew	Teacher	2
Trevor	Sheet metal worker	6
Jackie	Factory worker- biscuit factory	7

Using the Standard Occupational Classification (2000) all personal assistants and homecare workers were classified as social class 6. Table 12 shows that generally direct payment users in the study were of higher social class than homecare users and all of the personal assistants and homecare workers. Yet Tables 10 and 11 indicate that the direct payment sample reported a closer

relationship than the homecare sample despite the greater disparity in terms of social class, which contrasts with the findings in Twigg's study. This may reflect the point made earlier that social class can be an inaccurate indicator of a disabled adult's circumstances (Leece and Leece 2005), also it is likely that other aspects of the relationship were more important in determining the strength of feeling than people's social class.

For example, in Tables 10 and 11 we see that personal assistants were providing a great deal more support to their employer than homecare workers. The support by homecare workers ranged from 2 ½ - 8 ¼ hours per week, whereas personal assistants were supporting their employers from 6-144 hours per week. This does not imply that homecare workers were supporting people who required less care than personal assistants, but rather the amount of care required was shared between more people. Homecare users in the study on average saw twelve workers over a six month period whereas direct payment users were supported on average by just one and a half personal assistants in this time period. Homecare users in Staffordshire generally have 2-4 regular workers during the daytime Monday-Friday, although when support is provided in the evening or at weekends many different workers will be involved. Also if regular homecare workers are ill or taking annual leave different workers would be provided and this accounts for the larger number of workers involved (personal communication with Homecare Manager). Correspondingly, a study in the US of twenty personal assistants found that workers and employers who spend a lot of time together and have a lot of time to talk to each other, were more likely to develop closer relationships (Eustis and Fischer 1991).

Sue, a personal assistant in my study, who worked part time for social services, also identified the importance of the time element in the development of close relationships:

Sue: I would say it [the relationship] is very close but professional, when I'm in her [DP Users'] home as we are now I respect her home and I'm here for her purpose, whatever she wants we do as compared with a carer agency type relationship who haven't got the time to spend with people and although you do build up a relationship with your service users, it is much closer with Linda (DP User). (PA)

JL: Why do you think it is much closer?

Sue: Because of the time, the time factor. You know, when I worked for the agency we had a particular time, we had an hour or half an hour call and Linda was just one of many service users on our list to do that day. As a direct payment system, Linda is my only client so to speak… obviously your relationship develops rather than just a name on a list and with the agencies, you go to so many people anyway, you know you're doing 15 calls a day

The similarity of tasks to those completed by informal carers has been argued to lead to roles becoming blurred in the support relationship (Twigg 2000, 2004) and may also encourage close family-like relationships to develop. The literature shows that personal assistants often undertake a much wider range of tasks than homecare workers with many providing support similar to that performed by family members (see chapter 3). During the interview I asked all the respondents to talk about the type of tasks undertaken. In all cases the work completed by personal assistants in the study was greater in range than

the support provided by homecare workers. For instance, personal assistants were acting as companions, undertaking domestic work, chauffeuring, undertaking personal care, pet care, childcare, decorating, gardening, laundry, shopping, socialising, providing emotional support and so forth. This may have contributed to their closer family-like relationships. Whereas the tasks reported by homecare workers were more limited and mainly related to personal care such as bathing, help to the toilet, help to eat and help to bed.

The more restricted range of tasks performed by homecare workers in the study, reflects the defined task-based approach adopted by local authorities following the community care reforms of the 1990's. As discussed in chapter 2, local authorities moved away from low-level support such as domestic work, to the provision of personal care for highly dependent people. Direct payment users whilst assessed in the same way as homecare users, can use their payment in almost anyway they wish, as long as it meets their assessed needs (DoH 2003), and this flexibility means that they were able to obtain a greater range of support. It also means that direct employers had more power and autonomy to decide the boundaries of the relationship than homecare users.

Another form of direct employment relevant to the discussion is the employment of nannies. The literature in chapter 3 suggests that close family-like bonds form in the employment relationship between nannies and their employers, because of the sense of obligation that mothers feel towards their nannies who enable them to achieve working motherhood (Gregson and Lowe 1994). An analysis of the transcripts of the interviews showed that

personal assistants appeared to feel a similar sense of obligation or responsibility towards their employer with almost all saying they would find it difficult to leave their employment:

Win: I have a very high regard and respect for her (DP User) and I'm not sure that I could leave her in the lurch (PA).

JL: When you say that you worry about him (DP User), would that stop you leaving the job if you wanted to leave?

Tom: I think it would......I don't think somebody else could do as good a job as I do because I actually care for him, not just doing it for the money, I like to look after him, make sure he is okay (PA).

Some direct payment users too felt this sense of obligation. Peter, who had live-in support, clearly felt a sense of responsibility about what would happen to his personal assistant in the event of his death. This shows how complex the boundaries of the direct employment relationship can be in live-in situations:

JL: Is that do you think, because you worry about him (PA)?

Peter: Yeah I think it probably is. I think I'd like to, especially in this last few weeks, when I've got a life threatening illness. What I've been trying to do is put together, I know this sounds morbid but to tidy my affairs so that if the worse did happen, I'm not leaving a burden for somebody else to solve and Ian (PA) is top of that list.....so that is a concern of mine of him that he is going to be left not just without a job but without me, difficult. (DP User).

In contrast the homecare workers did not express a sense of responsibility or obligation towards homecare users with regard to leaving their job:

Tess: No. I'm just one of a team aren't I, there is always, if I was taken ill or left then someone else would be going in (HCW).

The data shows distinct differences between direct employment and non-direct employment in terms of the way relationships were described and experienced. In the non-direct employment sample most workers portrayed it as a professional working relationship, probably reflecting social services Guidelines for Practice, whilst homecare users tended to see it as friendly. In contrast both personal assistants and their employers generally described the relationship in closer terms, often 'like-family'. This suggests that the direct employment sample had less clear limits, as friendly, family-like relationships are more likely to have unclear boundaries, than those that are more distant and professional (Piercy 2000).

Furthermore, there was greater compatibility in how they experienced the relationship between members of the direct employment sample, most likely caused by the ability of direct payment users to employ people with whom they were already friendly. Personal assistants provided a wider ranging support in a similar way to many families, with employers having more power to define the boundaries of this support. Direct employment relationships had greater continuity, and were generally of longer duration probably leading to people developing a sense of obligation towards each other.

5.3 The Types of Boundaries

Analysis of interview data shows both homecare users and workers talked more about the limits of what was allowed in the relationship, than either direct employers or personal assistants. To check this I completed a word search using a specialist computer program SR NVivo (N6), for words associated with boundaries, such as lines, limits, allow/ed and distance; the results of this are detailed in Appendix 19. These results confirmed my initial impression, as the homecare sample (workers and users) used these words fifty-five times, whilst direct employers and personal assistants did so only twelve times in total. These data also demonstrated that whilst some of the homecare workers used the words associated with boundaries more than others (Jane, Jill, Beth), all of the homecare workers used them at some point, whereas only three personal assistants used these words at all. Returning to the transcripts of the interviews to look at this in greater depth showed that all homecare workers talked about the limits or boundaries that they must not cross:

Jill: When I started the job I was told not to do that [share personal information], you can't go there it is one of the things you can't do.....so I told her (HC User), I said look I can't do that cause it isn't allowed, I said if I do I'll be in trouble, I don't want that to happen... (HCW)

Homecare workers talked in terms of what was 'allowed' in the relationship and this related to the Guidelines previously mentioned, which gave instructions to workers about maintaining professional boundaries in their relationships with users. Homecare managers also reinforced these

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guidelines during supervison, induction and team meetings (personal communication with Homecare Managers). Whilst homecare users were unlikely to have seen the Guidelines, many users would be aware that workers are constrained in their practice. It is likely that workers talked to users about what they could or could not do, as the previous quotation suggests. Homecare users would also be affected by a worker's behaviour, such as maintaining a professional distance. In the interview five of the homecare users talked about the boundaries and limits of their relationship with home care workers for as Daniel explained:

No, that's become less and less these days because they are not allowed to clean or nothing no more. They tend to just do what jobs they are specifically allowed to do now. I mean they always wipe the side down and things like that, they always leave the house clean but no, you couldn't really ask them to do anything now (HC User)

In contrast to this as shown in Appendix 19 there were very few instance of direct payment users and their personal assistants mentioning limits to their relationship (only twelve times in total). Only two direct employers were (Linda, Gemma) were concerned about this:

Linda: Yes I mean some care workers, if you let them they will take over, they will decide things for you that you are quite able to decide for yourself, that is where you have to put the break on and say I'm employing them, no that's not what they are here for, you know what I mean? It can be tricky but it can be done, like if you do it in the early stages, not let them do it too often and then

put the brakes on, if you do it in the early stages it is so much easier to crop that proper, do you know what I mean? (DP User)

Gemma: There is a very fine line between being their friend, well not so much being their friend but being on friendly terms. Sometimes I am friendly towards them, it is very easily taken that they can overstep the mark and forget that I am their boss (DP User).

The crossing of boundaries referred to here relates to issues around control in the support relationship. In chapter 2 I referred to the disability literature where studies revealed many examples of support that is disempowering (Henwood et al 1998; Clark et al 1998; Twigg 2000), with some homecare workers behaving in a patronising and custodial fashion (Morris 1993). Both Gemma and Linda, as previous users of the homecare service, may have experienced this in the past, and decided to maintain a distance from their personal assistants. I look more closely at issues of control and power in the following chapter.

Only three personal assistants used words associated with boundaries during the interview. Sue talked about the limits of the relationship more than the other personal assistants, probably because she also works for social services, and was influenced by the local authority Guidelines. Another personal assistant (Ian) mentioned difficulties in maintaining boundaries within a live-in relationship, because of closeness to his employer. He talked about the involvement he and his employer had with each other's family and friends. Social contact with family and friends in this way is an indication that the

relationship has similarities with informal care (see Table 4) and that the boundaries of the relationship are unclear:

Ian: If my sister rings up and says can I come and visit with the kids, he [DP User] loves it, he says this house needs children in it, he loves it, so we do it all together and I wouldn't want to do it any other way (PA).

Some of the other personal assistants (Joy, Liz, Tom) said they had involvement to varying degrees with each other's family and friends, and three personal assistants (Joy, Ian, Liz) had been on holiday with their employer. All of the personal assistants and direct employers exchanged Christmas and birthday presents. Some bought and sold things to each other, used each other's shopping catalogues, and one direct employer regular bought things for his personal assistant. The ability of disabled adults to 'give something back' in this way and the importance of reciprocity in maintaining equality within relationships has been identified in the literature (Allan 1979; Adams and Allan 1998; Eustis and Fischer 1991), and I develop this further in chapter 6. This also reinforces Zelizer's (2005) point that money and intimate relationships are entwined:

Harry: I'll lend him (PA) money of he is short, I put him petrol in, buy him lunch whatever, it doesn't come into It (DP user).

Win: I have brought a lovely clock off Wanda [DP User] and the most charming condiment set I would suppose you would call it, a real eye catcher.... She was getting rid of some bits and pieces to the auction and I think, I can't remember how it happened but I bought a clock and paid her for

it within a couple of days when I'd been to the bank and the condiment set I think the following day when I'd been to the bank (PA)

Only two direct payment users (Linda, Gemma) tried to maintain a more professional distance:

Gemma: I think they [pause] I don't know really, I think they [PA's] think it is okay for them to be involved in all aspects of my life but then they want to keep their lives separately, which is fine by me. I don't really want to get involved with their family and friends because it can cause complications.

It became clear in the interviews that unlike the direct employment sample, homecare workers and users had very little contact with each other's family and friends, other than when family or friends were present during the homecare worker's support visit. Only two homecare users (Sandra, Jeanne) said there had been any other involvement and this was minimal (a homecare worker once bringing her small child to see the homecare user). None of the homecare workers had been on holiday with homecare users, nor did any users or workers buy or sell goods to each other. Workers and users generally exchanged Christmas cards with most homecare users saying they gave their homecare work a gift at Christmas. This suggests that the direct employment relationship had fewer formal boundaries than the non-direct employment relationship, and as such was more reminiscent of support provided by family and friends.

A further indication of differences in the homecare and direct employment relationships appeared when I asked all the workers, during the interview, if they shared their worries and concerns with the person they support. Most of

the personal assistants (Mim, Tom, Joy, Dot, Sue) said that they would share personal worries and concerns with their employer, again displaying a sign of an informal relationship; whilst none of the homecare workers said they would do this. The Guidance issued by social services states that homecare workers should not divulge personal information. The sharing of concerns by workers is developed further in chapter 7 in relation to job satisfaction and stress.

There appeared to be particular difficulties in setting boundaries in the direct employment relationship where a relative was employed. One of the direct payment users (James) employed his aunt (Dot) as his personal assistant, and he talked about the difficulty of expressing dissatisfaction to a relative when things go wrong, as other family members can become involved:

James: Family yeah, that has been a problem and I think she [the PA] pushes the boundaries all the time like. When she first came she was really keen and she was doing things and I must admit yes, she was doing a really good job .....and then it got that she did less and the way she cleaned isn't as good as when she first started, and it has slowly gone down. I find it hard to try and say something like... I've said things, like. My dad said 'how is Dot [PA] going on, is everything all right?' I've said well yeah it was all right to start with and it started going off. 'Oh well you know, she's got a lot on'. I said well yeah I know she's got a lot on dad, (DP user)

James also talked about the boundaries of their relationship in terms of his personal assistant not behaving in the way he expected an employee to behave. James was clearly using his experience in a more formal occupation (the building trade) on which to base his expectation of the boundaries of the

employment relationship with his personal assistant, whilst she appeared to be operating more informally. This demonstrates the difficulty for relatives in separating their roles with the possible conflict in the boundaries in the relationship that this will entail:

James: ....and they all know [her family] when she comes to work here, the time she starts, the time she finishes but she'd be on the, the phone would start ringing and she would answer and it would be her son that is in the wheelchair. So she is here for an hour, so she is on the phone sometimes only five, ten minutes, sometimes it can be 20, half an hour and of course as the time clocks by and I noticed several times it was happening, when her hour was up she still goes at the same time even though she's been sat on the phone for a half an hour talking. To me when I was at work, if I wanted time off I asked for time off, I wouldn't dream of saying oh well my wife's phoned up she wants me to take her shopping. It is not done and it is not acceptable and she is doing things like that and the door bell will go and it will be one of her other sons at the door, oh I want you to do this mum, I want you to do that and they will ask her to baby sit and he has come here with the kids and dropped the kids off here and I'm thinking hang on a minute and she is letting them just run round and I've said look Dot [P]) I don't want them coming here. (DP User)

Dot also identified difficulties in setting boundaries of the relationship because her employer was her nephew. She said there were times when she worked longer hours than she received payment for, because as his aunt she felt unable to refuse:

Dot: Well like you've got days when I help him [James] with his shopping like yesterday, it went over an hour extra. Then there was one day last week I took him down into town to get some money from his bank, he forgot his book so we had to come all the way back and I took him back down...so that was another couple of hours extra, which I didn't get paid for. I think with it being family it is more difficult to say no, do you know what I mean? (PA)

Dot expressed concern about being paid for the work that she did for her nephew:

I think going back to being family, I think it is worse that way.....that he is having to pay me sort of thing, do you know what I mean? It is a family thing I think.

In section 3.2 I argued that one of the crucial differences between direct and non-direct employment is that direct employment brings the issue of money out into the open, because disabled adults pay workers wages directly. Homecare users on the other hand pay workers wages in a roundabout way, either through their financial contribution to the local authority for their support, or from income tax payments to the Inland Revenue in the past, with the responsibility for paying workers wages remaining with the local authority. At the time the study took place, fifty-nine per cent of homecare users in Staffordshire were paying the authority for their support, with the average amount being £27 and the maximum charge £105 per week (personal communication with Fairer Charging Team Manager). Yet this is a hidden part of the homecare relationship, and none of the homecare users in my study talked about paying their workers' wages.

5.4 Pushing at the Boundaries

I asked all respondents to tell me about any unpaid, extra work performed by workers and in response all of the personal assistants, except one (Sue), said they were undertaking unpaid work for their employer. This ranged from doing baking in their own home or decorating free of charge, to spending many hours doing unpaid work. The three personal assistants (Joy, Ian, Tom) doing the most unpaid work were amongst those who described their relationship as that of family:

Tom: I mean effectively you could say I work 8-10 hours a day for him (DP User)........ I spend most of my time with him anyway, he would come round to mine for meals or for dinner, stay here overnight if we went out drinking, things like that (PA).

JL: So you are working 8-10 hours a day, but only paid for 16 hours a week?

Tom: Yes

Joy: I don't look at the hours I am paid for I just do what needs to be done. Sometimes, like yesterday I was here all day, I suppose I never sat down and thought about it, I'm here most the time really (PA)

The live-in personal assistant (Ian) experienced particular difficulties in separating work and non-work time, which corresponds to Glendinning et al's (2000a) study where live-in personal assistants had problems establishing rights to free time. Ian's employer referred his personal assistant's unpaid work as 'friendship time':

Peter: But because this is his [the PA's] home he would spend time in the garden and doing things in the house, which would be outside the direct payments extent. So it is very difficult to differentiate between what are the paid hours and what are the friendship hours or own interest hours if you like, very complicated (DP User)

Some of the homecare workers too were doing unpaid jobs, although these were on a much smaller scale than those undertaken by personal assistants, such as posting letters or fetching small amounts of shopping when doing their own shopping:

Jill: I post a letter, yes, I'd post a letter. Mind you saying that, I did pick some gloves up for her once when I was shopping. I didn't go out of my way to do it, I was going shopping so I got them while I was doing it, yeah I did do that once and I posted a letter (HCW).

Only one homecare worker (Lucy) was doing more substantial work (ironing at home), for which she was not paid. This relationship was described in closer terms than any other of the homecare relationships with the worker saying it was friendly and the user describing it as 'like family'. It may be that the homecare user talked about the relationship in these terms, because the worker was performing unpaid work in the same way that many family members do, or it could reflect a sense of obligation felt by the worker because of their long, close relationship:

JL: Do you do anything for her (HC User) that's unpaid at all?

Lucy: No, we are not allowed to (HCW)

JL: You wouldn't do anything like posting letters, getting a bit of shopping?

Lucy: Well if I'm honest I do but it wouldn't be right if it was known that I do cause we are not to do it.

JL: This study is confidential.

Lucy: Like this week for instance, they've [social services] been in and stopped her (HC User) housework and her ironing.

JL: I see.

Lucy: So they've stopped it this week and on Friday she goes into, well she goes to respite, I can't remember now where she said, so therefore it has stopped and she's left with no clothes ironed. So I've had to bring them all home to iron them because what can you do.

JL: And you don't get paid for that?

Lucy: No.

Performing unpaid extra work appeared to be linked to the closeness of the relationship, indeed two direct payment users referred to this by saying that their personal assistant did more for them, because of their friendly relationship:

Karen: Well yes of course if she wasn't my friend she would just go when the time was up instead she is here all the time to help me (DP User)

And this was echoed by one of the personal assistants:

Tom: Well I think if he wasn't such a good friend, I wouldn't be here so much so there would be less hours, then if you have to pick him up, when he has been out on the town or something, that would be different cause it doesn't say that in my contract, so I wouldn't do that unless he was a good friend.' (PA)

These findings are similar to those of a study of forty-one direct payment users where it was suggested by the authors that: 'it paid to have friendly relationships with personal assistants: Personal assistants didn't mind doing extra work' (Clark et al 2004:18). Working unpaid or longer hours has become increasingly common in many occupations, with boundaries between work and home life have becoming eroded (Hochschild 1997; Bunting 2004). The trend towards longer hours at work and greater numbers of women in employment (discussed in chapters 2 and 3) results in childcare and housework being condensed into smaller amounts of time. This means that for many people home is no longer a haven, but a place where they struggle to catch up with tasks and effectively start the 'second shift' (Hochschild 1989).

Work can become an escape from this as it offers more control and positive feedback with 'home becoming work and work becoming home' (Hochschild 1997:38), and some people choosing to work long hours, because they find it more pleasurable than being at home. Guest and Conway (2002) for example, argue that working long or extra hours at work does not necessarily reflect pressure or coercion, but can reflect workers' involvement with their work. In my study one of the personal assistants (Mim) provided an example of this

when she talked about feeling more relaxed in her employer's home than when she is in her own home. It could also be argued that the market will reconcile any conflict in the support relationship, as a worker will leave a job, which does not satisfy their needs. Working additional unpaid hours could then could indicate that workers were happy and satisfied at work; a theme explored in terms of job satisfaction in chapter 7.

On the other hand doing unpaid work may suggest that workers felt a sense of obligation towards the person they support in the same way that family members do, and this in turn made it difficult for them to refuse to help. We have already seen in this chapter, that almost all of the personal assistants appeared to feel an obligation towards their employer in terms of not feeling able to leave their job. Then again the unclear boundaries of the direct employment relationship may mean that working extra, unpaid hours was considered by both employers and personal assistants to be a normal part of the job, whereas for homecare workers it was not. It seems significant that the only personal assistant (Sue) who was not undertaking unpaid work, was employed part time as a homecare worker for social services, and as such could use the local authority Guidelines, as a model for the boundaries of her role as a personal assistant.

During the interview I asked whether workers were expected to provide cover for emergency situations. Five personal assistants (Joy, Sue, Tom, Mim, Ian) said their employer expected them to cover for sickness absence, or to be were 'on-call' for some emergencies when they were not working. Four of these personal assistants described their relationship with their employer in

family-terms. Direct payment users as employers were aware of their personal assistant's home address and telephone number and can call them if an emergency occurred:

Sue: .there is only four of us [PA's], that if anybody goes on holiday or is sick, we had one worker that actually passed away earlier this year, we all had to, Linda (DP User) needed care every morning and every night so you are responsible, you know, if everybody goes off you have to come to work (PA)

Mim: It can be a problem because if Gemma (DP User) needs care and she hasn't got it like she did a fortnight ago when someone let her down and she rings me to go on, I will do my utmost to go on. But then I've got my husband shouting at me, you don't need to go let someone else do it, you do enough, because I do other things as well. So yes it can cause a problem (PA).

The live-in personal assistant (Ian) was on-call both day and night:

Peter: He's [The PA] probably told you he's got a lounge upstairs that he can use and then he'll get me to bed and the last two injections of the day and he'll be then free to do whatever he wants to do but he's still a sentinel for me. In the night-time if I have a hypo attack, he will administer the sugar and the glucose perhaps a biscuit or whatever it might be until I've recovered sufficiently and that can sometimes happen twice in a night (DP User)

JL: So he [PA] is sort of on call through the night as well?

Peter: He's on call through the night as well and he does, I suppose you would say night sits really.

In contrast homecare workers said that in emergencies homecare users contacted social services not individual workers. Only two homecare users had their worker's home 'phone number (Mathew, Jackie) and neither of these had used it in an emergency. Homecare workers were instructed in the Guidelines not to give their home 'phone numbers or addresses to service users.

In the study undertaking unpaid work, covering for other workers in emergencies and being on-call during non-working time were generally a feature only in the direct employment relationship. This provides evidence that direct employment appears to increase the likelihood of the boundaries of the care relationship being unclear. I would argue that that the undertaking of unpaid work is more likely to be in the interests of employers rather than workers, indicating that blurred boundaries may tend to favour the needs of disabled adults. This provides tentative evidence that where there is a conflict of interests in the relationship employers needs are more likely to prevail, as employers have greater power in the setting of the boundaries.

5.5 Conclusion

Existing research suggests that blurred boundaries occur in many support relationships and that direct employment can encourage this. My study found that blurring of the boundaries existed to some degree in both types of relationship, but was much more prevalent in the direct employment situation. Personal assistants were more likely to be undertaking significant amounts of unpaid work, to do a wide range of tasks, to have responsibility for emergency cover, to mix with each their employer's family and share concerns. They had

a much closer relationship with their employers than in the homecare relationships; they had generally known each other longer (many before the employment started), spent more time together, with some going on holiday with their employers. Where a personal assistant was either a relative or lived-in, the potential for blurring appeared to be even greater, and the unclear limits seemed to favour the interests of employers rather than workers. The study thus confirms the suggestions of previous research, and for the first time, because of its comparison between direct and non-direct employment, provides empirical evidence that the direct employment of support workers increases the likelihood of the relationship having blurred boundaries.

The research was in-depth and so I was able to look at possible explanations for direct employment having this effect on the relationship. The lack of local authority guidelines for personal assistants practice may encourage confused limits and can make it difficult for workers to set boundaries that suit them. The close relationships that develop may result in personal assistants feeling similar obligations to those of real family members, indeed in this study personal assistants were completing a wide variety of tasks in the same way as many family members, with those who had the closest relationships doing the most. The paying of wages directly to personal assistants, brings money out into the open and can change the way workers and employers relate to each other, giving employers the power to define the boundaries of the relationship to suit their interests.

This analysis indicates not only the extremely complex nature of the direct employment relationship, but suggests that when differences of interests arise

between employers and personal assistants it is the interests of employers that seem most likely to prevail. In the next chapter I develop these arguments further and consider the data from the study relating to the concepts of autonomy and power.

Chapter 6 Autonomy, Independence and Power

I argued earlier in this thesis that the literature about independence is confused and contested, whilst notions of power in the direct employment relationship are inadequately understood. Yet my reading of the literature and analysis of the data emphasised the importance of appreciating the complexities of these concepts, if we are to understand the affect of money and direct employment on the support relationship.

In chapter 6 I look at the findings from the interview data that relate to the respondent's independence, autonomy and power in the support relationships. Section one briefly reminds us of earlier discussion and considers the meanings of independence and autonomy for respondents. I examine the ability to reciprocate, as it emerged as an important concept, and is an indication of autonomy. Section two follows by looking at power, control and workers' perceived status in the relationships.

6.1 Independence and Autonomy

In chapter 3 I argued that disabled activists' redefinition of independence, as control of decision-making is problematic, and that these ideas can be more usefully understood in terms of autonomy. The concept of autonomy can enhance our understanding of the care relationship, as it encompasses the experiences of both users and workers. This is particularly helpful when we look at possible conflicts of interest and whether workers are operating freely in the support relationship, or whether the nature of their work means that aspects of their autonomy have been compromised. In studying the literature I identified a model, based on ideas by Collopy (1988), which I used in the

analysis of the data to help distinguish between different types of autonomy (see Table 3), decisional, executional, authentic and delegated.

6.1.1 Meanings of Independence and Autonomy

In the study issues relating to autonomy emerged through analysis of certain aspects of the interview. During the interview respondents were asked what independence meant to them (Appendix 6). The word 'independence' was used in the interview rather than 'autonomy', as this term is more commonly used in everyday language. Three direct payment users (James, Harry, Wanda) talked about independence in terms of doing everything themselves (executional autonomy) and how they could no longer do this. Wanda said she had lost her independence along with her ability to drive herself about, even though her personal assistant now performed this role. In the study Harry demonstrated this by stressing that he tried to remain independent by doing as much as he could for himself

Harry: Just because it takes you longer to do something doesn't mean you shouldn't do it necessarily because the more you do it, the more practice you get, the better you get and the faster, the less time it will take. No I'd rather walk than be in a wheelchair to be honest, only because I can, if I couldn't then it wouldn't be on the cards would it? (DP User)

Five direct payment users (Peter, Freda, Gemma, Karen, Linda) described independence in terms of decisional autonomy rather than doing things themselves:

Gemma: Independence means everything to me. I think it allows me to be the person who I am and obviously living at home with my parents was nice but it

was a bit claustrophobic....it means having my own home and being in control

of my life, being able to say and do what I want to do and when I want to do it

(DP User).

Linda: Different people have got different views of independence. Me, I see

independence as being in control of your life. It doesn't mean particularly not

being able to dress yourself or toilet yourself or anything like that. (DP User)

The language used by Linda when she talked about independence is interesting, as it is similar to the language describing independence used by members of the disability movement. Linda was the only person in the study to be involved in disability organisations; she was the chairperson of an access group and also a user group (see pen picture in Appendix 15). Linda's involvement with these groups is likely to have influenced her views about independence and autonomy.

Only two homecare users (Trevor, Mathew) described independence as making decisions:

Trevor: Big question that is. Independence to me means being able to live

here and do things that I want to do, when I want to do them, that's

independence (HC User)

The other six homecare users discussed independence in terms of executional autonomy such as being able to go to the toilet unaided, cooking, washing, or having a bath. For these people autonomy had been lost (in the same way as the three direct payment users) when they became unable to do these things for themselves, even though workers were providing support in these areas. It is worthy of note that more of the direct payment users than

homecare users described independence in terms of decisional autonomy. I would suggest that being an employer could encourage people to have this view of their life. On the other hand people who believe they have decisional autonomy may be more likely to take the direct payment option.

There may also be a link between respondent's perception of autonomy and the length of time they have been disabled. The seven people (homecare users and direct payment users) who defined independence in terms of decision-making had been disabled, on average almost twice as long as those who did not (twenty-three years and twelve years respectively). Charmaz (1991), in her work on self-identity, argues that the threat of permanent disability makes individuals re-evaluate their perception of independence. People may therefore need time to adopt a view of autonomy based on decision-making. For example, a direct payment user in my study, who described independence in terms of executional autonomy and had been disabled for a relatively short time (five years), described his difficulty in coming to terms with being disabled and needing support:

James: I mean I still feel it is early days for me cause I'm still learning and I'm still, I've been finding it hard to accept what has happened to me and I do struggle, I do struggle being disabled. Because when you've not been disabled and you've been a normal healthy person and then you know, something like this happens, it is a big shock and it is hard to accept it. I've still got it in my head that I can still do everything that I used to do before. So you are still trying to do as much as you did before. I feel embarrassed having to get people in to do things, you know, cause all though my life I've never had anybody I've always done everything myself (DP User)

Autonomy may also mean something different for men and women. Many cultures define men through notions of action, strength, self-reliance and potency. Becoming disabled with its associated negative connections with dependence, weakness and vulnerability may cause men to question their masculinity (Robertson 2004). Morris (1997c) argues that many women, including older women, who have become disabled in adult life measure their progress towards independent living in terms of whether or not they can still look after their family. The view in society that women are responsible for care of the family and domestic work can mean that their social identity is threatened, if they are unable to undertake these tasks (Hockey and James 1993). One of the homecare users in my research alluded to this by relating her independence to being able to do things associated with being a woman:

Sandra: I think independence means to me being able to do the things that you just take for granted. I mean I used to go to work, I used to play netball three times a week, I used to drive a car, I had my own money, that doesn't bother me one iota but what does bother me and bother is the wrong word because it doesn't so much now. What I find I miss the most is being able to do things for myself. Perhaps it is because I'm a woman and personal care means more to a woman. I mean when I was first disabled I was having periods every month and because I was going through the early stages of menopause my periods were quite heavy and I really did get very upset then.... Being able not to put make up on, you know which is something I took for granted...

Turning to workers, the findings show that as with disabled adults, there were differences between the two groups. Five personal assistants (Joy, Sue, Win,

Liz, Tom) talked about independence in terms of decisional autonomy, whilst only three homecare workers (Tess, Lucy, Jess) defined it in those terms. For most of the homecare workers independence was being able to do everything themselves:

Jill: Being able to get out and about on my own, look after myself, you know I don't want anybody to do anything for me, to be able to do everything for myself....I wouldn't like anybody else in my house, if I was disabled I wouldn't want anybody in my house, I wouldn't want a home care worker (HC Worker).

JL: Why not?

Jill: Because I can't imagine what it is like to be disabled. I've got to be independent. I wouldn't want anybody to do anything for me.

Most homecare workers also related this to the autonomy of disabled adults stressing that homecare users should be encouraged to do as much as they could themselves, to achieve the greatest level of independence possible.

JL: What would you say to disabled people who say I don't want to take half an hour to put my socks on even though I could do it, it would be a struggle. I'd rather go to work instead so I'd rather you put my socks on so that I can go to work?

June: Well I would say probably if they've done something for themselves they would feel better for it than having everything done for them. (HCW)

This idea with its focus on executional autonomy was reflected in the training material for homecare workers in Staffordshire, which I obtained during a meeting with a homecare manager:

The support workers do not 'do' for the individual, but allow them to 'do for themselves'. Having said this, support workers need to know when to provide assistance, when the individual has struggled enough (Staffordshire County Council 2001b)

The word 'struggled' in the above statement is telling. It gives not only a rather negative view of disability, but it also shows us the potentially powerful position of homecare workers to decide when homecare users should be helped and when they should be left to 'struggle' (in the guise of rehabilitation) to provide their own care. The ability of homecare users to decide whether or not they need help, and at what point they need help would clearly be diminished by this practice. We saw in chapter 5 that respondents in the study generally described the direct employment relationship as friendly or family-like, whilst in contrast for homecare workers, the provision of support was mainly a professional working relationship. I argued that one reason for this was that the local authority Guidelines for Practice encouraged homecare workers to adopt a professional style of working. As discussed in chapter 5 maintaining a professional stance can influence the power balance in the care relationship, as it can confer power and autonomy upon workers (Clements 1996). I would suggest therefore that having the status of a 'professional' with the power to decide when to help users increased homecare workers autonomy, whilst at the same time reducing the autonomy of homecare users.

It is difficult to untangle the cause and effect of these results. However I would tentatively suggest, that whilst the length of time they had been disabled and their gender may have influenced people's views about independence, direct employment appears to have contributed to disabled adults' ability to feel and

be more autonomous. In both chapters 2 and 3 I made reference to the modernising agenda for social welfare with its emphasis on independence through rehabilitation and prevention, which has helped to create a rehabilitation ethic in social service departments (Secker et al 2003). As we saw in this section, both direct payment users and their employees were able to avoid the rehabilitation culture in social services, assisting employers in retaining the autonomy to decide when they needed help, rather than this decision resting with their workers. Direct employment may also have encouraged personal assistants to see their employers as being autonomous further reinforcing employers' view of themselves. However, personal assistants' lack of professional status, may result in their own autonomy being reduced, and I go on to consider and develop these arguments further in the following sections of this chapter.

In chapter 3 I discussed notions of independence and autonomy emphasing that the ability to reciprocate in a relationship is an important indication and element of the ability to be autonomous. The inability to reciprocate is associated with dependency (Johnson 1993) and inequality (Allan 1979; Adams and Allen 1998). Following on from this in the next section I explore autonomy further by considering disabled respondent's ability to reciprocate in the care relationship.

6.1.2 Autonomy and the Ability to Reciprocate in the Relationship

Previous research has suggested that disabled people do try to 'return the caring' to the workers providing their support, for example Piercy (2000) in a study of homecare workers, found that some older people gave gifts, advice, food and opportunities to watch television. To examine the degree to which

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disabled adults in my study were able to reciprocate in the support relationship, and whether there were any differences between direct and non-direct employment, I carefully scrutinised the transcripts for examples of reciprocity. In the homecare users' sample there were few examples of users reciprocating with workers. Some users gave workers sweets (Jeanne) or hot drinks (Jeanne, Rachel, Daniel, Jackie). One user had agreed to help with a homecare worker's NVQ (Brenda), whilst another (Rachel) loaned her worker a book. Direct payment employers in my study were also reciprocating in their relationships with their personal assistants, and the level and amount of reciprocation was far greater than in the homecare sample. For example, Freda had made her personal assistant a birthday lunch and cake, Karen sometimes looked after her personal assistant's children, Linda obtained information from the internet for her worker, and Harry helped his personal assistant, who had a lot of financial commitments, by giving him small gifts, buying his lunch and lending money.

A number of direct employers were also being reciprocal in terms of what they permitted their personal assistants to do whilst at work. We saw in chapter 5 that direct employers had greater power to decide what their workers could do, what tasks they should undertake and to determine the boundaries of the relationship. Direct employers were essentially able to *set the agenda* in the relationship in a way that homecare users could not, and I would suggest that this aided their ability to be more reciprocal. For example, in the study personal assistants were permitted by their employers to do many things that homecare workers were not allowed to do. Win could bring her dog with her to work, Joy could do her own shopping whilst at work, Dot looked after her

grandchildren in her employer's home occasionally, and Tom brought his 14-month old daughter with him to work at times, so that he could look after her. Mim was allowed to undertake her hobby of making sugar flower cake decorations, and Ian was able to keep chickens in his employer's garden.

Another important indicator of whether a relationship is reciprocal is whether people share worries and concerns with each other, as failing to do so can indicate that the relationship lacks equality or symmetry (Eustis and Fischer 1991). I identified in chapter 5 that whilst most of the personal assistants shared their worries with their employer, none of the homecare workers did, probably because they were following social services guidelines not to give personal information to users and to create professional boundaries. This may be an example of personal assistants having authentic autonomy (see Table 3, Page 74) where they display behaviour that is in character, they are 'true to themselves' and do not have to hide their feelings.

There was greater reciprocity by direct employees than homecare users, one reason for this was employers' ability set the agenda, and to decide the boundaries of the support relationship. There are also other elements of direct employment that may help disabled adult's ability to reciprocate. For instance, the capacity to pay wages in the direct payment relationship brings the payment for care into the open, and was likely to be seen by workers as giving something back for the support they provide. Three of the personal assistants in the study (Tom, Joy and Ian) were friends with their employer and had provided support, without payment, prior to their employment. To them the payment of wages was likely to have been particularly significant,

because they were previously unpaid. Tom made reference to this when he talked about how much the payment of wages has meant to him:

Tom: I met Harry last year, and he was doing a foundation course for the degree we're doing, and I was helping him about college then, cause obviously he needed help. I used to take him around, and what not, and then this year he asked me, if I wanted to work for him, as I was looking for a part-time job, and that has really, really helped me. I need the money, cause I've got a little one, and a family (PA).

These findings correspond with those in the previous section and suggest that direct employment makes it easier for disabled employers to be more autonomous than homecare users. However there are risks in that increased autonomy for employers may correspondingly reduce workers' autonomy. We have seen in chapter 5 that employers appear able to ensure their interests prevailed over those of workers, and greater autonomy could contribute to this. To look at the possible effects of this section 6.2 examines the balance of power within the relationships.

6.2 Power and Control in the Relationship

In chapter 3 I argued that in previous literature the impact of money and direct employment on the power dynamics of the care relationship are poorly understood, with little consideration given to the effect that a possible shift in power could have on the relationship and workers in particular. I emphasised the crucial importance of understanding the power relations in helping us gain insight into the complexities of the direct employment relationship. When looking at power in the relationships I wanted to discover in whom

respondents felt the power resided, and how this affected the relationship. In the interview I asked all the respondents: 'Who do you think is in control in the relationship?'

Five direct payment users (Peter, Harry, Karen, Gemma, Linda) said that they were in control in the relationship with one (Linda) linking this to her ability to pay her personal assistants' wages and check their time sheets. Linda was one of the direct payment users who described the relationship with her personal assistant in professional and friendly terms, rather than like family. Three direct payment users (Freda, James, Wanda) found the issue of control in the relationship blurred and talked about there being a mutual or shared control, although Freda did make the comment 'I'm the piper, I pay the money', again suggesting the importance of her capacity to pay wages. Freda also talked about feeling less in control when she was ill or in pain, which corresponds with the point made by Twigg (2000) about disabled adults' vulnerability. Four direct payment users (Peter, Harry, Karen, Gemma) related the source of their power or control to their personal assistant undertaking work for them:

JL: *Who do you think is in control in your relationship with Ian (PA)?*

Peter: *I am, but I sometimes allow him to think he is (DP User).*

JL: *Why do you think that you are?*

Peter: *Because the need is mine and not his. I have a need that he is fulfilling I have a problem that he is able to solve. He doesn't have a problem that I'm able to solve, not in day-to-day terms. So I'm the boss if you like, through need and necessity rather than attitude and if I need to go to the loo right now,*

I need to go right now, not when Ian thinks I need to go and it is little things like that which means there has to be somebody that is the boss.

Four of the homecare users (Daniel, Trevor, Jackie, Sandra) said they were in control, because homecare workers met their needs in the way that they wanted. Whilst two of the homecare users (Rachel, Brenda) felt in control with some workers, but not others:

Rachel: There is just one lady who used to come to me regularly that I felt as though I didn't get on with her, she is a little bit bossy, a bit brisk and a bit brash .....She seems as though she has got power over me. With being sort of in control of my personal habits and personal care and that sort of thing. Cause I feel pretty weak at the moment, I might be a large lady but inside at the moment because my health is bad I feel pretty weak, I've not the strength of character that I used to be. Yeah I would say, I know it is irrational perhaps to be afraid of her, I know she couldn't hurt me physically or perhaps any other road but maybe it is because she is so bossy and so domineering and I resent that because I think there is no reason to be that way with someone (HC User)

Rachel clearly agreed with the view that her vulnerability made it more difficult to achieve control with this worker. A number of studies have indicated the disempowering nature of homecare with users describing care workers as 'bossy, 'bombastic, 'domineering' and 'overbearing' (Twigg 2000:186-187). A homecare user in my study (Brenda) explained how she retained control with some homecare workers by telling them what to do and bossing them about, whilst she was afraid of other workers, because they handled her roughly causing her to experience pain. This reflects Foucault's argument that the

care relationship is a prime area for the exercise of power, with workers trying to gain control over their work and users struggling to resist being dominated by workers (cited in Twigg 2000*)*. Brenda said that some of her homecare workers took 'reprisals' following a complaint she made to social services about one of them:

Brenda: ...it is little spiteful acts like closing the door in the lounge which means that then I can't get through to the dining room in an electric wheelchair and being left dangling in the hoist, in the sling on the hoist for several minutes at a time on some visits and you know it is just petty and spiteful and you think well what sort of person actually demeans themselves to think of such actions, especially when you are in my condition, you know.

JL: Since you made the complaint?

Brenda: Yeah, they know my left hand side is sore and they know that if they want me in tears all they have to do is give it a good push and that will be it, I'll be in tears and I can't do anything then, they can do what they like.

Brenda said that some homecare workers gained control by treating her as a child. I noticed during the interviews and subsequent reading of the transcripts that a number of homecare workers used language associated with children to describe homecare users, whilst personal assistants appeared not to do this. The language people adopt is very important, indeed Hockey and James (1993:35) in their discussion of the infantilisation of disabled adults, argue it 'plays a central role in the creation and re-creation of social meanings'. Morris (1998) discusses a study where users reported homecare workers speaking to them and treating them as children, whilst Twigg (2000) cites examples of

homecare workers treating users like babies. To consider infantilising language I conducted a word search of the transcripts of workers for words such as: naughty, demanding, baby, girl and the results are given in Appendix 20. These results show that personal assistants in my study did not refer to their employers in these terms at all, whilst in contrast two homecare workers (Anne, June) used infantilising language to describe homecare users a number of times, and four other homecare workers used it occasionally:

June: ..some [HC Users] are very demanding, some can be

like babies actually and they are very demanding and then you sort of

notice the difference between, say you've had two children, one has been

hard work and one has been a doddle to bring up and that's the same with

service users. Jeanne [HC User] can be very, very demanding and I don't

actually take any stick from her sort of thing. She knows that she doesn't pull

the wool over my eyes and I sometimes have to tell her and be quite sharp

with her about how demanding she is (HCW).

Anne:...It can happen and a lot of people who are disabled that do take a ...

they are really naughty when they start being like that with you because we

are only there to help them (HCW).

One homecare user (Mathew) said that no one was in control in the relationship, whilst another (Jeanne), said it was the homecare workers who were in control, as they decided what care should be performed. It has been highlighted by disabled activists, that as well as being in control (or not) of what support is provided, and how it is undertaken, another aspect of control concerns the ability to choose who provides support (Hasler et al 1999).

Continuity and trust are of great significance to disabled adults, because 'it may not matter who picks up your rubbish in the street, but it does matter who wipes your bum… and that ought to be the same person day in and day out because it is a very personal service and you have to trust that person' (Wistow et al 1996:125).

For homecare users this was an area where all but one (Trevor) said they lacked power, as they were not able to choose the workers who supported them. Trevor said he refused to accept workers that he was not happy with by 'being strong and defending my corner'. However, even this strategy did not work in terms of the number of workers who came to support him:

Trevor: …some days you can see three or four during the day and perhaps one in the evening, five people. Then like this week and last week because one of the carers is off, she's not coming in to do my evening meal so there is a different one every night, now that annoys me something shocking. You know, because you tell one thing one night and you've got to exactly the same the next night at tea time, that annoys me and I have complained about that in the past, but it is like talking to myself sometimes because they don't listen. I've heard crap from some of the managers, saying oh I haven't got the staff, well they have got the bloody staff, that is a bug bear (HC User)

JL: So would you prefer just one or two regular workers?

Trevor: I much prefer regulars, the same people.

All of the homecare users said that they had no control over the number of workers who supported them. Homecare users generally have the same workers, but they can see up to twenty different people at times (personal

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communication with Homecare Manager). Many of the homecare users in the study said they would much prefer to have the same people supporting them. This suggests that the way homecare is organised, with users having little control over who provides their support, reduces their power and autonomy. Some homecare users (Jeanne, Brenda, Rachel) even said that they had asked for certain workers not to be sent to them, but on occasion these people still came

Rachel: Yeah I was surprised when they did put her [HCW] in as a relief now and again because I did express to H [HC Manager] that I really, really didn't want this lady [HCW] coming again and that's why I was surprised, they do occasionally send her when they've got to fill in for someone.

In contrast for the direct employers this was not an issue, as they could choose whom to employ (subject to successful recruitment) even, as we have seen, family and friends. The power to choose the person providing their support in the direct employment relationship meant that employers had greater autonomy, and they were able to define and develop the relationship right from the start in the way that suited them. For example, as we saw in chapter 5 most direct employers chose to employ a person already known to them, with the result that the relationship was friendly from the outset, whilst another (Linda) chose to employ a number of workers so that the relationship would be more distant. Other research has noted the frequent recruitment of friends by direct payment users, but I would suggest that the significance of this has not previously been highlighted, in terms of the power it gives employers to determine and define the type of relationship that develops. Thus it would seem that the ability to employ workers of their choice aided

direct employers in achieving greater power and autonomy in the support relationship than homecare users.

Moving on to look at workers, six personal assistants (Joy, Ian, Sue, Mim, Win, Liz) attributed control in the relationship to the direct payment user, because of their status as an employer and also because the support is provided in their employer's home. One of these personal assistants (Liz) did suggest that the power in the relationship could shift towards her at times because of her employer's physical dependency. For the other two personal assistants, Dot said that there was no control element she just came and did her work, and Tom that control was shared: 'it is a team thing'. Conversely only one homecare worker (Jess), described the homecare user as being in control and related this to his decision-making about how the support was provided (decisional autonomy), and because it was provided in his home. Five homecare workers (June, Beth, Anne, Jane, Tess) talked about the relationship being one of shared control:

Beth: I think it is very mutual and you've got to be very mutual with your service users, there is a lot of give and take. I don't think anybody should be in control cause I don't think they should be giving you orders when you get in there and I don't think you should be going in and taking over, it has got to be a mutual thing (HCW).

There was recognition from homecare workers, that whilst homecare users were often in control of certain aspects (how the support was undertaken), they were not in control of others such as what support was provided. For instance, homecare workers talked about only doing the tasks detailed on the care plan (assessed by social services) and following office guidelines

indicating that the control rests with the organisation rather than with users, again reducing users' autonomy. This corresponds with the findings reported earlier in this chapter, suggesting that homecare workers were less likely to see users as acting autonomously. Indeed two homecare workers (Jill, Lucy) said they were in control of the relationship with all their homecare users:

JL: What is it that makes you feel in control?

Jill: It is just that you go in there to do a certain thing and that's it really, you go in there to do a certain thing, you know what you're going to do and you do know more about them than they know about you cause they are vulnerable anyway. They don't really know anything about you, you could be anybody, so you feel in control of the situation, you know you have got to be self assured, to make them feel more relaxed anyway (HCW).

JL: Do you think you should be in control?

Jill: Yes I do.

JL: Why do you feel you should be?

Jill: I think you've got to be in control because if you're not, if you let your defences down anything could happen, they'd take advantage of you, I can't have that. So yes I have to be in control.

Social class can be important with suggestions that middle class people often retain the power associated with their class, despite increasing physical frailty (Hockey and James 1993). I discussed the social class of all the respondents in chapter 5 (Table 12, Page 156). Generally direct payment users in the study were of higher social class than the homecare users and all the workers, and it may be that direct employers were aided in their ability to

achieve power in the relationship by their higher social class and type of previous occupation (barrister, company owner, counsellor). Although as previously discussed, there are difficulties in determining disabled adults social class based on their previous occupation.

In terms of how well users and workers agreed in the way they attributed control in their relationships; four of the direct payment relationships (Karen and Joy, Peter and Ian, Linda and Sue, Gemma and Mim) corresponded exactly by agreeing that control rested with the user. In the homecare relationships none of the workers and users agreed in their view of the relationship, as four homecare users (Daniel, Trevor, Jackie, Sandra) said that they were in control, whilst three of their workers (Anne, Beth, Tess) considered it to be shared control, and one (Lucy) said the control rested with her. This is consistent with previous findings in this research, which found that direct employers and their personal assistants had a greater shared understanding of their relationship than in the homecare relationship.

6.2.1 Undertaking Healthcare Tasks

An area where power can be exercised in the support relationship is in the tasks or jobs that workers are required to complete. In chapter 3 it was reported that personal assistants in one study were reluctantly undertaking some healthcare work (Glendinning et al 2000a). At the time of writing government guidance to local authorities stresses that direct payments should not be made for any services that are the responsibility of the NHS (www.dh.gov.uk), however the research in this thesis predates this guidance, and furthermore anecdotal evidence suggests that direct payments are being made for some aspects of healthcare. Therefore it was important to look at

this element of the relationship, as undertaking work they are unhappy about, could be an indication that workers lack power or autonomy. To examine this all of the homecare workers and personal assistants were asked if they did any healthcare tasks for the person they supported. None of the disabled adults required any healthcare tasks to be completed, although one personal assistant (Ian) measured his employer's insulin. Ian had attended a course at a health centre to obtain appropriate training, and was responsible for his employer's emergency injection pack, which was required in case his employer became unconscious. This was clearly a big responsibility and very stressful as Ian explained:

Ian: Last Christmas he [employer] had a really bad one, [diabetic emergency] it was opposite to a hypo....I rang for an ambulance cause I thought this is getting too bad, no ambulance turned up so I tried it again and he is sitting here, rang for another ambulance... he goes unconscious, falls off the chair here, hits this [floor] and there wasn't a carpet here then it was just the hard floor. So I have to... the controller rang me back, he'd [employer] stopped breathing virtually... and this was like, I don't know what time this was now 1 o'clock or whatever. Anyway about an hour later two ambulances turned up, like I say he was okay but it is nerve racking...it is actually hellish really (PA)

Following on from this, I asked all of the workers if they manually lifted the person they supported, as manual lifting can be an area of conflict between disabled adults and workers (see section 3.3). Five homecare users in the sample did need lifting and this was completed using a hoist with two homecare workers present, as this is the policy of Staffordshire's homecare service (Staffordshire County Council 2001a). Direct employers did not

require manual lifting, so personal assistants were not doing this, although Ian was required to physically assist his employer, who was a large man, in and out the bath. Whilst these findings are inconclusive, they do suggest that for live-in workers especially, there may be times that employers' interests take priority in the relationship to the possible detriment of personal assistants.

In this section I have shown that the balance of power in the relationship lay much more with direct employers than with homecare users. Whilst explanations for this are complex and may include issues such as the social class of respondents, the increased power of direct payment users related to their employer status, indeed six of the personal assistants and two direct employers made this link. Unlike homecare users, disabled employers had the power to choose the person who provided their support, the number of people who supported them, and to define the nature of the relationship right from the start. Personal assistants appeared well aware of their employer's power and did not from refer to them as children, although this was not the case for homecare workers.

The findings demonstrate the complex nature of power in the relationship and the ambiguous position of support workers. In chapters 2 and 3 I considered the analogy of care work with the work performed by domestic servants, and argued that in the literature these ideas are contested and unresolved. Nevertheless this aspect of the power dynamics can help us to understand the impact of direct employment on the relationship. For instance, whether personal assistants were more or less likely to feel like servants than employees of social services. In the next section I continue to examine

notions of power by exploring whether the role of workers was similar to that of domestic servants.

6.2.2 Invisible Support: Like Master and Servant?

Britain's long history of domestic service, with its grounding in status relationships, is argued to influence care workers' perception of their work. For instance, Twigg (2000) suggests that care workers reject the idea that their role resembles that of a servant, because of the connections with being subordinate, servile and menial. In her study Twigg found that workers who emphasised their position as carers instead of cleaners were keen to present a semi professional status, and were pleased if users referred to them as nurses. To look at this further I asked all the respondents during the interview whether their relationship was similar to that of a master and servant, with disabled adults being the master and the worker being the servant. All disabled adults in the study denied that the relationship was one of master and servant:

Karen: No not at all we do things together....I don't just sit around telling her what to do, we share things and do them together. I don't tell her what to do and boss her about (DP User)

Rachel: No, just equal, feel normal.... I don't think for one minute that they feel as though I am bossing them, which I don't. (HC User)

In terms of workers one personal assistant (Liz) however said that there was an element of being a servant in the nature of the job, because she was being paid to 'serve' someone, whilst another (Mim) described herself as 'subservient, saying that if she wasn't she couldn't do the job. Interestingly six

homecare workers said that whilst the relationship was not one of master and servant with the users in my study, they did feel like servants at times with other homecare users.

Lucy: Well you feel like a skivvy, she [homecare user not in the study] is a really horrible woman, I hate the call, I dread going. It is like, it is purely to do her tea, but she'd go without the tea while you are doing all the jobs that she is dictating you to do, you know, put the hose pipe on, do this and do that, take that upstairs, fetch this down, take that down there, do this... I really do feel a servant there (HCW)

Jane: I do feel like that [like a servant], not necessarily with Brenda [HC User] but yes sometimes I do (HCW).

JL: How does that make you feel?

Jane: That makes you feel like that, that you feel a bit worthless

I discussed in chapter 3 that one of the qualities of servants was the ability to work 'invisibly'. For example, in an article about the history of servants in Britain they were described as: 'Shadowing the family members and anticipating their needs- meals appeared on the table, fires were found miraculously lit, beds warmed and covers turned back by an invisible hand' (Light 2003). To consider whether workers were providing invisible support, and if there were any differences between the direct and non-direct employment relationship, I asked all the respondents about workers providing support in an invisible way. When they were asked none of the direct payment users said they would like their personal assistant to be invisible. The general view was that they valued the friendly relationship and enjoyed the company

provided by their personal assistant and seemed to feel this would be spoiled if workers were invisible. Although as discussed in chapter 5, two direct payment users mentioned another reason for being friendly with their personal assistants:

Karen: No I think that's not right. If you treat your personal assistant like a broomstick then they won't be there to help you if you need it. Say you fell or your children were ill. If they are your friend then they will help you even if it is not their time to be at work. If they are like a broomstick then they would just go when their time is up (DP User).

JL: So you feel that by being friends your personal assistant will help you more than if they are not your friend

Karen: Well yes of course

The idea that personal assistants would do more for their employers where the relationship was friendly may suggest that friendly relationships are more in the interests of users than workers, and could be one of the reasons why many of the direct payment users in my study chose to employ people that they already knew. Homecare users also said they valued the company of workers with some expressing gratitude for the support provided:

Rachel: No not at all. Like I say I'm so glad that they come out, I'm grateful if that's the right word for the service that is available to me and I have it. So I feel that however long they need to be here to see to me and to do their job to help me I'm grateful cause I've been without the service and I know how I've struggled without it and I'm more than grateful enough for them to come to spend as much time as they want here (HC User).

Two homecare users though, said they would like their workers to be less visible and related this to workers doing their job without having to be told what to do:

Sandra: Yes I agree with that to a certain degree, this is where I come back to knowing they just do things without you having to ask. I think this is what they mean by invisibility. If you've got to continually keep saying to a carer oh can you pick that up or can you move that, or can you put that away, you feel as though not only are you on and on all the time, so you are feeling a bit of a boss if you like, you know. But the fact that it is showing once again that you can't do it. Whereas if you've got a carer that sees something on the floor and picks it up, that sees something that shouldn't be there and puts it away, or says to you do you want me to do so and so, oh yes please. (HC User).

This aspect of invisibility is more relevant to homecare users who can see up to twenty different workers at certain times (peak holiday periods). Homecare users need to explain details of the support required to these 'occasional' workers. Direct employers on the other hand have the power to decide who provides their support, and do not need to explain their requirements to different people (unless they recruit new staff). Personal assistants in the study all knew their employer's needs and talked about how they just get on with their work:

Sue: ....but if you have finished doing your one-to-one care with that person and you are just doing your other sort of work then you do, you just sort of disappear [laughs]. I'm only here for two hours so I'm not going to sit and chat and drink coffee and I've got my little jobs to do (PA).

Dot: …..I mean as soon as I come in, I usually come in here and say hello to him and them I'm straight back out and I'm doing whatever jobs I've got to do round the kitchen and bathroom and bedroom or whatever. Then I'll come in here and hoover and do what I've got to do in here. No I usually just leave him to his own devices (PA).

To consider indirect references to invisible working I reread all the transcripts of the interviews looking for evidence of what workers did. I found that a number of the personal assistants had developed ways of being unobtrusive or invisible. One personal assistant watched television in a different room or withdrew unless asked to stay (Ian), another did her work without talking unless her employer started a conversation (Win), whilst one personal assistant went in another room to read a book:

Mim: ….there are times, yes when Gemma [DP User] wants to be on her own. She likes her own music, she likes the things on the television that she likes and I sometimes like to read a book so I will ask if she minds if I go out and read a book so that she can have some time (PA).

All of the personal assistants tried to be unobtrusive when their employer had visitors or went out with friends and family:

Mim: Her [DP User's] mum will come out with us and they go off together and I meet up with them. They give me a ring on my mobile and say we're going to have something to eat now so I can go back again (PA)

Sue: I excuse myself [when employers friends call] and go out to have a cigarette and Linda knows I am there if she needs me (PA)

Liz:...there are occasions when, say coffee time, I will say do you just want to be on your own today, she normally says no it is alright you can come in (PA)

Only one of the homecare workers described a method of becoming invisible with her homecare user:

Jane: .... it is just through watching Brenda [HC User] and seeing what she does need and I never discuss things with her unless, if she wants to say something to me I'll listen, and I might have something to say about it but I never fish. Once it has been said, I'll leave it, if she mentions it again she does and if she doesn't she doesn't, I never. I think I've just learnt to some extent how Brenda wants me be, how she wants my role to be and I just try and fit into that role really (HCW)

Two homecare workers said they could understand disabled adults wanting workers to be unobtrusive (Beth, Jill), however three homecare workers (Tess, Anne, Lucy) expressed annoyance at the idea of being invisible with one saying she wanted appreciation:

Tess: Well we are there to do a service aren't you, there to help and you don't want to be sort of shoved in the cupboard do you? You like a bit of appreciation, don't we all (HCW)

JL: Some disabled people have talked about wanting their workers to be like a broomstick in the cupboard, to be unobtrusive but there when needed.

Tess: Well I wouldn't be that broom in that cupboard.

To examine the idea of workers providing support that is unobtrusive further and to identify differences and similarities between the two groups I gave all respondents a brief scenario during the interview. The scenario was drawn

from the comments made by Bailey (2002) a direct payment user who describes the difficulty she has in dealing with the intrusion of having a personal assistant present during social occasions. Bailey describes her dilemma about whether to involve her personal assistant in the conversation during dinner, whilst she is friendly with her personal assistant and requires their help with personal care, Bailey wants to enjoy a meal alone with her friend. All the respondents were given the following scenario and asked for their comments:

If a disabled adult were to go out with their partner or friend for a meal and a homecare worker (or personal assistant) went with them to help, perhaps by cutting up food or assisting them to the toilet. The disabled adult may ask the worker (or personal assistant) to sit elsewhere until needed, so that the disabled adult could talk privately with their partner or friend. What are your views about this? (Appendix 6)

This part of the interview created a lot of strong feeling from both homecare users and direct payment users with both samples being similar in their responses. All except one homecare user (Jackie) said they would not ask workers to sit elsewhere, as they felt this would be rude. Some people said it would be snobbish or arrogant to expect workers not to sit with them:

Trevor: No I wouldn't do that. If I was going with somebody I wouldn't be going there to leave them on their own, that's something I wouldn't do. I mean that's arrogant, ignorant it is not really something, definitely not (HC User).

Linda: But that is a very difficult area isn't it really? You know, I mean you can't say to them buzz off, while I have a little word with R [husband], you can't do that really. At the dinner they are there and should be treated with respect for being there (DP User).

James: I don't know, I don't think it is the right thing to do, if you come out for a meal and you've got your carer which you need, to me it is just bad manners and ignorance to say well go and sit somewhere else I don't want you sitting with me, I want to talk to them (DP User).

These responses are comparable to the view of a person using the ILF to employ a worker directly who said: 'It's somewhat demeaning to expect someone to just sit in the corner and not think for themselves' (Kestenbaum and Cava 1998:50). In my study only one disabled adult, a homecare user (Jackie) said that she would ask her workers to sit elsewhere, although in practice she did not need to do this, as her husband always accompanied her to help:

Jackie: Well if I did need any more help, I think that I'd tell them to go away, just come back when I need them..... I would talk to my friend and call the girls [HCW's] when I needed them (HC User).

Two direct payment users (Harry, Gemma) and one homecare user (Daniel) said they could understand that disabled adults may want privacy when they had a meal, but would not expect workers to sit elsewhere. All the personal assistants and homecare workers said they understood that disabled adults might wish to have some privacy, and they would be willing to sit elsewhere if asked to do so, although one personal assistant and one homecare worker

(Sue, Tess) said they would be uncomfortable about sitting in a restaurant alone. I feel this scenario was not as effective as it could have been in further opening up the discussion about power and invisible support, as users were sidetracked into issues of courtesy and good manners. They perhaps did not feel able to express their views for fear of appearing rude. In retrospect it would have been better if I had used a less controversial scenario. On the other hand it is significant in that it raises issues about the limitations of this study in terms of differences in what people say and what they do. This is discussed further in chapter 8. .

The findings have again shown the impact which direct employer's ability to choose whom to employ had on the relationship. Employers were more likely than homecare users to have support provided unobtrusively, because they could employ dedicated personal assistants who knew what needed to be done without having to be told. Turning to workers, most homecare workers in my study felt like servants at times, whilst the majority of personal assistants said they did not. However despite this personal assistants were adopting methods of working unobtrusively suggestive of the way domestic servants traditionally performed their tasks.

What does this tell us about the direct employment of support workers? It may infer that although personal assistants were mimicking servant's ways of working, something about their relationship with their employer stopped them from considering themselves to be servants. I would suggest the friendly, often family relationships with their relaxed boundaries experienced by personal assistants may have influenced this, in a way that the more distant, professional approach adopted by homecare workers did not. It could also

suggest that whilst employers have greater power in the relationship, personal assistants either did not feel their autonomy was compromised or were willing to sacrifice some of their autonomy. In the next chapter I look at job satisfaction and stress and develop these arguments further.

As I discussed earlier, carework is generally viewed as low status work in society, influenced by notions of servants and domestic labour. Status can be defined as the position a person occupies in the social hierarchy, with low status work failing to bring the same prestige and respect to workers that is associated with higher status roles (Giddens 1989; Sennett 2003). I was keen to discover whether direct employment had any impact on notions of status in the relationships.

6.2.3 The Status of Support Work

Support work is argued to be 'the bottom of the heap' (Twigg 2000:125), chosen by young women with few qualifications or choices in the labour market (Skeggs 1997). It is poorly paid, gendered work, often considered lacking in status because of its connections with 'women's work' (Balloch et al 1999; Johansson and Moss 2004). But does direct employment of support workers alter this in any way? Were personal assistants seen as lower or higher status than homecare workers? To look at this area in my study I asked all disabled adults to talk about how they perceived the status of their worker. Most disabled adults (six direct payment users and five homecare users) described the job as either high status or very high status, linking the standing of the work to the importance of the support to them:

Linda: Yes because if it wasn't for care workers where would some people be? Stuck in bed all day not able to get up wouldn't they? They wouldn't be able to go out, they wouldn't be able to do anything, they would just be vegetables basically, wouldn't they? (DP User)

Sandra: Because I think anybody that can do the job that they do with the wage that they get and if you say to people I'm a care worker, the first thing people say, oh I don't know how you can do that. I have got so much admiration for a good care worker, they're top of my league as far as I am concerned. As high as my doctor is anyway, that's where I put them (HC User)

One homecare user (Trevor) said he wouldn't categorise it as high or low status making the point that it is an essential service for him. Two homecare users (Brenda, Daniel) and two direct employers (Gemma, Wanda) described it as low status work. One of the homecare users clearly felt herself to be superior to the workers providing her support:

Brenda: I think it is a low status work. I mean I couldn't do what they do, you know, cleaning up people's poo all the time ...you know, they don't have to be the brightest people in the world to be in the job so maybe it is that. I know I'm more intelligent than most anyway....you know, obviously you don't have to have a PhD to work in the community care group (HC User).

Another method of revealing respondents' views is to examine the language they use. In a study by Johansson and Moss (2004) many homecare users referred to middle-aged female workers as girls, and the authors argue this can imply that users see workers low in status, because women who are in

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highly paid positions of authority, such as judges, are rarely described in this way. The word 'girl' is thus a diminutive low status version of womanhood. Workers who describe themselves or co-workers in this way are likely to consider themselves, or their job to be of low status. To look at this area I conducted a word search of all the transcripts for the terms 'girl' and 'girls' with the results being reproduced in Appendix 21 Tables 1 and 2.

The findings from the search show that all the homecare users, with the exception of Mathew, used the words when talking about homecare workers thirty times in total. In contrast only one direct payment user (Linda) described her personal assistant as a girl. This suggests that whilst most homecare users said that the job was high status, as the support was important to them, they still saw the worker as low status. Furthermore, homecare workers all used the words to describe other homecare workers a total of sixty-one times, yet only one personal assistant (Sue) did so. Perhaps unsurprisingly Sue was the employee of Linda (who also used these terms), and was the only personal assistant employed as a part time homecare worker for social services.

The use of the term girl has associations with domestic service where it has been used to refer to adult women servants (Hockey and James 1993). The findings in this section thus are compatible with those earlier regarding servants and invisible service. Most homecare workers described feeling like servants with some users, and they also appeared to feel that their job was lacking in prestige. In contrast personal assistants generally did not feel like servants or that their work was low in status. Looking back at the discussion about language in section 6.2 we can see that many homecare workers also

used infantilising language when talking about users and I will return to this in chapter 8.

6.3 Conclusion

Notions of independence are disputed and confused in the literature, and this research attempts to untangle this confusion to enhance our understanding of the impact of direct employment on the support relationship. To do this I focussed on the concept of autonomy, and the findings show there were clear differences between the direct payment and homecare samples, which appears to relate to the direct employment of workers. Most direct payment users and their employees described independence in terms of decisional autonomy, suggesting that employers saw themselves as autonomous, as they were able to control the decision-making process, and that their employees believed them to be autonomous. Conversely, homecare users and workers generally subscribed to the view of independence commonly held in society, of independence as 'executional autonomy'. This meant that both homecare users and workers saw users as having lost their autonomy when they became unable to self-care.

The ability to directly employ workers is likely to influence disabled adults in feeling and being more autonomous. They were not subjected to the rehabilitation and executional autonomy culture prevalent in social services and had retained autonomy to decide when they needed help (unlike homecare users and workers). Corresponding with the findings in chapter 5, direct employment also enhanced an employer's ability to reciprocate in the relationship, so important for maintaining autonomy. Direct employers had greater control in determining the boundaries of the relationship, and in the

things their workers could and could not do. This gave them the power to grant favours or perks to workers, such as allowing a dog to be brought to work. Employers were also able to pay workers' wages directly, and so be seen to be returning the support provided by their employees.

This research provides crucial evidence to confirm the suggestion, made by previous literature, that direct employment involves a shift or power towards direct employers. In my study the balance of power was to be found far more in the hands of employers than employees. This redistribution of power in the relationship is complex and may include issues such as social class, however direct employment of workers appears to have an enormous impact. For instance, unlike homecare users direct employers had the power to choose the worker who provided their care, the numbers of workers who supported them, and to define the nature of the relationship from the very start. Personal assistants appeared well aware that their employers were 'powerful people'.

I examined the similarity of carework with domestic service in an attempt to explore the affect of direct employment and unpick the complexities noted in the literature. Again there were differences between direct employment and non-direct employment. Direct payment users were more likely to be receiving their support unobtrusively; the approach used by domestic servants, because by employing their own workers, employer's support was provided by a worker who knew what to do without being told, whereas homecare users' support could be provided by a number of different workers.

These findings appear to be very positive from the point of view of direct payment users. Employing workers directly gave disabled adults greater power, autonomy and an enhanced ability to reciprocate in the relationship.

As we saw in chapter 5 it also brought power to set the boundaries, and may help employers to achieve their interests. However the result of this for personal assistants was that their power and autonomy in the relationship may have been correspondingly reduced.

Surprisingly, although personal assistants were working in a way evocative of domestic servants, it was homecare workers who described feeling like servants, rather than personal assistants. Furthermore, all the homecare users appeared to feel that their job was of low status, whilst personal assistants generally did not. I argued that the difference in how workers experienced their job could be the result of the direct employment relationship having more relaxed boundaries and being generally much closer than that of homecare workers. Perhaps being their employers' friend, helped to stop personal assistants feeling like servants. Personal assistants may have felt they had autonomy; after all they were able to negotiate 'perks' in a way that homecare workers apparently could not. Working for one employer, who had the power to define the relationship, may bestow greater autonomy upon workers than being employed by a large organisation, such as social services with its rigid rules and guidelines. The direct employment of workers may thus be creating an environment more favourable to the development of reciprocal, interdependent relationships than in traditional homecare provision.

Chapter 7 Investigating Stress and Job Satisfaction: Positive and Negative Aspects of the Support Relationship

In chapter 3 I examined current literature and argued that it is inadequate in helping us to understand the impact of direct employment on the support relationship. I suggested that we needed to compare direct and non-direct employment, looking at positive as well as negative aspects of the relationship. An investigation of stress and job satisfaction in the homecare and direct payment relationships can enable us to do this. An examination of the extrinsic elements of job satisfaction, such as pay and conditions, can also assist in our understanding of the impact of direct employment on future trends, such as whether direct payments are continuing the move towards a low paid casualised workforce in social care.

In this chapter I discuss data relating to stress and job satisfaction from the study, whilst continuing to develop arguments from chapters 5 and 6 regarding the boundaries of the relationship, autonomy and power. For example, we have seen that personal assistants in the study were more likely to be working extra unpaid hours, perhaps reflecting the greater power and autonomy of direct employers in the relationship. To set the scene I begin the chapter by briefly summarising the main points of the discussion about job satisfaction and stress from chapter 3, and then consider data from two questionnaires completed by respondents, followed by findings from the in-depth interview with respondents. Consideration is given to the reasons workers chose their job, what gave them most satisfaction about their work and areas where workers and disabled adults felt dissatisfied or stressed. I then go on to examine extrinsic elements of workers' experiences.

7.1 Stress and Job Satisfaction

Stress and job satisfaction are linked, with high levels of stress generally associated with low levels of job satisfaction, although high stress levels and high satisfaction are not incompatible, as work can be enjoyable and stressful at the same time (Mclean 1999; Cameron and Moss 2002). There is a dearth of research that specifically examined notions of stress and job satisfaction for personal assistants in the UK, although Ungerson (2004) suggests that whilst personal assistants in her study appeared to be satisfied with their job, their working conditions were unsatisfactory with some undertaking unpaid work. Two studies that looked at these areas in the US found that direct employees were slightly more satisfied with their relationship with users than agency workers, but were a little more stressed about user safety (Benjamin and Mattias 2004; Dale et al 2005). Both studies identified how direct employees related to their employer, may face additional stress in terms of the range of tasks required and providing unpaid help.

7.2 The Job Satisfaction Questionnaire

In chapter 4, I discussed the difficulty in measuring stress and job satisfaction, as many aspects of a person's life can influence how they see their work. I have therefore adopted a multi method approach advocated by other researchers (Shipley and Orlans 1988; Rose 2000, 2004; Coffey et al 2004) to try to overcome this and gain a more accurate understanding of respondents' experiences. I used a qualitative interview, a job satisfaction questionnaire developed by Warr et al (1979), and to measure the stress levels of the participants the 12-item General Health Questionnaire (GHQ12) (Goldberg and Williams 1988).

All the personal assistants and homecare workers in the study completed a job satisfaction questionnaire (Appendix 7). There are sixteen questions each of which has seven possible responses and each response was scored on a 0-6 scale as detailed in Willcocks et al (1987). Higher scores indicate greater job satisfaction, with a minimum score of 0 and a maximum score of 96. The scores are reported in Table 13 below and show an average score of 80.8 for personal assistants and 69 for homecare workers. This suggests that as a group, personal assistants in the study have a higher level of job satisfaction than homecare workers.

Table 13	Job Satisfaction Scores
Personal Assistants	
Joy	85
Sue	76
Mim	91
Liz	79
Win	68
Ian	89
Dot	77
Tom	82
Total	**Average Score 80.8 647**
	Overall Average Score per Question 5.05
Home Care Workers	
Jane	77
Lucy	33
Jess	65
Jill	65
June	88
Tess	72
Anne	69
Beth	83
Total	**Average Score 69 552**
	Overall Average Score per Question 4.31

To put these results in context by comparing them with data from other studies using the same research tool, the scores were converted to an overall

average score per question. This was calculated by dividing the average score by the number of questions in the questionnaire (16). Table 13 shows that the overall average score per question was 5.05 for personal assistants and 4.31 for homecare workers. Direct comparisons with other studies are difficult; none contain personal assistants and previous studies in local authorities have included workers from a range of jobs such as social workers, team managers and childcare workers, rather than focusing on home care workers alone. This can affect findings, as people in different types of job report differing levels of job satisfaction. For example, social services' employees working with children score lower on the job satisfaction scale than those working with older people (Balloch et al 1999).

A study of employees in social services, including homecare workers that used the same questionnaire, reported an overall average score of 4.36 (Balloch et al 1999). The workforce studies in England, which look at a number of occupational groups, had an overall average of 4.65 (McLean 1999), whilst a study by Mullarkey et al (1999) had 4.35. More recently research by Coffey et al (2004) of 1234 workers including approximately 200 homecare workers, reported that job satisfaction was declining, as respondents had an overall average score of only 4.19. The score by homecare workers reported in my study of 4.31 is similar to the earlier studies and shows a higher level of job satisfaction than the later study by Coffey et al (2004). The personal assistant sample shows a considerably higher overall average of 5.05 than any of these studies, suggesting that as a group they reported a higher level of satisfaction with their work.

7.3. The Stress Questionnaire

To measure levels of stress all respondents in my study completed the General Health Questionnaire (GHQ12), which consists of twelve questions covering areas such as concentration, depression, decisiveness, confidence, insomnia and happiness. Each question has four possible responses listed in columns (Appendix 8). This questionnaire was scored as suggested by Goldberg and Williams (1988) with a score of 1 being given to a response in columns 3 and 4, whilst responses in columns 1 and 2 were scored as 0. There is a minimum score of 0 and a maximum score of 12 the higher the score the greater probability that the respondent is experiencing stress. People scoring 3 or more can be classified as 'cases' with a possible 'hidden psychiatric illness' (Goldberg and Williams 1988:9). None of the data from either the satisfaction or stress questionnaires were analysed using statistical tests, as this would be flawed given the small sample size. The results of the stress questionnaire for workers are detailed in Table 14.

These results show that the average score for homecare workers was 2.63 whilst for personal assistants it was 1.75, suggesting that as a group, the homecare workers in the study reported higher stress levels than personal assistants. Two of the homecare workers appeared to be particularly stressed. (Lucy and Jess) who scored 11 and 7 respectively. Personal assistants had lower stress levels on average with the highest being reported by Ian and Tom who both scored 4. However, it is important to note that the use of average scores should be treated with caution when a sample size is small, as the impact of individual responses on the results is much greater than in larger samples, and this may produce inaccuracies. For example, if

the highest scoring respondents from each sample (Lucy and Ian) are removed, and the average recalculated, the average score of both samples changes to become 1.43, which would then suggest that stress levels are the same for homecare workers and personal assistants. Therefore, the evidence provided by this aspect of the analysis is tentative.

Table 14 Stress Scores from GQ12 for Workers	
Personal Assistants	**GHQ Score**
Joy	0
Sue	1
Mim	3
Liz	0
Win	2
Ian	4
Dot	0
Tom	4
Total	**14**
	Average Score= 1.75
Home Care Workers	
Jane	0
Lucy	11
Jess	7
Jill	0
June	0
Tess	1
Anne	0
Beth	2
Total	**21**
	Average Score= 2.63

Relating the findings with other research using the GHQ12 is also difficult as there are no UK studies that investigate stress levels in personal assistants and few that focus on homecare workers. Two studies that did use the GHQ12 are by Balloch et al (1998), which reported an average score for homecare workers working with older people of 1.33 and McLean (1999) with an average score for homecare workers of 1.71. Both of these are lower than

the average scores of either personal assistants or homecare workers in my study. Previous literature (see chapter 3) has indicated that stress at work is increasing and this may account for the lower reported stress levels in these earlier studies, or it may reflect the problems of using average scores with a small sample.

When the results from the two questionnaires are combined (see Table 15 below) the findings tentatively suggest that as a group, the personal assistants in the study on average reported lower stress levels and higher job satisfaction, than the group of homecare workers. Previous research has linked high stress levels with low satisfaction and for two homecare workers (Lucy, Jess) this appears to be the case, with a further four homecare workers displaying the opposite of this by having low stress and high satisfaction (Jane, June, Tess, Anne). This also corresponds with four of the personal assistants, who have low stress and high satisfaction (Joy, Sue, Liz, Dot), although three of the personal assistants have both high stress combined with high job satisfaction (Mim, Ian, Tom).

Table 15	Combined Job Satisfaction and Stress Scores (Workers)	
Personal Assistants	**Job Satisfaction Score**	**Stress Score**
Joy	85	0
Sue	76	1
Mim	91	3
Liz	79	0
Win	68	2
Ian	89	4
Dot	77	0
Tom	82	4
Home Care Workers		
Jane	77	0
Lucy	33	11
Jess	65	7
Jill	65	0
June	88	0
Tess	72	1
Anne	69	0
Beth	83	2

Turning now to disabled respondents, Table 16 details their results for the GHQ12, and shows that direct payment users had an average score of 5.1 and homecare users 3.5, suggesting that homecare users, as a group, were less stressed than direct employers. I was unable to find another study either of homecare or direct payment users that utilised the GHQ12, to act as a comparison, and so used the British Household Panel Survey (BHPS). The BHPS is an annual survey of a nationally representative sample of households in England, Wales and Scotland. In this survey the results of the GHQ12 are converted to percentage figures with 45.8% of disabled adults scoring 3 or higher (www.iser.essex.ac.uk/bhps, Weich et al 1998), which is much lower than my study where 62.5% of homecare users and 75% of disabled employers scored 3 or over. This could indicate that disabled respondents were more stressed than the national average, or that the

definition of disability used in the BHPS (people with a limiting long standing illness) encompasses people with lower levels of impairment than in my study, as disability is associated with higher scores (www.iser.essex.ac.uk/bhps). It may also reflect the inaccuracy of using percentages with a small sample (Bryman 2001).

Table 16 Stress Scores from GQ12 for Disabled Adults	
Direct Payment Users	GHQ Score
Linda	0
Freda	2
Harry	3
Karen	4
Gemma	7
James	8
Wanda	8
Peter	10
Total	41
	Average Score= 5.1
Home Care Users	
Daniel	0
Mathew	0
Jeanne	1
Trevor	3
Jackie	3
Sandra	3
Brenda	8
Rachel	10
Total	28
	Average Score= 3.5

In Table 17 I have aggregated the GHQ12 results for all respondents. Disabled adults and their workers have been placed together in the same row in the table, to enable an examination of whether their stress levels correspond. This shows that in three of the direct employment relationships (Gemma/Mim, Peter/Ian, Harry/Tom) and one homecare relationship

(Sandra/Lucy) both workers and users have high levels of stress. In the majority of the relationships though the scores do not correspond, so that one person can be stressed, whilst the other is not (for example Brenda/Jane, Rachel/Jill, James/Dot). This table also shows that for the groups as a whole, there is a greater disparity of levels of stress between direct employers and their personal assistants (total scores 41 and 14 respectively), than homecare users and workers (28 and 21 respectively).

Table 17		Combined Stress Scores (All Respondents)	
Direct Payment Users	**GHQ Score**	**Personal Assistants**	**GHQ Score**
Karen	4	Joy	0
Linda	0	Sue	1
Gemma	7	Mim	3
Freda	2	Liz	0
Wanda	8	Win	2
Peter	10	Ian	4
James	8	Dot	0
Harry	3	Tom	4
Total	**41**	**Total**	**14**
Home Care Users		**Home Care Workers**	
Brenda	8	Jane	0
Sandra	3	Lucy	11
Mathew	0	Jess	7
Rachel	10	Jill	0
Jeanne	1	June	0
Jackie	3	Tess	1
Daniel	0	Anne	0
Trevor	3	Beth	2
Total	**28**	**Total**	**21**

The findings from the questionnaires are intriguing. Existing literature detailed in chapter 3 argues that the emotional nature of carework can cause workers to become stressed. Therefore we could expect that care relationships that are close, would be more likely to be stressful for workers, because of their emotional involvement with users. We saw that in chapter 5 that close

relationships and relaxed boundaries were much more a feature in the direct employment relationship, yet the data from the questionnaires show it was personal assistants who as a group, appeared to report lower stress levels and higher job satisfaction than homecare workers. For disabled adults too the literature describes direct employers as having greater levels of satisfaction with their support than with traditional services, but in my study disabled adults had higher scores in the GHQ12 questionnaire tentatively suggesting higher levels of stress than homecare users.

We need to examine this further, and in the following sections I use these results together with the interview data to gain a greater understanding of the relationships. I start by considering and comparing the reasons workers gave for choosing their job.

7.4. The Choice of Job

The Audit Commission (2002) argues that people choose their jobs for a variety of reasons influenced by motivation, individual behaviours and market forces. When choosing a job people consider how well it matches their expectations, their skills, how well it is rewarded and the image and status the job brings in comparison with other options available. Employment is also influenced by local factors, such as the availability of suitable housing, levels of employment and the type of work available (Twigg 2000). For instance, if there is an abundance of competing employment in supermarkets then fewer people may choose to become care workers.

Studies have found that many people are attracted to homecare work because of the flexible nature of the job (Aylott and Mackie 2001) and the

chance to care for people whilst making a positive difference to their lives (TOPSS 2003). In a study in Staffordshire, of both local authority and independent sector homecare workers, ninety per cent of the respondents said the best part of the work was the satisfying nature of contact with service users (Henwood and Waddington 2002). As these studies and others in chapter 3 have shown, it appears to be the intrinsic relationship elements of the role that encourage people to choose carework and from which homecare workers gain greatest satisfaction. For personal assistants I could not find any previous research that provides evidence of the reasons they give for choosing their job, although Ungerson (1999) speculates that direct employment would attract people who want to work in an intense and intimate way for just one person.

To look at this I asked workers during the interview why they chose their job. All of the homecare workers talked about the intrinsic aspects of their work in terms of helping people, as reasons for choosing and doing the job:

Jane: I like going into people in their own home and assisting them in their own homes. I like that friendship that you build up between the two of you. You don't really have that same thing in care homes and it is more varied work as well (HCW).

Tess: Well it is the people. You know, being able to go in and make difference to their lives (HCW).

Personal assistants also talked in terms of wanting to help their employer, but there was a crucial difference in that it was the prior relationship with their employer that made almost all of the personal assistants decide to take the

job. In both chapters 5 and 6 I discussed the pre-existing relationship between most direct employers and their personal assistants, where six personal assistants knew their employer before working for her or him. Sue worked as a homecare worker and provided support in this capacity prior to her employment as a personal assistant, and Dot was the aunt of the direct payment user who employed her. Tom, Joy, Liz and Ian were friends with their employer and three of them were already providing some unpaid informal support:

Ian: I was just helping him out. We'd become friends and it was round about, when he really started needing help Yeah, and that's how it all started and then two social workers came out to the house and interviewed him and they decided he needed 24/7 and that's really how all that direct payments thing started. So they said he's got to have cover all the time so I said well that means I'll have to move in cause I had my own place (PA).

Other studies report that many personal assistants are relatives, neighbours or friends with their employer before becoming their employee (Lakey 1994; Dawson 2000; Kestenbaum 2001; Flynn 2005), but as I suggested in chapter 6 the significance of this has not previously been noted in terms of the power it gave to direct employers to determine the type of relationship that developed. My research also indicates that the pre-existing relationship was of great importance to personal assistants, as for most it was the reason they decided to do the job, and this may be a major cause of their job satisfaction.

During the interview I asked all the workers about their previous job history and formal qualifications. The results of this are detailed in Table 18. This shows that personal assistants had less experience and far fewer formal

qualifications relating to carework than homecare workers. Only one personal assistant (Sue) had a qualification in social care, and she obtained this through her part time employment as a homecare worker with Staffordshire social services. Conversely only three homecare workers were unqualified, with five homecare workers either having an NVQ level 2 in social care or working towards this award. In many ways these results are not surprising, as most personal assistants chose their job, because of their existing relationship with their employer, and so it was this that qualified them for the job rather than an NVQ. These data correspond with other research, which found that many direct payment users preferred to employ untrained and unqualified workers (Morris 1993; Clark et al 2004; Stainton and Boyce 2004).

Research in the US, which compared direct employees with agency care workers, reported that directly employed workers had less formal training provided (Benjamin and Matthias 2004; Dale et al 2005). In the UK the Care Standards Act (2000) requires organisations providing personal care, such as local authorities to register with the Social Care Commission and to meet minimum care standards. At the time my study was undertaken, one of these standards required at least fifty per cent of homecare staff delivering personal care to complete the NVQ in Care level 2 as a minimum qualification (DoH 2002a Standard 20.2). Direct payment users are exempt from this legislation, and at the time of writing no funds were made available by Staffordshire social services for employers to train their personal assistants to NVQ standards.

Table 18	Work and Qualifications	
Personal Assistants	**Previous Work**	**Qualifications Obtained**
Joy	Cleaner, Care worker in residential home	No Formal Care Qualification
Sue	Homecare worker for social services	NVQ level 2 in Social Care GNVQ Health and Social Care
Mim	Sales demonstrator, Support worker for people with learning disabilities	No Formal Care Qualification
Liz	Shop worker	No Formal Care Qualification
Win	Store detective, civilian in police force	No Formal Care Qualification
Ian	Day center support worker	No Formal Care Qualification
Dot	Cook	No Formal Care Qualification
Tom	University student, shop worker, factory worker	No Formal Care Qualification
Home Care Workers		
Jane	Care worker in residential home	NVQ level 2 in Social Care
Lucy	Post office worker, hospital support worker	No Formal Care Qualification
Jess	School dinner supervisor, cleaner, childminder	NVQ level 2 in Social Care
Jill	Care worker in residential home, chef	No Formal Care Qualification
June	Care worker in residential home, pottery worker	NVQ level 2 in Social Care
Tess	Cleaner, school dinner supervisor	NVQ level 2 in Social Care- in progress
Anne	Care worker in residential home, bakery worker	No Formal Care Qualification
Beth	Shop worker, factory worker	NVQ level 2 in Social Care- in progress

The gender of workers may have an impact on their choice of work. Whilst many men undertake informal care, and there are 2.5 million male carers in the UK (Census 2001), most informal and paid support is undertaken by working class women (Mathew 2000; Twigg 2000). The tasks and qualities of carework are generally those considered as belonging to women, and it is thus a gendered occupation (Twigg 2000, 2004). There is a stigma for men in doing women's work, and this can be problematic for men to overcome (Williams 2001). This was apparent for one of the two male personal assistants in my study. Tom was a full time university student working as a personal assistant for Harry also a student at the same university. Tom said he took the job because he wanted to help his friend and needed part time work whilst at university. Tom clearly did not see care work as his chosen career when his degree was completed, although the other male personal assistant (Ian) had been a support worker in his previous job.

In the study both homecare workers and personal assistants valued the intrinsic element to their work of helping someone, but it was the existing relationship with their employer that influenced the choice of job for most personal assistants. All of the workers lacked relevant qualifications when they took their present job, but many of the homecare workers were able to achieve their NVQ level 2 via social services, whilst personal assistants were not. This inability to gain formal qualifications while at work is likely to have considerable implications for direct employees in terms of reducing their options should they wish to seek alternative employment. This in turn could reduce their autonomy and power in the relationship. The pre-existing bond between personal assistants and their employers could have contributed to

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the formation of a relationship that was more satisfying, although we should not forget that this also has the potential to cause problems in the relationship. The results of the questionnaires in the study provide tentative evidence that personal assistants were more satisfied at work than homecare workers, and in the following section I explore this aspect in more detail.

7.5 Satisfaction at Work

To discover homecare workers' and personal assistants' views I asked them during the interview to tell me about the things they liked best about their job and the things that gave them the most satisfaction. Personal assistants in the study gave responses that mainly referred to the intrinsic elements of their work. Two (Ian, Sue) related it to the satisfaction of providing support to their employer:

Ian: What I like best about the job is when you see the person happy and not so ill and you think yeah it has all been worthwhile (PA).

Another two personal assistants talked in terms of liking the variety of work involved:

Joy: Well because Karen [DP User] is here as well like you know as well I take her out shopping and there's something new every day. You know like. It gives a bit more to the job. Before when you went to clean other people's houses you never see them. Like you know when Karen's here it's different everyday. Before it's the same thing everyday. It was like a routine (PA).

Other personal assistants gave differing features that they liked best. For one it was the hours worked which then gave him free time with his family (Tom), for a previously retired personal assistant (Win) it provided motivation to get

up in the morning, whilst another (Dot) found the cleaning satisfying. One female personal assistant (Mim) said she liked the work, because it was 'natural and relaxing' and this may relate to the similarity of the work with that performed by women in their caring roles as housewives and mothers (Warren 1990). Many of the personal assistants talked about how much they enjoyed their job, and how well it suited both them and their employer. In the direct payment relationship the notion of *it suits us both* came to mind:

Joy: Because I like doing what I do. I do enjoy what I'm doing. It suits me it suits my kids it suits her and it suits her kids. And as I say I wouldn't want to be stuck in an office all day (PA)

Tom: Well Harry [DP User] needed a carer and I needed a job so we both got what we wanted and we both enjoy it (PA).

Mim:.....it is a really comfortable job, hence the fact that I've been here just over five years and we get on really well (PA).

One personal assistant even explained that it wasn't like being at work:

Joy: No its, I don't class it, it as a job because I forget, I'm just here. If I didn't come round she'd miss me. That's what I always say [laughs]. No it's not like being at work (PA).

In chapter 6 I argued that direct employers had greater ability to reciprocate in the relationship, because of their greater power in what they allowed their workers to do than homecare users. A number of the personal assistants talked about things they did in working time that they would be unable to do if working in 'traditional employment', such as Joy who went swimming with her employer whilst she was at work. The blurred boundaries of the relationship,

which enabled these 'perks', appeared to be contributing to personal assistants enjoyment and satisfaction with their work.

Homecare workers also talked about being satisfied by the intrinsic elements of the work. Two homecare workers (Anne, Jill) said it was the variety of meeting lots of different people they liked best about the job, whilst the other six expressed satisfaction with helping people, forming relationships and being able to make a difference:

Beth: The satisfaction knowing that I've been able to do something for him that's helped him. Them things, them little things that he can't do, I mean I know we go in to do personal care and cook his meals but the things that he can't do which we take for granted, them sort of things are satisfying when you know you can do them for him (HCW)

In chapter 2 I discussed how in recent years homecare work has changed to become more targeted and task-based, with workers having little time to spend with homecare users to build relationships. During the interview I asked all the workers for details of the hours of support they provided to users in the study, and how many other workers were involved. These details are listed in chapter 5 Tables 10 and 11. The results show that homecare workers provided support to many different users, and had much less contact time with them, than personal assistants had with their employers. I discussed these results in chapter 5 and suggested that this method of working resulted in fewer close bonds developing in the homecare relationship than in the direct employment relationship. It is not surprising that homecare workers in my study expressed lower levels of job satisfaction, as it is the intrinsic relationship elements of the work that they generally valued, yet the way they

had to work means they had less time to form close and satisfying relationships.

7.6 Stress and Dissatisfaction

To look at areas of stress and dissatisfaction I asked all respondents if there was anything in the relationship (or work) that made them stressed or dissatisfied. These are direct questions and in chapter 4 I discussed the use of direct or leading questions in research, because the way a question is asked can influence the responses made. I identified the usefulness of direct questioning in that it can enhance the data by obtaining essential information (Kvale 1996), but on the other hand it could mean that respondents in my study defined situations, which they may otherwise not have done, as stressful or dissatisfying. However, a number of respondents mentioned stress before I introduced it into the interview, and as Forbat (2002) argues the term stress is in common use, so people will often make the link between their experience and stressful situations.

Using word searches of transcripts can provide a check of the data. Accordingly to look at the language used by workers in connection with stress, I conducted a word search of the transcripts using SR NVivo (N6), for words such as: pressure, worry, anxiety, concern, hassle and stressful. The results of this are reported in Appendix 22 and show that homecare workers used words associated with stress slightly more than personal assistants. Ian, Tom and Mim whose scores in the stress questionnaire (GHQ12) indicated they were the most stressed of the personal assistants used the words more than any of the other personal assistants. However, the homecare workers who scored highest in the GHQ12 stress questionnaire (Lucy, Jess), did not use

the words as much as some of the other homecare workers with lower scores. This suggests there are possible limitations to the questionnaires and also confirms the importance of using more than one method and cross checking the data for reliability.

When asked in the interview about stress four of the personal assistants (Joy, Dot, Sue and Liz) said there was nothing about their work or the relationship that made them feel stressed. Both Joy and Sue drew parallels with other jobs they have done (cleaning, homecare work for an agency), to say that these jobs were more stressful. All of these four personal assistants used words associated with stress very infrequently or not al all. Their responses also corresponded exactly with the results of the GHQ12 questionnaire as they scored the lowest scores of all the personal assistants (a low score indicating low stress levels).

Another personal assistant (Mim) said that an area of stress for her was that her husband did not feel she should be so involved with her work, particularly when she had to cover for other personal assistants in an emergency. This relates to difficulties in setting boundaries in the relationship discussed in chapter 5. Mim did go on to say however that she was more relaxed in her employer's home than when she is in her own home, which infers that it may be her life at home with her husband which was stressful rather than the working relationship with her employer:

Mim: It is very easy, so natural, so comfortable. In fact when I come to Gemma's [DP User] I actually de-stress from home because there is so much going on at home, there is always the telephone and the post I have to do and

meals to sort out. It is lovely to come here because I can just totally relax (PA).

One personal assistant (Win) said she felt stressed when her salary cheque was 'bounced' by her employer's bank. She did not feel able to discuss this with her employer, and so mentioned it to her employer's daughter in law and the situation was rectified. The two personal assistants who scored highest on the GHQ12 stress questionnaire were the two male personal assistants (Tom and Ian). Tom said he felt stressed because he had so little time to himself after caring for his child and supporting his employer. In chapter 5 we saw that Tom was providing many hours of unpaid work for his employer. Meanwhile Ian talked about the stress of having to watch his employer in pain 24 hours a day, and that as a live-in worker he was unable to get away from this. He said he was stressed and felt he had to hide this from his employer. For Ian the worst part of the job was the fear of his employer dying:

Ian: The worse part of the job for me is the fear of the person dying, it is very panicky...... What I hate the most about the job is having to sit and watch someone in agony 24 hours a day, 7 days a week because even though I can't feel the pain, believe it or not mentally it is just as bad. It is like you having to sit and watch someone in agony all the time and there's nothing you can do about it, absolutely nothing you can do about it, other than provide the drugs and all the things you're supposed to do. (PA)

These findings reflect a study in the US where a small number of directly employed care workers reported greater 'emotional strain' than workers employed by an agency (Dale et al 2005). It also highlights the lack of formal emotional support provided for personal assistants and the need for this to be

available (this will be discussed further in the next section). Ian also talked about his concern about what his employer's death would mean for his employment and this demonstrates the precarious position of live-in personal assistants. Should Ian's employer die he could be left without a job or a home:

Ian: I am a little bit hazed with everything, I don't think that's because I've got a problem, I think anyone would be like this given the same situation and I of course have been worried. I shouldn't of said this but I said to him the other day, I said you know, if anything did happen to you with this, which is at the end of the day there is a good possibility, where do I stand with my job and all the rest of it. Now do they [social service] just cut my wages off the first day, I mean there is some people saying they have to pay you for six months, someone else says three months. Deep down in my heart and my mind, because of the trouble we had with Stafford [social services], I know what they will do, they will cut it all off and maybe sort it out later on - high and dry with no job. So that has been playing in the back of my mind (PA).

Four of the homecare workers (Beth, Jane, Anne, Jess) also talked about the emotional element of the work and said that it was seeing people who were ill and in pain that they found the worst part of their jobs:

Beth: The worst thing is watching when people are in pain and its not nice when you go in and they are in a lot of pain. You try and cheer them up but it is a bit daunting really (HCW)

Jess: Seeing people who are very poorly. I say that because I went into a man who'd got Parkinson's, then my mum was diagnosed with Parkinson's and when I went in to the man I saw just what was going to happen to my mum.

Jess also told me that her husband had died eighteen months prior to our interview, and this may have contributed to her high levels of stress.

The close family-type relationships, found in the direct employment sample, are likely to have a greater emotional content than the more professional involvement of homecare workers. Tables 10 and 11 in chapter 5 show that most of the personal assistants in the study (Ian, Liz, Mim, Tom, Joy) described their relationship with their employer as 'like family' or 'almost like family', whilst two considered the relationship to be friendly (Dot, Win) and one as friendly and professional (Sue). In contrast most homecare workers said that the relationship with users was a purely professional working relationship, with none describing it in family terms.

When these findings are considered together with the results of the GHQ12 stress and job satisfaction questionnaires it can be seen that the five personal assistants (Ian, Liz, Mim, Tom, Joy) who described their relationship in family terms scored higher on the job satisfaction scale than the other personal assistants and all except one of the homecare workers. However three of these personal assistants (Mim, Tom, Ian) also scored higher on the GHQ12 than the other personal assistants, so indicating high levels of stress. It appears then that *becoming part of the family* with its associated emotional involvement brings workers more satisfaction, which is unsurprising, as it is the relationship aspect that workers say they value, but it can also bring with it greater stress. Another study had similar findings in that directly employed workers were more satisfied with the relationship aspect of the relationship, but were worried about their employer when they were not with her or him, whilst in contrast agency workers were not (Benjamin and Matthias 2004).

In both chapters 5 and 6 I discussed the sharing of worries and concerns between disabled adults and their workers, identifying that most of the personal assistants (Mim, Tom, Joy, Dot and Sue) were sharing their worries with their employer, whilst none of the homecare workers were doing this. I argued that the sharing of concerns between personal assistants is an important indicator of whether a relationship is reciprocal. A close caring reciprocal relationship where concerns are shared may also help to make personal assistants more satisfied in their job.

An area of dissatisfaction for many homecare workers in the study was rushing from one user to another. Five homecare workers (Jill, Lucy, Jane, Anne, Tess) said that they were frequently rushed in their work.

Jill: You have one of those days when everything goes wrong, I'd got this huge list of people to see but I couldn't get to grips with the times that you were going to people's houses so they'd written them down for me and I'd got three people to see at the same time. That was really stressing me out, I was getting so worked up about it thinking oh god, oh god (HCW).

Jane: The rushing from one job to another, I don't like it. You are looking at the clock, it isn't that short a time you are there but I'd rather have more time than less so you are not rushing. There is time to talk to them, when you've done what you've got to do it is nice to just have a little chat, before or after, even when you go in more than after. So you can feel a bit more comfortable with each other (HCW).

One of the homecare workers (Lucy), who described how she felt under pressure to hurry from one user to another, also said that she missed the

cleaning element that was present when she started the job as a home-help twenty-two years ago:

Lucy: Well I started about twenty-two years ago and I came on as a home help and I was a home help, which I really enjoyed because I enjoyed the cleaning. Then we went on the new contracts and became care workers... there was no training. On the Monday you were cleaning, on the Tuesday you were nursing more or less. It was quite a change cause we didn't have anybody showing us anything really. I miss it really, the cleaning part (HCW).

Earlier and also in chapter 2 I explained how the nature of homecare has changed following the community care reforms of the 1990's. Homecare work has moved away from a predominantly cleaning role to the provision of personal support with some low level nursing care (Leece 2003b). Lucy's scores on the stress and job satisfaction scales indicate she was the most highly stressed and least satisfied of all the workers in the study. It may be that for Lucy the work has changed, so that it no longer meets her expectations and as such is less satisfying and more stressful.

In comparison none of the personal assistants in my study talked about rushing from user to user since they all worked for just one disabled adult. This does not mean however that personal assistants were unaffected by work intensification such as working long hours or doing unpaid work. I identified in chapter 5 that all except one of the personal assistants were undertaking some work for their employer that was unpaid, and I suggest it is significant that two of the personal assistants who were doing the most unpaid work (Ian, Tom) scored highest of the all the direct employees on the stress questionnaire. Moreover the only homecare worker (Lucy) to be undertaking

unpaid work scored the highest stress score out of all the workers. Performing extra unpaid tasks appears thus to be associated with higher levels of stress. This provides further tentative evidence that unpaid work in the support relationship is generally in the interests of users rather than workers.

Four of the homecare workers (Beth, Jess, June, Tess) said they felt stressed when they initially provided support to homecare users, although this resolved itself as they got to know them:

JL: Is there anything in the relationship or your work with Trevor [HC User] that makes you feel stressful?

Beth: [laughs] He stresses me out all the time but in a nice way. But no I can cope with Trevor now quite well. I used to get quite frightened when I first went in when I didn't know him very well but again it is on that level of getting to know them (HCW).

JL: What did you get frightened about?

Beth: Well just him really, he can be quite daunting when he wants. Like when I used to make his meals at night he used to sit in the kitchen and watch me. I mean it is quite scary when you're cooking something that you don't normally cook yourself. I am thinking oh am I doing this right and it is like getting it how he wants.

Jess: Well when I first went in to Mathew's [HC User], he was a school teacher and that sort of thing came over do you know what I mean, if he wasn't comfortable or he was in pain... he'd say stop and of course you'd jump. Then when I got put there permanent I thought I'm going to dread this, and when I'd been going for a while I sort of got to know he was OK and I

could see when the pain came and it wasn't just with me he was doing that, it was with everybody. I said to Mathew I used to feel so inadequate when I came and he said I'm dreadfully sorry I made you feel that way.

For some homecare workers meeting new users was clearly a cause of stress and unlike personal assistants they would meet many different users in the course of their work, although two of the homecare workers (Anne, Jill) described meeting lots of people as the best part of job.

In chapter 6 I identified that most of the homecare workers in the study said that they felt like servants at times in the support relationship, whilst the majority of personal assistants did not. Homecare workers also talked about themselves using language, which inferred they believed their job to be of low status, whilst only the personal assistant who works as for social services used this language. I would suggest that feeling like a servant and doing work, which they consider to be of low status was likely to increase homecare workers' dissatisfaction with their job and may contribute towards their stress.

Turning to disabled adults, five direct employers (Karen, Linda, Freda, Wanda and Harry) said there was nothing about the support relationship that made them feel stressed, although three of them scored 3 or over in the stress questionnaire, with Wanda scoring 8 which suggests she was very stressed. Peter scored 10 and had the highest stress score of all the direct employers. Both Wanda and Peter were told they had cancer prior to my study taking place. Wanda was diagnosed six months before and Peter just as I was due to meet him. He cancelled our interview initially, but then said he would still like to take part. It seems highly probable that their illnesses caused much of Wanda and Peter's stress, and this shows how the interaction with life events

such as illness makes the measurement of stress challenging. It also demonstrates again the benefits of using a multi method approach to cross check data.

Peter did talk about an aspect of his relationship with Ian that caused him to feel stressed: his fear that Ian may not be able to continue providing support:

Peter: I get stressed if Ian [PA] is not up to par or if he is ill or there is a possibility of him becoming ill. That's stressful (DP User).

JL: Why is that stressful?

Peter: Well it is the loss of service to me I've reached the stage now where I wouldn't want other people providing that service even in the short term because I've got lazy and it's a bit like being married to somebody, you get lazy and you don't try hard any more and the thought of starting all over again with somebody new is what keeps most couples together, the fear of the unfamiliar. I like things to be done in a certain way that are my peculiarities, food is the obvious thing. There is an unspoken understanding between us that I've never been provided with a bad dinner that I can't eat. That takes a long time and it takes a lot of explaining and I wouldn't want to dedicate that much energy at the moment, if you like retraining somebody, so that's a stressful thing.

Peter's concern reveals the vulnerability of direct employers to the potential loss of their personal assistant, in that they then need to recruit and train another worker. In chapter 6 I discussed this issue and the consequent incentive for direct employees to make sure their worker is satisfied at work, so that they will not want to leave their job. Having to take workers' wishes

into account in this way is likely to temper direct employers ability to ensure their interests take precedence in the relationship. Two other direct payment users experienced stress over employment issues. Gemma who said her previous personal assistant: 'Walked out one night without being paid and the next day she brought her boyfriend down and he almost threatened me, she told him a pack of lies about the situation. It was so stressful', and James who wanted to dismiss his personal assistant, but didn't feel he could, because she is his aunt. We saw in chapter 5 that employing a family member can be problematic in terms of separating roles and setting boundaries, and James' high score of 8 in the stress questionnaire perhaps reflected this:

James: Well with a family member you tend to put up with it more if it was somebody else you employed, you wouldn't put up with it, as soon as things were happening you would say something there and then. It is easier to tell an outsider than it is a family member because you don't want to cause them upset obviously and they are at the end of the day still a family member. Well with somebody outside you haven't got all them ties. (DP User).

JL: If Dot wasn't family what do you think would have happened?

James: If she wasn't my aunt I would have sacked her by now, most definitely.

In the non-direct employment sample for six homecare users (Trevor, Jackie, Jeanne, Rachel, Sandra, Brenda) it was the lack of control over who came to provide their support that made them stressed:

Jackie: it's stressful not knowing who will come and how they will behave. If they send in new ones [HCW's] that I don't know then I worry in case they do

things that I wont like. You get used to it one way then someone else comes and does it different (HC User)

Brenda explained how she made a complaint to social services about one of her workers and now felt stressed about who came, as some workers were 'paying her back for the complaint'. While Rachel was afraid of one of the homecare workers and dreaded her coming: Both Brenda and Rachel had high scores on the stress questionnaire:

Rachel :Well I do feel really stressed if I think they are going to send a certain lady to me. I do panic...it puts the fear of god into me if one of my carers says well I'm off this weekend and you might have such a body coming. Then the night before I think oh god no what shall I do, shall I put a note on the door cause I don't want her coming again (HC User)

The data reported in this section is dense and reflects the complex nature of the support relationship. For half of the personal assistants in my study there was nothing about their work that made them stressed and this corresponded with their results in the GHQ12 questionnaire. Having a close family-like relationship was associated with high satisfaction for the majority of the personal assistants, but for three of them, including the two men, this was a doubled-edged sword, as it also brought high levels of stress. This stress was linked to difficulties in boundary setting, long hours of unpaid work and the emotional element of the job. In contrast the majority of homecare workers were stressed and dissatisfied by having to hurry from one user to another without the time to develop the close relationships that they found satisfying.

Additionally, for disabled adults the study shows that homecare users preferred continuity of workers, and provides empirical evidence that the lack of control over this aspect of their support can cause reported stress. It suggests that direct employer's power in the relationship was likely to be lessened by their need to ensure their personal assistant was happy at work, to avoid them seeking another job. The findings again demonstrated that where a direct employer and personal assistant were related there were additional difficulties. My study tentatively suggests that direct employment can increase disabled adults levels of stress.

In the next section I examine workers experiences of the extrinsic elements of job satisfaction.

7.7 Extrinsic Job Satisfaction: the Pay and Conditions of Employment-

The changes in social care brought about by the community care reforms also resulted in local authorities reducing the amount of care provided in-house and instead buying more care from the independent sector (Means 2002). In chapter 3 I discussed how this shift in care provision resulted in a move away from employment of care workers by local authorities where they have reasonable pay, pension provision and union representation to casualised low paid work in the independent sector (Eborall and Gameson 2001). It has been suggested in the literature (National Union Research 2000; Witcher et al 2000) that the employment of personal assistants is a further continuation of this trend and in this section I consider these aspects.

Poor pay and conditions of employment for personal assistants have been reported in previous studies (Ungerson 1997a; Pearson 2001; Clark et al

2004), with some lacking access to a pension scheme (Yeandle 2003), many

not having a contract of employment even though this is a legal requirement

(McMullen 2003; Flynn 2005), and some not receiving holiday and sickness

pay (Rivas 2003). Yet these are important extrinsic elements of a job that

affects satisfaction for employees (Rose 2004). To examine this and to enable

a comparison between direct and non-direct employment I asked homecare

workers and personal assistants to complete a questionnaire after their

interview had finished, detailing their pay and conditions of employment (see

Appendix 16). The results of this are reproduced in Table 19 and 20 below.

Table 19	Job Conditions					
	Numbers of Personal Assistants			Numbers of Homecare Workers		
	Yes	No	Don't know	Yes	No	Don't know
Sick Pay	2	4	2	8		
Holiday Pay	7	1		8		
Access to Pension Scheme		8		8		
Member of a Union		8		5		
Compassion ate Leave	3	2	3	8		
Unsociable Hours Payment	2	6		8		
Guaranteed Hours	7	1		8		
Paid Travelling Time	2	6		8		

The differences between the pay and conditions of the two groups of workers

were striking. All the homecare workers received sick and holiday pay, access

to a pension scheme, compassionate leave, unsociable hours payment, guaranteed hours, paid traveling time and five were members of a trade union. In contrast half of the personal assistants said they did not receive sick pay, one had no holiday pay, two did not get compassionate leave and six were not paid if they worked unsociable hours or for travelling time. Two personal assistants were unaware whether they received sick pay or not. Furthermore none had access to a pension scheme or the protection of a trade union. During the interview one of the personal assistants (Mim) said that she went to work even when she was ill, because she could not let her employer down. Other personal assistants who either did not receive sick pay or did not know whether they were entitled (5 people) could also have been going to work when they were ill:

Mim: Oh no, no, you could have a day off there [in a previous job] without a problem if you didn't feel too clever but if you've got a cold here, you can't let Gemma (DP User) down, you don't want to come, you don't want to give her a cold, but what alternative have you got. I have seen what problems it causes when someone doesn't turn in, it is an absolute nightmare (PA)

JL: So if you are ill, will you come to work?

Mim: Yes.

In chapter 2 I explained that an organisation representing disabled people, called the Rowan, had a contract with Staffordshire social services to provide a support service to direct payment users. This involves the Rowan giving information to users about the direct payment scheme, explaining employment law, helping users to recruit personal assistants, operating a

payroll service for users and so forth. At the time the study took place all disabled adults considering using direct payments were referred to the Rowan for their support and help with recruitment of staff. All of the personal assistants in this research were entitled to both holiday and sickness pay, and the Rowan should have advised employers that the hourly rate received from social services to employ a personal assistant included an amount for sickness and holiday pay. It may be that the Rowan did not explain this to all the employers in the study, or that they had not understood correctly. Another interpretation is that employers chose not to tell their employees of their entitlement, perhaps to avoid disruption to their support provision. This could be another instance of employers having the power to ensure their concerns took precedence over the interests of workers.

In Table 20 I detail the hourly rate of pay received by each of the workers. The personal assistant providing live-in support (Ian) gave a weekly figure of £400 per week. This has been divided by the hours of support he provided each week (144) to give an hourly rate of £2.77, which was well below the national minimum wage which was £4.85 at the time I conducted the fieldwork (www.dti.gov.uk). The results show that the average hourly rate for homecare workers of £6.14 was much higher than the average for personal assistants of £5.16. When the live-in rate is removed the hourly rate for personal assistants increases to £5.50, but was still considerably lower than the homecare rate. The pay difference meant that a personal assistant working full time (37 hours per week) would have received an average gross salary of £190.92 per week, as opposed to £227.18 per week for a homecare worker.

Table 20	Rates of Pay
	Hourly Rate of Pay (Mon-Fri)
Personal Assistants	
Joy	£5.00
Liz	£6.50
Sue	£5.50
Dot	£5.50
Tom	£6.00
Mim	£5.00
Ian	(live in support night and day) £2.77
Win	£5.00
Average hourly rate	**(£5.50 if Ian is removed) £5.16**
Home Care Workers	
June	£6.06
Jill	£6.06
Jane	£6.06
Jess	£6.06
Tess	£6.06
Lucy	£6.25
Beth	£6.06
Anne	£6.50
Average hourly rate	**£6.14**

An examination of the results of the job satisfaction questionnaire relating to the specific question about pay (Appendix 7, question 7) shows that five personal assistants (Joy, Ian, Dot, Tom, Mim) were either extremely satisfied or very satisfied with their rate of pay, whilst the other three were moderately satisfied. For Joy, Ian and Tom this may reflect that they were being paid for work they had previously done for free. On the other hand it may be a further indication of the importance workers attach to the friendship element of their job, in that the satisfaction of the close relationship outweighed their poor pay and conditions. It is significant that four of these personal assistants (Tom, Dot, Joy and Ian) had a prior relationship with their employer. Alternatively, it may be a sign of personal assistants' knowledge that their options of alternative better paid employment were low given their dearth of formal qualifications (Table 18). The lack of trade union support is likely to have

placed personal assistants in a weaker employment position than homecare workers. Increases in their rate of pay would have to be negotiated directly with their employer in contrast to county council employees, who are subject to a pay scale with automatic increments, negotiated on their behalf by a trade union (Unison).

Workers can obtain support in their work from a trade union, and they can also receive it from managers and colleagues. This support can be significant in terms of reducing stress and increasing job satisfaction (Brown et al 2001). The literature has suggested that many personal assistants do not have access to formal support systems in their employment (Glendinning et al 2000a; Askheim 2003), and to investigate this in my study I asked workers to tell me about any support they had in their job. Most of the homecare workers said they received good support from their manager, although two (Lucy, Jill) felt the support was poor. Both June and Jill said they felt isolated at work and wanted the opportunity to mix more with their colleagues, whilst Jane said she didn't want the support of colleagues, and much preferred to work on her own. One of the homecare workers explained how homecare users who are considered to be 'hard work' are 'shared' amongst homecare workers, by managers, to protect workers from becoming depressed:

June: And if a client is depressed and you are going into, we have found this and we've spoke about this with other colleagues, sometimes what we do, if there is a client who is hard work as we'd call it, a hard work one, where they are depressed, I suppose it would be like living with a depressed partner, they'd gradually bring you down with them wouldn't they? So what we tend to

do is share that client because it wouldn't be fair on a colleague to go into that client every single day (HCW).

Personal assistants on the other hand, as direct employees, did not have a manager, and thus needed to rely on their employer for direction and advice. Without exception all of the personal assistants in the study said they did not miss having a manager's support. Four personal assistants (Tom, Mim, Joy, Dot) said that if they were experiencing problems they would discuss these with their employer, whilst other personal assistants said they would use different people (employer's husband, employer's daughter in law, the Rowan). Nevertheless this lack of support could be problematic for personal assistants. We saw in the previous section that Ian was stressed, because of his employer's illness, and felt he had to hide this, rather than receiving support from his employer. Perhaps this absence of support contributed to Ian's high level of stress. There is a danger for personal assistants who have problems, which cannot be resolved with their employer, as they did not have a manager to support them or the support of a trade union to protect their interests. Personal assistants also lacked colleagues to support them, although the majority (7) said they did not miss this and saw it as a positive part of the job:

Tom: I can't say I do [miss having colleagues] no cause most jobs I worked with my colleagues have been hard to work with, I've had to leave cause I just don't get on. So at least this way I know, I was friends with Ben before I worked for him so we got along and it is just hassle free (PA).

It seems probable that most personal assistants in my study preferred not to have colleagues and managers, because their close relationship with their

employer meant they did not feel the need for further support or companionship. Indeed Makin et al (1996) suggest that having colleagues and managers can be a mixed blessing, as they can be a major source of stress. Nevertheless as I have highlighted this does pose risks for direct employees, and because many are relying on their employer for friendship, support and employment the saying 'putting all your eggs in one basket' rather comes to mind.

7.8 Conclusion

The literature has little to say about stress and job satisfaction in the direct payment relationship with studies in the UK focussing on users. In the US however there is some evidence from research that personal assistants are slightly more satisfied and a little more stressed than agency workers. The data my study provides is distinct in using two well-validated questionnaires to compare stress and job satisfaction in the non-direct and direct employment relationships, and this enables us to explore both positive and negative aspects. There is a need however to exercise caution when interpreting data from these research tools, as they have limitations, which are discussed in the following chapter.

Data from the questionnaires provide tentative evidence that personal assistants as a group, reported less stress and greater satisfaction with their work than homecare workers, and when I explored these results together with the data from the qualitative interview, a complex picture emerged. Both groups of workers valued and found satisfying the intrinsic relationship elements to their job, with homecare workers generally choosing the work, because they wanted to help people, while most personal assistants already

had an established relationship with their employer prior to being employed, and took the job to help that particular person. This prior friendship is likely to give the relationship greater significance to personal assistants and may be a cause of their greater satisfaction.

It was the intrinsic relationship elements of their job that workers enjoyed. Unsurprisingly, the closer, caring relationship with direct employers generally brought personal assistants higher levels of satisfaction than in the professional homecare relationship. The greater power of direct employers to set the boundaries of the relationship, discussed in chapter 5, enabled both disabled employers and personal assistants to create a relationship that suited them. Yet there were dangers in this for some of the personal assistants, a family-type relationship involving the undertaking of unpaid work was associated not only with greater satisfaction, but also higher levels of stress. This was a double-edged sword indeed. Furthermore there were additional difficulties for the live-in personal assistant and in the relationship where a relative was employed.

Dissatisfaction and stress for homecare workers were connected to the practice of moving between users without time to build meaningful relationships and being rushed in their work. This suggests that the new professional, impersonal role, created by the community care reforms is essentially less satisfying for workers who value the intrinsic aspects of the work. I would suggest this method of working reduces homecare workers autonomy and contributes to their feelings of being like servants and that their work lacks status.

The research provides evidence of considerable disadvantage for personal assistants in terms of their pay and conditions of employment compared with those of homecare workers. Additionally it provides some evidence that the direct employment of support workers, funded by direct payments, is continuing the trend towards a lower paid, casualised employment, started by the community care reforms. The examination of personal assistants conditions has served to emphasise their vulnerability at work, in that they lack the protection of either a trade union or managerial/colleague support and the chance to gain formal qualifications at work. This indicates the potential for employers to ensure their interests are met, as we saw by the 'confusion' about sickness pay. On the other hand, the data also suggests that employers' power in the relationship was alleviated to some extent by their need to keep their personal assistants happy and working for them.

In the next chapter I draw all the main points from my research together and discuss the findings.

Chapter 8 Discussion

This research has investigated how the direct employment of workers by disabled adults, affects the care relationship, by comparing it with support provided by a local authority homecare service. The study encompassed a wide range of literature and consistent with other research found that support relationships are enormously complex. Underlying all the findings in the research were elements of power, and the data has indicated that the way to understand the effect of direct employment is through the concept of power. Disabled adults, by their use of cash payments, become direct employers of their support workers, and it is this employer status, together with the ability to pay workers wages directly, that leads to their greater power within the relationship. In contrast to non-direct employers, direct payment users had:

- The power to choose the worker who provided their support

- The power to determine the boundaries of the relationship

- The power to set the agenda in the relationship

- The power to be more reciprocal

- The power to make their interests take precedence

- The limited power to set the terms and conditions of employment

In this chapter I have drawn together all the main threads of the study to present a coherent picture of the research. In the first section, under a number of subheadings, I discuss the findings, situating them within existing literature to show the location of the research, highlighting the contribution made by the

study to existing knowledge. This is followed by a reflection on the research process.

8.1 Discussion of the Research

In the analysis of the research data the notion of power became central to my understanding of what was happening in the relationships, and in many ways this came as no surprise, as previous literature about support relationships, highlights power as an area of great importance (Silvers 1995; Kittay 1999; Twigg 2000, 2006; Forbat 2005). In chapter 3 we saw the relevance of Foucault's analysis of power in developing an understanding of the dynamics of intimate care relationships. Foucault's work has been criticised for its lack of evidence base and human agency (Hamilton 1996; Twigg 2006), yet his ideas draw attention to the significance and all encompassing nature of power in human relations, and are pivotal for explanations of health and social care (Twigg 2006). Foucault's analysis of power has been helpful in understanding the power dynamics of the relationships in this research.

For Foucault power is all around us, it is constitutive of relationships, both in and of them, interlinked with knowledge, and operating through the practices and discourses of 'expert bodies of knowledge' (Foucault 1973, 1977, 1979; Twigg 2006:4). The notion of the pervasiveness of power, and the influence of powerful organisations is helpful in understanding the complexity of care relationships, where care givers and care receivers can both be vulnerable to the exercise of power (Twigg 2000, 2006). Existing research for example, suggests the ambiguity of the support role where workers can come to occupy powerful positions due to users' physical vulnerability, yet often undertake menial work (Aronson and Neysmith 1996; Twigg 1997, 2000, 2006;

Ungerson 2000; Forbat 2005). The findings presented in the three preceding data chapters show many aspects of the power dynamics of direct and non-direct employment, and these are discussed in the following sections.

8.1.1 The Power to Choose Workers

The power to choose the person who provides support was one of the many differences highlighted by the comparison between direct and non-direct employment. Corresponding with market theory, discussed in chapters 2 and 3, direct payment users were transformed from 'passive recipients of care into active consumers' with the power to buy their own support (Le Grand 197:152). Direct employers reported being able to recruit workers of their choice, and in the same way as other studies, (Lakey 1994; Dawson 2000; Kestenbaum 2001; Flynn 2005; Poll et al 2006) many chose to employ friends or family, some of whom were already providing unpaid support prior to employment. The literature on friendship, discussed in chapter 3, suggests that employing people with whom there is a previous friendly relationship increases the likelihood of the support relationship being close (Adams and Blieszner 1994; Adams and Allan 1998). Indeed all of the direct payment users and personal assistants in the study, who had a prior friendly relationship, described their involvement in closer terms than respondents who had not.

Not all direct employers in the study chose to employ friends or family. A direct payment user explained that one reason she employed a number of personal assistants was to ensure the relationship would be less close, and correspondingly both employer and employee described the relationship in more professional terms. This suggests that direct employers were able to

influence the nature of the relationship that developed right from the outset by their choice of employee. Other research has noted that many direct payment users employ friends and family (see above), although currently there are no statistics regarding the numbers involved, but the significance of this in terms of the power it gave employers to determine the type of relationship that developed has not previously been emphasised.

In contrast homecare users generally had no choice of worker and had to take whoever came. At times, some homecare users even reported receiving workers they had specifically asked social services not to send, and participants told of how they were afraid of certain workers. A number of homecare users said that this lack of control over who provided their support was stressful. This disempowering element of traditional homecare provision corresponds with existing research, which suggests that most users prefer to have consistency of care with the same workers helping them (Morris 1993 1997b, 1998; Henwood et al 1998; Commission for Social Care Inspection 2005b). A national study into homecare services for older people argues that while surveys often demonstrate high levels of overall satisfaction with homecare services, when more detailed interviews are conducted, a more critical picture is revealed, such as users being unhappy about the numbers of workers provided (Commission for Social Care Inspection 2006).

8.1.2 The Power to Determine the Boundaries of the Relationship

The research suggest that as well as giving direct employers the power to determine the nature of the relationship, employing their own workers, also helped them to shape the boundaries of the relationship. In chapter 3 I explored notions of boundaries in care relationships, and found that many

studies report unclear and ambiguous boundaries (Eustis and Fischer 1991; Aronson and Neysmith 1996; Karner 1998; Twigg 2000). The data in my study corresponds with this literature, with blurring of the boundaries of the relationship reported to some degree, in both types of employment.

Researchers also speculate that direct employment exacerbates this lack of clarity (Ungerson 1999, 2004; Glendinning et al 2000a, b, c). The research in this thesis adds to this literature, in that for the first time, it provides empirical evidence of the greater ambiguity of the boundaries in the direct employment situation, when compared with non-direct employment. For instance, the study provides evidence of the more varied range of work undertaken by personal assistants, such as gardening and decorating, whilst the tasks completed by homecare workers were more restrictive, mainly relating to personal care. Unlike homecare workers, many personal assistants said they were expected to cover for emergencies, and to be on-call when not working, with one employer describing his live-in personal assistant as his 'sentinel' both night and day. Personal assistants reported that they were also more likely to be undertaking significant amounts of unpaid work, in some cases this amounted to many hours of extra work each week, whilst homecare workers said they were doing only minimal amounts of unpaid work, such as posting letters. This suggests that direct employers were able to define the boundaries of the relationship to suit their needs and interests.

There was further evidence of the greater blurring of the boundaries in the direct payment relationships, in that most were reported to be much closer than those of homecare workers and users, with employers and personal assistants describing their relationships in friendlier terms, often like family. I

developed a table to show generalised differences between formal and informal care (see Table 4, Section 3.5) based on the work of Finch (1989), Ungerson (1990) and Qureshi (1990). Comparing this table with the data we can see that personal assistants were providing support similar to that provided by many family and friends. For example, they describe spending more time together, most had known each other longer and their lives were intertwined in a way that homecare workers and users were not. Similar to other research (Clark et al 2004; Ungerson 2004) the study found that some personal assistants socialised with their employer, going out together for meals and drinks, many were involved with each other's family and friends, whilst some went on holiday together. Experience of time differed depending on whether respondents belonged to the direct payment or homecare sample. In the direct employment situation people were able to spend far greater amounts of time together, with some personal assistants even spending time *just being there,* whilst in the homecare relationships time appears to be almost rationed.

Ungerson (1999, 2004) suggests that treating care as a commodity is leading to the distinctions between formal and informal care breaking down, and the data from my research appears to provide some tentative evidence of this. The research helps to extend this literature by providing empirical data that the direct employment relationships have greater resemblance to the characteristic of informal support, than do the home care relationships. This suggests that direct employment may be moving the provision of support towards a model based on informal care.

In chapter 3 I discussed work by Eustis and Fischer (1991) who identified four patterns of relationships from their study: 'personal', 'formal', 'asymmetric' and 'collegial' (see Table 5 Section 3.5). In comparing this typology to the data in my study I tried to apply these patterns of relationship to the descriptions given by respondents. This proved to be impossible, as the categories relate only to users' perceptions (i.e. 'user views worker as a friend'), so that where the perceptions of workers differed from those of users, and we saw in chapter 5 that many did disagree, there was no category that could be applied. This reveals the inadequacies of research that does not encompass the perspective of both parties in the relationship.

Another aspect that contributed to the ambiguous boundaries of the direct payment relationship was the ability of direct employers, by employing their own workers, to avoid the effect of the 'Guidelines for Practice', produced by Staffordshire social services. These Guidelines reflect the governments move to modernise and professionalise social care, which I discussed in chapter 2. The data suggests that homecare workers and users were influenced by these guidelines in the formation of the boundaries to their relationship, with both homecare workers and users talking far more about the limits of their contact, than in the direct payment relationship.

In using these Guidelines, homecare workers were implementing the regulations laid down by the organisation for which they worked, implying that in contrast to the direct employment relationship, the power to determine the boundaries in the homecare relationship, rested with social services rather than users or workers. Certainly the language used by many homecare workers and users suggests that both parties in the homecare sample

appeared to feel disempowered by the relationship. For example, consistent with other studies (Morris 1998; Twigg 2000; Johansson and Moss 2004), both homecare users and workers used infantilising language when they spoke about each other. Personal assistants, on the other hand, did not use this language when they discussed their employer, inferring their respect, and that they saw their employers as *powerful people.*

Foucault's (1977) analysis suggests that power is present in all kinds of administrative contexts, and by avoiding the Guidelines for Practice direct employers were able to avoid this element of institutional power. Direct employers were able to determine the boundaries of the relationship for themselves, to suit their needs, rather than have the limits of the relationship controlled by the local authority. Existing research argues that direct payments result in a transfer of power from workers to employers (Hughes et al 2005), however the findings in this research suggest a different explanation. The power transfer in the direct payment relationship appeared not to be so much from workers to employers, as *from social services to direct employers.*

8.1.3 The Power to set the Agenda in the Relationship

Previous research argues that direct employment brings users greater power (Zarb and Naidash 1995; Dawson 2000; Leece 2000, 2001; Carmicael and Brown 2002; McMullen 2003; Lord and Hutchison 2003; Clark et al 2004; Stainton and Boyce 2004; Commission for Social Care Inspection 2004). The research in this thesis adds to this debate. I was able to explore the concept power in a way that has not been previously been undertaken, because of the involvement of both users and workers in the study and the comparison between direct and non-direct employment.

The research found that direct employers appeared to have greater power to decide what their personal assistants did, when they did it and how they did it, than homecare users, for whom this was much more limited. As noted in section 2.1, whilst direct payment users were assessed by social services in the same way as homecare users, they could use their payment in almost anyway they chose, as long as it met their assessed needs. This meant that direct employers were able to control their employees' time in a way that users of homecare could not. They were able to decide the way things were done in the relationship or in other words to *set the agenda*. Direct employers had the power to allow personal assistants to do things they would not be able to do in formal employment (the perks of the job), such as being able to care for their children whilst in their employers' home, to bring their dog to work, and to undertake hobbies whilst at work. In her cross-national research Ungerson (2004) found similar instances to this. Setting the agenda gave direct payment users greater autonomy over their support arrangements, and also contributed to the blurred boundaries of the relationship (discussed in the previous section).

In contrast, the findings from the research suggest that homecare users had little power or autonomy in the relationship, they were unable to choose who or how many workers supported them; they had little control over the tasks that were completed; the type of relationship that developed, or the nature of the boundaries of that relationship. Consistent with other research (Clement 1996; Twigg 2000) homecare workers also appeared to lack power; their behaviour in the relationship, and their methods of working were controlled by social services. Chapter 2 discussed the community care reforms and outlined

the task-based method of support that local authorities have adopted following these reforms. Task-based working requires workers to hurry between users, completing a series of tasks, without time to build meaningful relationships. Working in this way provides few opportunities for users to exert control over the tasks completed and restricts the amount of time workers have to spend with them.

The literature about time suggests that there is a trend in many jobs for workers to 'dole out their time in tightly defined time modules' (Brannen 2005:115), and whilst this is intended to make them more efficient and productive it detracts from workers' autonomy. Workers can appear to be acting autonomously, but in reality they are being externally controlled by their employers' (i.e. social services) working practices. In the homecare relationships power thus resided with social services rather than either workers or users.

The research measured workers' levels of stress and job satisfaction. This showed that in common with other studies homecare workers' responses implied a link between the task-based method of support and dissatisfaction and stress. For example, Sinclair et al (2000) identify how being rushed in their work due to lack of time to spend with users, was a major cause of dissatisfaction for homecare workers. Other research in Sweden found that homecare workers felt dissatisfied because they did not have enough time for users, and so were unable to do a good job (Ingvad 2003). Furthermore, another study reported that homecare workers felt stressed about elements of their job over which they had least control, such as the ability to provide the standard of service that they wished to provide (Ballock et al 1999).

In contrast personal assistants in my research did not have to rush between users, as they were employed to provide support to just one person. Although in a study in France, where personal assistants were working for multiple employers who required a few hours of support per week, workers experienced a 'constant battle with time and location' as they moved between employers, in much the same way as the homecare workers in my research (Ungerson 2004:200).

8.1.4 The Power to be More Reciprocal

In chapter 3 I argued that the literature on independence is vague, contested and focuses on the perspective of disabled adults (Brisenden 1986, 1989; Morris 1993; Oliver 1993; Reindell 1999). I suggested that using the concept of autonomy presents us with a more useful way of exploring the dynamics of the support relationship, and enables us to understand the experiences of both users and workers. Consequently, the study uses a model of autonomy developed by Peace et al (1997), based on the work of Collopy (1988) (see Table 3 Section 3.4.1). This model has been helpful in exploring conflicts of interest in the relationship and distinguishing different states of autonomy: decisional autonomy; executional autonomy; authentic autonomy and delegated autonomy.

The research explored respondents' own definitions of independence, and as such adds new data to the literature. It found a crucial difference in reported notions of autonomy between the direct employment and non-direct employment samples. Direct employers generally related independence to the ability to control the decision making process (decisional autonomy), as did their personal assistants. This was likely to mean that direct employers

considered themselves to be autonomous, as they were able to make decisions, and to be seen by their personal assistant as having autonomy. For homecare workers and users on the other hand independence was executional, and so users would feel and be seen by their workers as non-autonomous when they became unable to self-care.

The research suggests, that homecare workers and users views about autonomy were likely to have been influenced by the rehabilitation ethos, which exists within social services. In a discussion of autonomy Reindal (1999:353) argues that: 'Professionals tend to define independence in terms of self-care activities. So independence is measured against skills in relation to performance of these activities'. Goble (2004) also found this in his research about people with intellectual impairments, where he argues that professionals see their role as assisting disabled adults to lessen or remove the effects of their impairments to help them achieve greater normality and independence. Social care workers are trained to encourage self-determination, independence and self-reliance; indeed these values are enshrined within the British Association of Social Workers 'Code of Ethics for Social Work (2002). Homecare workers and users were subject to this influence, whilst direct employers and their personal assistants were able to avoid the effects of this culture.

Ungerson (2004) argues that direct employment fails to enhance employees' independence, because they are susceptible to exploitation based on emotional blackmail. The comparative nature of the research enabled me to explore this idea and the data provides some evidence to support it. The findings suggest that both homecare workers and personal assistants had

little power or autonomy in the relationships. For homecare workers the power to determine the nature of the relationship rested with social services, whilst in the direct payment situation it was employers who held the power, with the relationships being geared to fulfil their interests. Therefore on balance, the findings appear to indicate that although the work might be more pleasing, there was no evidence to show that direct employment increased workers' power or autonomy.

We saw in chapter 3 that an important element of retaining self-respect and autonomy within a relationship is the ability to 'return favours' or reciprocate (Allan 1979; Maus 1990; Johnson 1993; Allan and Adams 1998; Forbat 2005). Indeed as Douglas (1990:vii) points out: 'Charity is meant to be a free gift, a voluntary, unrequited surrender of resources. The difficulty is that though we laud charity as a Christian virtue we know that it wounds'. Sennett (2003), in his work on equality, argues that giving or helping people who are unable to reciprocate reinforces those individuals' dependency, and can even be a way of gaining control or manipulating them. Additionally Galvin (2004) found that disabled adults felt shame and frustration about having to rely on the goodwill of informal carers.

However, as I identified in chapter 3, whilst the literature has emphasised the importance of reciprocity, it has little to say about the effect of direct employment on disabled adults' ability to reciprocate. Studies relating to direct payment users imply there are some instances of reciprocal behaviour by users (Dawson 2000; Clark et al 2004), whilst research involving personal assistants is unclear about any occurrence of reciprocity (Glendinning et al

2000a; Ungerson 1999, 2004; Flynn 2005). The research in this thesis has specifically explored the notion of reciprocity and so develops this debate.

The study found that direct employers did indeed appear to have a greater capacity than homecare users to reciprocate in the relationship, and this related to employers' greater power. For instance, the power to set the agenda and decide the boundaries of the relationship, discussed earlier in this chapter, meant employers were able to: help their personal assistants; listen to their worries, and allow them 'perks' in a way that homecare users could not. Employers also reported having much more time in which to be reciprocal with their workers. The ability to be more reciprocal in the relationship may be an example of direct employers having authentic autonomy, where they are able to be the person they really want to be, for instance a person who has the power to 'give something back' for their support.

There is tentative evidence in the data to suggest that the ability to pay workers wages directly, instead of indirectly as homecare users do, was also seen by some personal assistants as reciprocal behaviour by employers. For example, one personal assistant who was helping his employer informally (unpaid) prior to his employment, stressed how much the payment of wages meant to him. Many direct employers too made the connection between the ability to pay wages and their power in the relationship: 'I'm the piper, I pay the money'. This highlights and extends the wider debate about money and personal relations, where Zelizer (2005) argues that economic transactions and intimate relationships are intrinsically interconnected. Money and intimate care may be interlinked, as Zelizer suggests, but in the homecare relationship this is hidden, whilst in the direct payment arrangement money is *out in the*

open, and this appears to be the crucial difference which influenced respondents' views. It also reflects market theory and the notion that the contractural nature of cash payments changes the dynamics of the support relationship, by giving employers' greater power.

Furthermore, not only did direct employers have greater power to be reciprocal than homecare users, they also had more incentive to do so, to create a satisfying working environment, which personal assistants would be less likely to leave. Market theory suggests that the ease or difficulty with which employers can recruit workers varies depending on the job market; at times of high employment when workers are scarce, employers have greater incentive to ensure their employees are happy at work (Le Grand and Bartlett 1993). The research took place at a time when the social care workforce was argued to be in crisis, due to longstanding recruitment and retention difficulties (Social Services Inspectorate 2003; UKHCA 2004; Commission for Social Care Inspection 2005a). There is also evidence that some direct payment users were (and still are) experiencing difficulty in recruiting 'people of the calibre they want' (Commission for social Care Inspection 2004; Flynn 2005:10; Heng 2007; Davey et al 2007*).* Consequently direct employers in the study were more likely to be reciprocal to encourage their personal assistants to stay in their employ.

The existence of reciprocity is likely to be an indicator of an interdependent relationship (Fine and Glendinning 2005), and certainly the words of one of the personal assistants: 'it suits us both'*,* came to mind as I interviewed many of the direct payment respondents. These relationships generally appeared to be in harmony with many of the personal assistants talking about how much

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they enjoyed their work, with one even saying that: 'it's not like being at work'. This provides tentative evidence that direct employment can help to create support relationships that are more reciprocal and interdependent.

In chapter 2 I examined the feminist ethic of care and the social justice and rights perspective, identifying that the primary interest for feminist academics resides on the person giving care, whilst for disabled activists it lies with the person receiving support. I suggested that this discrepancy is significant, as it results in both perspectives tending to ignore the interests of the other. Notions of interdependence have been explored by both of these perspectives with some convergence of ideas (Forbat 2005). For disabled activists, interdependence is at the heart of their struggle to reposition explanations of the need for support, as a fundamental part of everyone's life (Oliver 1993; Morris 1993; Barnes 2004), at the same time in the care literature, interdependence can be explained as an exchange of help across the life span (Forbat 2005).

The research in this thesis provides a rather contradictory addition to this debate. On the one hand it suggests that the feminist and disability perspectives are being brought closer by notions of interdependence, after all the direct employment relationships contained many elements to suggest they were reciprocal and interdependent. Alternatively the research suggests a divergence remains between the two debates, because of workers and users conflicting interests. The following section goes on to discuss conflicts of interest and the power of direct employers to ensure their interests take precedence in the relationship.

8.1.5 Direct Employers' Power to make their Interests take Precedence

In the study we have seen how the friendly informal direct employment relationships with blurred boundaries had some benefits for personal assistants. I have already mentioned that personal assistants took 'time out' from their job, enjoyed 'perks', socialised with their employer, and generally seemed content in their work. For direct employers too, the research shows that, consistent with other studies the relaxed boundaries held many advantages (Vasey 2000; Glendinning et al 2000a; Clarke et al 2004; Dale et al 2005). Two direct payment users openly acknowledged this by saying that their personal assistants would do more for them because of their close friendship, and this is corroborated in the data, as personal assistants with the closest relationships, tended to report doing the most unpaid work for their employer. This suggests that the relationships were primarily geared to serving the interests of employers; after all it was employers who held the power to define the boundaries of relationship and set the agenda. One of the direct payment users talked about his control in the relationship, as stemming from his need, however it appears that this was another way of saying that it was his interests that set the agenda; his interests that were paramount.

Clement (1996:62) refers to this conflict of interest in her work on personal service where she argues that carergivers and employers often have different priorities and 'because the caregivers continued employment depends on accepting her employer's priorities her role as a carer often compromises her own autonomy'. Similar to other studies (Glendinning et al 2000a; Ungerson 2004), there were several instances where personal assistants interests appeared to take second place to employers. Unlike homecare workers,

personal assistants were on-call for their employer's emergencies. Employers could call them out as necessary, as they had their personal assistant's home phone number and address; many of the personal assistants cited examples where this had happened. Consequently the working life of personal assistants in the study encroached upon their *own time* in a way that homecare work did not.

This reflects the broader debate (discussed in chapter 3), about the increasing difficulty for many employees of maintaining a balance between their home life and their working life (Hochschild 1993; Bunting 2004). It also shows that although the notion of time has been given little prominence in the literature, it is of relevance in explanations of the care relationship. Brannen (2005) for example, argues that being on-call eats into family time and fails to respect the boundaries between home and work. This again infers that employers' needs were of greater importance in the relationship than those of their workers, as did the precarious position of the live-in personal assistant who said he would lose both his job and his home on the death of his critically ill employer.

However that is not to say that direct employers had absolute power in the relationship. We saw in chapter 3 that social services retained certain power, for instance the power to impose restrictions on the employment of co-resident relatives, and the power to assess users' needs. Also, as mentioned in the previous section (and in accordance with market theory), it was in direct employers' interests to *keep their workers satisfied* to avoid them seeking alternative work, and the need to do this is likely to have tempered employers'

power. Certainly some direct payment users in the study expressed concern about their workers leaving.

Satisfaction or stress at work are important elements of our experiences of employment. In chapter 3 we saw that a number of studies suggest that satisfaction with work generally is declining, because employment is becoming more stressful, due higher work loads and longer hours (Oswald and Gardiner 2001;Taylor 2002). Yet there is little research that investigates job satisfaction and stress for homecare workers, and none in the UK that specifically focuses on these areas for personal assistants. Earlier in this chapter I mentioned that the research measured respondents' job satisfaction and stress, and this adds new empirical data to the literature.

In the study, the stress and job satisfaction measures tentatively suggest that personal assistants as a group were more satisfied, and had lower levels of stress than homecare workers. However three of the personal assistants had high scores on both measures, indicating that whilst the work was satisfying it could also be very stressful. These personal assistants were amongst those who described their relationship in family terms, suggesting that whilst 'becoming part of the family' may bring more satisfaction, it can also bring greater stress: the proverbial *double-edged sword*. Two studies in the US had similar findings reporting that directly employed workers were slightly more inclined to worry about their employers' safety, than non-direct employees (Benjamin and Matthias 2004; Dale et al 2005).

Close family-like relationships therefore came at a psychological cost to some personal assistants, echoing the literature on emotional labour discussed in chapter 3 (Hochschild 1983, 1989, 1993). Work that requires employees to

use their emotional skills as part of their job can be very stressful, for as Bunting (2004:87) argues, it is offering 'feelings for sale'. In contrast to homecare workers, personal assistants reported feeling a sense of obligation towards their employer, with all saying they would find it difficult to leave their job, even if they wished to do so. Glendinning et al (2000a) allude to this in their study by referring to personal assistants as having the 'boundless obligations' of real family members. My research also found evidence to support suggestions in the literature that the direct employment of family members can be particularly problematic (Benjamin and Matthias 2004). One of the direct payment relationships involved the employment of a relation and both employer and employee reported difficulties in setting boundaries in their relationship, because of their family connection.

The research explored an area that is contested in previous literature: the master and servant analogy. For instance, some researchers suggest that direct payments will create a system that 'reverses rather than abrogates the master/slave relation' (Hughes et al 2005:26; Twigg 2006), with personal assistants becoming a 'new breed' of domestic servants. Others disagree arguing this is unlikely to happen as the days of domestic service are long gone (Clark et al 2004; Ungerson 2004). In my research, personal assistants reported working in a manner that was indeed reminiscent of domestic servants. They worked unobtrusively, with many using methods that made them seem 'invisible', such as working silently unless their employer started a conversation.

The in-depth nature of the research helped me to explore this further, with the data suggesting that the ability of personal assistants to work unobtrusively,

was partly the result of their working for just one person, as they were more likely to know what to do without being told. It also seems likely that the greater amount of time personal assistants spent with their employer increased their need to develop ways of appearing invisible. There were for example, periods of time when personal assistants were not providing hands-on support, but were required to be present in case of an emergency, and so had *time on their hands*. Personal assistants thus sometimes had to occupy themselves within the relationship in a way that homecare workers did not.

Perhaps surprisingly, the study found that although personal assistants were using servant-like methods of working, most denied feeling like servants, neither did they use language to suggest they considered their work to be of low status. The high levels of job satisfaction and low levels of stress that, most personal assistants reported, and their closer relationship with employers may have influenced their perceptions of the relationship, so that they felt like friends rather than servants. On the other hand it may reflect data that is based on what respondents say rather than observation of their behaviour. Equally whilst personal assistants may have denied feeling like servants, their accounts of their work suggest they could have been described as such. This provides tentative evidence that the direct employment of support workers can result in a form of domestic service.

Homecare workers in direct contrast did not report using invisible methods of working, although most described feeling like servants at times, and many appeared to feel their work lacked status. Earlier in this chapter I highlighted the link between the task-based approach to carework and homecare workers' stress and dissatisfaction with their job. It may be that this method of

working also causes workers to have a low opinion of the status of their work, and to feel like servants.

In chapter 3 we saw that invisible working can come at a cost to workers causing them to feel demeaned, and lacking in credit for their work (Twigg 2000; Rivas 2003). For users however, having 'invisible workers' brings a number of benefits, such as increased power in the relationship (Rivas 2003) and help in maintaining personal space (Bailey 2002; Johansson and Moss 2004). The realm of 'master and servant' appears to be area where a conflict of interest can occur and direct employers' needs appear likely to take precedence over those of their workers.

8.1.6 The Power to set the Terms and Conditions of Employment

In an employment situation, an employer may have the power to set the terms and conditions of the employment, such as the rate of pay and whether it is pensionable. Direct employers in the study, in common with other direct payment schemes in the UK (Davey et al 2007), had a limited ability to do this. Employers were able to set an hourly rate of pay for their personal assistants, but they were restricted in the rate they could offer, by the amount of direct payment they received from social services. Direct employers were unable to offer pension provision to personal assistants, as pension contributions were not included in the direct payment rate paid to employers, although holiday and sickness pay were incorporated in the direct payment. Homecare users, as indirect employers, had no power to influence homecare workers pay and conditions, which were set by the local authority, in consultation with a trade union.

Researchers speculate that direct employees are likely to have poor terms and conditions (National Union Research 1998; Ungerson 2004), and the research in this thesis, with its comparison between direct and non-direct employment, provides evidence to add to this debate. The study found striking differences between the direct and indirect employment of support workers. Tables 19 and 20 in section 7.7 show that personal assistants reported having a lower rate of pay and much poorer terms and conditions than homecare workers. Unlike homecare workers, personal assistants said they did not receive pension provision, unsociable hours payments, access to a trade union, or to training for formal qualifications. Many personal assistants did not know whether they were entitled to sickness pay, or mistakenly believed that they were not, with some going to work even when they were ill.

The comparison between employment in the public sector and direct employment by disabled adults presents us with something of a paradox. The findings show evidence of significant disadvantages for personal assistants in terms of their pay and conditions; moreover they offer tentative support for the idea that direct payments are continuing the trend away from public employment of care workers, initiated by the community care reforms of the 1990's, towards a lower paid, casualised workforce with fewer employment rights. However, they also supply evidence that direct employment can bring, not only a source of income, but also employment rights for people providing unpaid informal care for disabled adults, as almost half of the personal assistants in the study were providing support informally to their employer prior to their employment. There is no reason to suppose this would be

different in other direct payment schemes, suggesting that direct payments may enable many informal carers to access the world of paid work.

Perhaps unexpectedly the research found that despite their lower pay and poorer employment conditions, personal assistants appeared generally more satisfied and less stressed than home care workers. It could be argued that personal assistants simply weighed up the pros and cons of their employment, and decided that overall it held more advantages than disadvantages for them. Conceivably money may not have been important, with personal assistants accepting lower pay in return for a less stressful, friendlier working environment. There is some evidence for this in the psychology and sociology literature (Rosenberg and McCullough 1981; Wellman and Wortley 1990), also the more recent economics of happiness literature (Putnam 2000; Helliwell 2003, 2006). For example, one study used British Household Panel Survey data to explore shadow pricing, to estimate the financial value to individuals, of their interaction with friends. The author estimates that increased contact with friends and relatives is worth £85,000 a year in terms of life satisfaction (Powdthavee 2007). Therefore personal assistants in the study may have felt that having a friendly relationship with their employer was worth the low pay.

On the other hand as we have seen in this chapter the direct employment relationships were designed by employers, primarily to serve their own interests, and the friendly, family-type arrangements they created resulted in obligations that made it difficult for workers to exit the arrangement, despite the many shortcomings of their position. Furthermore, it does not follow that workers should be paid a low wage, or have poor conditions of employment

simply because they like their job. These issues will be developed further in the following final chapter.

8.2. Reflections on the Research Process

Choosing a methodology for a study is always challenging, as each method has its own strengths and weaknesses. Details concerning how the methodology for the study was chosen and how the research was undertaken were given in chapter 4. I argued that the research question would be best investigated using a grounded theory approach, which informed by theory, a literature search and the data, would build a knowledgeable picture of people's experiences of the support relationship. The research involved both workers and disabled adults in an in-depth investigation, located within the symbolic interactionist tradition, with its focus on understanding social processes and interaction from an individuals' viewpoint, thus enabling an exploration of the complexities of the relationship. I used a participatory style to develop the research, including the involvement of disabled researchers, although the methods chosen for the study were ultimately my decision. Thirty-two respondents in either a direct payment or homecare relationship were involved, enabling the important comparison between the direct and non-direct employment of support workers that was missing from the literature.

I explained in section 4.1.5 that two well-validated instruments were administered to respondents to measure their stress and job satisfaction. The results were used to help interpret the interview data, and to provide a multi-method approach to try to overcome difficulties in measuring stress and job satisfaction. The instruments (questionnaires) worked well, in that they were

easy for respondents to complete, and the results provided a numerical measure, however they did have restrictions. The data from the questionnaires gave only a 'snapshot' of respondents' experience, and the wording of the statements was limited, although this was mediated to some extent by the ability to ask questions during the interview. A longitudinal study in which the questionnaires were administered two or three times, as in Balloch et al (1999), would have provided a longer-term picture, but this would have been difficult to achieve within the constraints of a PhD study.

Other aspects of the methodology caused some restrictions to the research. It was necessary to match the two groups (homecare and direct payments) to achieve a meaningful comparison. The shortage of male homecare workers employed by social services meant it was impossible to match the gender of the two groups of workers exactly (see section 4.3.6). Also I had hoped to include respondents from ethnic minority communities in the study, so that the research was as inclusive as possible, but as there were none in the direct payment sample the process of matching meant that people from ethnic minority communities could not be included in the homecare sample. This was disappointing as research suggests that race and ethnicity can be an important component in influencing the power balance in support relationships, especially in countries such as the US where carework is not only gendered, but also racialised (Anderson 2000; Twigg 2006).

The size of the sample was small, and did not represent the wider population, for example people with cognitive disabilities were not included in the study (section 4.2.2). It is probable that the findings would have differed if people with learning disability or Alzheimer's disease had taken part, especially in the

areas of power and autonomy. For instance, direct employers with a cognitive disability may not have been decisionally autonomous, but instead in possession of delegated autonomy, which could have influenced the power dynamics of the relationship. This is an area that would greatly benefit from future research.

The study used convenience sampling, with direct payment users chosen on a first come basis, rather than being randomly selected. I explained in section 4.3.5 that my ability to obtain a sample of personal assistants was limited, to making an approach through their employer, as social services did not keep records. This may have influenced the findings, as employers with problematic relations with their employee are unlikely to have agreed to take part. Direct payment users in the study were happy for their personal assistants to participate, and to be interviewed on their own, nevertheless the research still found evidence of many negative aspects of direct employees work. Research containing a sample of personal assistants recruited independently of their employer may have revealed a greater prevalence of negative features, including the existence of abusive or unpleasant employers. The method of recruiting homecare workers could also have distorted the findings, as homecare users were required to identify one of their workers to take part, and would probably have chosen workers with whom they had a good relationship. In retrospect I should have randomly selected one of their homecare workers myself.

In section 4.3.8 I explained how the interviews for the research took place. Both direct and non-direct employers opted to be interviewed in their own homes, whilst homecare workers chose either their own home or my home.

When it came to interviewing personal assistants however, all but one of their employers preferred them to be interviewed during the same visit, in the direct employers' home. Only one personal assistant was interviewed in her own home, as she was unavailable at the original visit to her employer. Being interviewed on their employers' 'territory', albeit privately in another room, may have influenced the responses that personal assistants made, making them less inclined to say anything negative about their employer. The control of the place and time of the interview is another demonstration of direct employers' power in the relationship.

Research that relies on respondents' views about their life is always open to criticism of 'what people say is not always what they do', and as mentioned in the previous section there may have been instances of this in my study. For example, during the interview I used a scenario to encourage respondents to be frank in talking about notions of master and servant in the relationship (see section 6.2.2). It appeared from their responses that users felt unable to express their views honestly for fear of giving me the impression they were impolite towards their workers. Therefore what they said may not necessarily have reflected their actions, and to try to minimise the effect of this methods of analysis were used to cross-check the data, such as word counts and instruments to measure stress and satisfaction. Ethnographic research avoids this methodological drawback, as researchers observe what people do rather than what they say, but as I discussed in section 4.1.5 this method was considered unsuitable for the study.

Other researchers (Glendinning et al 2000a; Taylor 2000) have identified two areas that have particular potential for a conflict of interests in the care

relationship: manual lifting and the need to undertake healthcare tasks (sections 3.3 and 6.2). The findings of the study were inconclusive in these areas, as none of the direct employers needed either healthcare or manual lifting. However, one of the personal assistants was required to help his employer (who was a large man) in and out of the bath, and had to be trained to administer insulin in case an emergency occurred. Further research into this aspect of the work is needed.

The study took place in Staffordshire social services, the local authority in which I was employed at the time. In section 4.2.4 I discussed my role as an insider researcher, and explained the methods I used to try and minimise the impact of this, such as not accepting funding from my employer for the study. Nevertheless being an insider must have had an affect on some of the respondents, especially homecare workers. They may have seen me as 'someone from headquarters checking up on them', and so been less likely to be open about their experiences. However, being an insider also had enormous advantages in terms of my ability to access the sample, which may have been denied to an external researcher.

The study involved only one local authority, which meant a more in-depth exploration was possible, than if two or three local authorities had been researched. However there were disadvantages to this, for whilst local authorities follow the same government framework for the implementation and organisation of direct payments, with many features of their schemes being consistent (DoH 2003; Davey et al 2007), there are differences. For instance, Staffordshire social services has not embraced the market approach to social care as fervently as some local authorities, with its development of direct

payments reflecting the slower approach of Labour controlled authorities in the North of England. As such, the findings from the study may not replicate the experiences of people in more market orientated local authorities such as Hampshire or Essex, where schemes have larger numbers of users.

8.3. Conclusion

In this chapter I have discussed the findings of the study, locating it within existing research and reflected on the research process. Researching the care relationship is complex requiring the consideration of a broad scope of literature; it has involved a comparison between the direct payment and homecare support relationships. For me, the findings from the research demonstrate that the key differences between the two types of care provision are derived from the employment relationship, and can best be understood through the notion of power. In the direct employment relationship the notion of money is no longer hidden, but clearly evident by the payment of personal assistants wages, and this together with disabled adults status as employers, is the source of their greater power and autonomy in the relationship. Direct employers were able to choose their worker, and avoid aspects of local authority control and culture, to create the type of support relationship that suited them, and was geared towards *serving their interests*. The findings suggest that in the non-direct employment relationship power resides, not with disabled adults or workers, but with the local authority, whereas with direct employment much of this power shifts to direct payment users.

The research found that direct employment appeared to be more satisfying and enjoyable for workers than homecare work, but it also had a considerable downside for personal assistants, as their interests took second place in the

relationship. Their job was lower paid and less secure, with poorer conditions of employment, it encroached on their home life, involved unpaid work, and created family-like obligations, in a way that homecare work did not. Furthermore, the methodological difficulty for this research of gaining access to personal assistants without the agreement of their employer, means that the negative aspects of direct employment found by this study, could occur more frequently and be more pronounced than this research suggests. Indeed it could be just the *tip of the iceberg.*

In common with other qualitative studies, generalising the research to the wider society is problematic, as it contains neither a representative nor random sample. It does though, provide a comprehensive examination of the comparison between direct and non-direct employment of support workers in the context of one local authority, and the findings encompass the immensely complex nature of support relationships. The research is one of the few studies to consider direct payments through the eyes of both disabled adults and workers. The study provides new evidence about direct employment with different understandings of power and reciprocity in the relationship; it also provides another way of looking at independence through its focus on autonomy, which has relevance to workers as well as users.

Chapter 9 Conclusion

Given the commitment of government to user-controlled support, numbers of people using direct payments are likely to increase significantly in the short term, at the very least (Leece 2006a, 2007). Consequently, research into the direct employment support relationship has great imperative and significance. Indeed as Glasby et al (2006:270) argue: 'In many ways the introduction of direct payments can be seen as heralding the most fundamental reform of social care for many years'. An indication of the relevance of the research in this thesis can been seen in that evidence from the study is already being cited in publications relating to social care (Social Care Institute for Excellence 2007; Davey et al 2007).

In this final chapter I situate the research in the wider context of policy, consider the implications of the research and make recommendations for practice and for future research.

9.1. The Policy Context

During the last twenty years the welfare state has been the focus of campaigns to transform, reform and modernise it. In common with other developed countries Britain has undergone significant changes in demographic trends such as the rise in the labour market participation of women, combined with reductions in fertility rates and an increase in longevity. This has resulted in an expanding shortfall between the numbers of women available to provide informal care, and an increasingly ageing population requiring care (Clarke 2004). Rising demand, greater consumer expectations and spiralling costs of care led to a growing consciousness

throughout the developed world that existing systems could no longer cope, and of the need to contain the costs of care (Ungerson and Yeandle 2007). The response to this has been a move towards the marketisation of welfare, with similar initiatives to direct payments being developed in other countries such as: 'consumer directed care', self-directed support', 'direct dollars' and 'personal allocations' (Glendinning and Kemp 2006). Pressure for the re-introduction of cash payments in the UK came not only from government determination to build a market economy, equally important was the powerful lobby by disabled people for independent living, social inclusion, and an end to second-class citizenship.

The development of a market economy with its focus on market forces was intended, amongst other things, to reduce the perceived inefficiency of state provision and improve value for money (Netton et al 2005). Direct payments can be argued to be a way of delivering support more cheaply without compromising the quality of care, as much of the cost of bureaucracy associated with organising support is passed on to users. A year-long review, commissioned by the Kings Fund, to look at funding for social care for older people to achieve high quality outcomes, argues that: 'overall direct payments or cash benefits appear to offer users improved outcomes at potentially lower cost to the public purse' (Wanless Review Team 2005:12). Indeed some have argued that government interest in cash payments has been fuelled by a perceived reduction in cost: 'the overwhelming justification for these types of scheme [user-controlled support] appears to be cost savings to the system' (National Union Research 2000:16).

It is significant that the legislation making direct payments legal in England came into force following research findings from the Policy Studies Institute. This early study reported that direct payments were considerably cheaper than traditional service based support (Zarb and Nadash 1994), which appears to have settled the debate at that time. However it is by no means certain that this will prove to be the case for, in a report for the Institute for Public Policy Research, which examined government proposals for individualised budgets, Rankin (2005:5) argues: 'there is no robust evidence available that would lead to the conclusion that individualised budgets {or direct payments] on a large scale will be cheaper, more expensive or cost the same compared to existing provision'.

Certainly more recent studies show a mixed picture. For instance, the evaluation of the first phase of *In-Control* (a national pilot scheme in which six local authorities have been developing a self-directed or individualised approach for people with learning disabilities), found that user-controlled support could be achieved using existing resources, with one local authority estimating it could save 20 per cent on funds for all people using direct payments (Poll et al 2006). On the other hand, an analysis of the costs and benefits of choice in public services by the Audit Commission suggests that paying direct payments are more expensive for local authorities, unless the rate set for the payment is lower than in-house provision, because of the greater costs associated with regulating the quality of care packages, monitoring the payment and providing support to direct payment users (Audit Commission 2006). Furthermore, research that looked at UK and international data argues that there is no conclusive evidence about the costs of user-

controlled support, as information is sparse and it is difficult to compare across countries, with many EU schemes based on an underestimate of cost partially due to 'unpredicted demand and previously undetected unmet need' (Social Care Institute for Excellence 2007:7). Nevertheless, despite uncertainty about the cost of an expanded system, individualised user-controlled support is high on governments' agenda for social welfare.

In 2003, the year the fieldwork for the study started, the government of the time was actively encouraging local authorities to increase the numbers of people using direct payments. It created the Development Fund pledging £3 million a year for three years to promote the take up of cash payments by under-represented groups. To further persuade local authorities to extend their schemes in 2004, direct payments were made an indicator of their performance. In February 2005 the government published its strategy called 'Improving the Life Chances of Disabled People' (Prime Minister's Strategy Unit 2005). This document, which applied to disabled people of working age, disabled children, disabled young people and their families plainly signalled the government's continuing commitment to extended use of direct payments. The strategy proposed a new funding structure, whereby several funding streams would be brought together in the form of 'individualised budgets'. Disabled people could choose whether to take these budgets as a combination of cash (direct payment), services brokered by an advisor, or services commissioned by a local authority (Rankin 2005).

The proposals in the strategy built on 'In Control' which focuses on the needs and interests of disabled adults (whilst ignoring workers), and aims to: 'Change the organization of social care in England so that people who need

support can take more control of their lives and fulfil their role as citizens' (www.in-control.org.uk). Instead of the current system of assessment and identification of services to meet needs, 'In Control' has developed a method of self-assessment based on certain criteria. This determines the level of severity of an individual's need, in a similar way to a social security benefit assessment, such as Attendance Allowance. The level of severity gives an entitlement to a specified budget to be spent on direct services, independent sector services, a direct payment or any combination of these (Glasby et al 2006).

The Green Paper 'Independence, Well-being and Choice: Our Vision for the Future of Social Care for Adults in England' (DoH 2005a) was published one month after the strategy for disabled people in March 2005, and this time older people were included in the vision. The Green Paper further reinforced government commitment to direct payments by calling for greater opportunities for disabled and older people to have choice and control over their support needs. There were proposals for new forms of support to help people currently excluded from direct payments such as the use of 'agents' to assist people with severe cognitive impairments deemed unable to consent. The use of individualised budgets was again central to the proposed changes, extending their use to enable people to buy local authority services, a provision currently denied to direct payment users.

In January 2006 a White Paper: 'Our health, our care, our say: a new direction for community services', which presented proposals for the whole health and social care system was published. This confirmed the vision for social care set out in the Green Paper that there would be: 'a radical and substantial shift in

the way in which services are delivered- ensuring that they are more personalised' (DoH 2006:6). The White Paper reiterated the expansion of direct payments and the introduction of individualised budgets explaining that eligible people would have 'a single transparent sum allocated to them in their name and held on their behalf rather like a bank account. They can choose to take this money out either in the form of a direct payment in cash, as provision of services, or as a mixture of both' (DoH 2006:83). The Department of Health started an 18-month pilot study in April 2006, to test the use of individualised budgets in thirteen local authorities in England (www.individualbudgets.csip.org.uk).

Uncertainty about the cost of an expanded system, the history of direct payments with its patchy implementation and slow take up (see chapter 2), all create uncertainty about whether individualised user-controlled support will in the future become a mainstream option, or remain a minor part of social welfare. My research looked at the impact of money on the support relationship, rather than providing evidence about the cost of direct payments compared with traditional services, but it has been demonstrated in other areas of the country, that if direct payments are not cost effective, then local authorities may withdraw their support (Community Care 2006a). Government allegiance too will almost certainly falter if, in the longer-term, individualised support proves to be more expensive than service provision. I would suggest, and have argued elsewhere (Leece 2006b, 2007), that government commitment to user-controlled support will, in the short term at least, result in a significant increase in numbers of people using direct payments, and that

research into the direct employment support relationship is consequently of great importance.

9.2 Implications of the Research

The greater use of direct payments will inevitably require radical changes to the social care workforce. This is acknowledged in a government publication 'Options for Excellence: Building the Social Care Workforce of the Future' (DoH and Department for Education and Skills 2006), which stresses that an increased supply of care workers will be needed to implement the proposed changes. Forecasting future demand for workers is always difficult, but if just ten per cent of the 1.7 million people presently supported by social services (DoH 2006) opt for direct payments then many thousands more personal assistants will be required.

Concern has been expressed about whether there will be an adequate supply of suitable personal assistants should the numbers of direct payment users grow significantly (Carmichael and Brown 2002; Scourfield 2005; Flynn 2005; Glasby et al 2006; Leece 2007). The move to increase direct payment use has come at a time argued to be one of crisis in social care, because of recruitment difficulties. The UK labour market is at present highly competitive with unemployment at a historically low level (Audit Commission 2002) and a number of local authorities and independent sector agencies experiencing problems recruiting sufficient numbers of care workers (Commission for Social Care Inspection 2005b).

Direct payments need to be considered within this wider context, as some employers seek to recruit their personal assistants from the care labour

market. Certainly, there is anecdotal evidence of direct payment users poaching care staff from homecare agencies, and also employing workers from other countries such as Russia via recruitment agencies. However as I have argued elsewhere, direct employment has the potential to ease the current 'recruitment crisis' by bringing into the workforce people who would not otherwise have entered, the relatives, friends and neighbours of direct payment users, thus increasing the supply of care workers (Leece 2003b). The research in this thesis provides an example, as a number of personal assistants were friends of their employer, one was a relative and two were over retirement age having retired from their previous work.

These issues raise two main points. Firstly people employing personal assistants need to have enough money to be able to offer a reasonable salary, so that they are able to successfully recruit staff. Other research suggests that, whilst the rate paid to direct payment users varies around the country, the trend appears to be for local authorities to pay a rate that is lower than that paid either to independent sector homecare agencies or in-house homecare, and this hinders direct employers ability to recruit workers (McMullen 2003; Unison Scotland 2004; Davey et al 2007). Certainly in Staffordshire there is evidence that poor pay offered by direct payment users can cause users to experience difficulty in obtaining personal assistants.

Problems recruiting workers in the care labour force generally have been associated with low pay (Audit Commission 2002; Social Care and Health Workforce Group 2003). A report by the Equal Opportunities Commission (2007) suggests that the poor rate of pay for carework is an example of market failure, due to distortions in the market, caused by restrictions in

central government funding for social care. The amount of funding local authorities receive influences how much they can pay workers, with care workers being paid well below the rate they could demand in a freely operating market (Equal Opportunities Commission 2007). This also affects direct employers, as the rate of pay they can offer to personal assistants is determined by the amount that local authorities give them as a direct payment, and this in turn is influenced by government funding, rather than the amount workers are 'worth' in the market place.

The second important point is the right of personal assistants to be paid a reasonable wage for their work, and to have good conditions of employment, such as pension provision and access to training, yet the research found clear evidence that personal assistants had significantly poorer terms and conditions than local authority homecare workers. Carework is generally a lowly paid occupation undervalued and underpaid 'because it is women's work' (Toynbee 2006:6). Direct payments can undoubtedly be seen as a way of cutting the cost of care by reducing the amount paid to the feminised care workforce, and lessening their collective bargaining power. The work that women do should be more fairly recompensed, with funding for social care sufficient to ensure that direct employers can offer pay and conditions that are at least comparable with local authority homecare workers. The Equal Opportunities Commission (2007) argues that undervaluing women's work matters, because it: damages Britain's productivity; undermines the quality of public services; contributes towards child and pensioner poverty, and is inherently unfair. The report goes on to suggest that the low value placed on care work is: 'a defining issue for 21st Century Britain because the reality is

that women workers form the backbone of our public services and increasingly the success or failure of public service reform hangs on the link between investing in the workforce and service delivery' (Equal Opportunities Commission 2007:1).

The idea that personal assistants have any kind of stake in direct payments is a stance that been advanced by only a handful of academics (Ungerson 1997a, 2002, 2004; Glendinning 2000a; Spandler 2004) and the public sector union Unison (Unison Scotland 2004). Certainly there appears to have been little political thought in the UK to the possible implications of large-scale direct employment by disabled adults. Moving to a support system, which requires large numbers of women to work in insecure employment, for lower pay than homecare workers, and without occupational pensions would be a further exacerbation of the income inequality between men and women in the workforce, and in old age (Walker 1998). Yet government has strongly indicated that there will be no extra funding for social care, reinforcing the trend towards the cost curtailment of care. Local authorities are exhorted to meet mounting demands for adult care through increased efficiency savings, rather than central government funding (Community Care 2006b), whilst the Gerson Review (2004) of public sector spending recommends that local authorities should make efficiency savings, set at 3 per cent per year for 2008-11.

This comes at a time when a local government finance survey reports that adult social care was overspent by 1.3 per cent in 2005-6 with many local authorities forced to tighten their eligibility criteria for the provision of care (www.ADSS.org.uk). Furthermore a King's Fund report on social care for

older people argues there should be a huge increase of cash to fund social care adequately for the future (Wanless 2006). I would suggest that government should give this serious consideration, so that more women are not disadvantaged, and user-controlled support does not falter on the inability of employers to recruit personal assistants. Without adequate funding it appears that local authorities are faced with the unenviable challenge of providing individualised user-controlled support to more people, with less money and uncertainty in the supply of workers.

Chapter 2 contained a discussion of user-controlled support in other countries where I explained that there are differences in the way schemes have been developed and funded. Systems also vary in the way they are regulated, with some such as Holland and the UK being highly regulated, where users enter into formal contracts with employees, and payments are made for tax and national insurance purposes (Ungerson 2004). In other countries (Canada, US, Austria, Italy) schemes are unregulated, and unlike the UK, the use of undocumented labour is permitted. This has resulted in these countries of the development of a 'grey care market' where users employ migrant labour, refuges or illegal workers, because they will work for lower wages (Osterle 2003; Ehrenreich and Hochschild 2003; Ungerson and Yeandle 2007). This can benefit direct employers who have access to a cheap labour supply, but places workers in a vulnerable position with very low wages, and non-existent social and employment rights. This highlights the disadvantages direct employees can face, in a similar way to the findings in my research, and also indicates the impact of government intervention on cash for care schemes.

We saw earlier in this chapter and in chapter 2 that the disabled people's movement was highly influential in their campaign to have direct payments legalised, with their demands for independent living strongly rooted in a human and civil rights ethos. Consequently the re-introduction of cash payments has wider implications than simply changing the way disabled adults receive their support. Some have questioned whether it is possible for a user-controlled support system to both empower users and curtail spending on the welfare state (Social Care Institute for Excellence 2007). Certainly there has been criticism from activists that their 'dream' of independent living may not always live up to the reality, with direct payments becoming onerous for some users, as they have: 'all the responsibility of arranging and accounting for the support' (Hasler 2006:286). My research found that some direct employers were more stressed than homecare users, with this stress often relating to their role as an employer. Thus schemes need to be developed that are less burdensome for direct employers.

The campaign by disabled activists was intended to improve the status and power of disabled adults by transforming them from passive recipients of services into active employers (Barnes 2004), with the focus being much less on 'who provides services than on who controls them' (Beresford 2005:479). The ability of the disabled people's movement, in recent years, to have their concerns placed on the political agenda, has resulted in notions of power being incorporated into political thinking. For example, Liam Byrne, the Parliamentary Under Secretary of State for Care Services, said in 2007, during a speech about health and social care in twenty-first century Britain, that: 'we need to change the balance of power in public systems', and that 'we

need a system that is based on people power' (www.doh.gov.uk). However I would argue that my research suggests what is being created is not 'people power', but instead 'disabled adults' power', with the interests and power of workers in this system being virtually ignored. It is assumed in market theory that employer's power will be moderated by their employee's ability to exit employment they find unsatisfactory, but the research showed that this was not straightforward, because of the sense of obligation felt by all the personal, which made leaving their employment problematic.

In chapter 8 I considered the evidence in the research of a significant shift of power from the local authority towards direct payment users. Direct employment places employers in a very powerful position in relation to their employee. Employers not only had the power to 'hire and fire', but also the power to determine the type of relationship that developed and the boundaries of that relationship. They set the agenda, based on their interests and could ensure these took precedence over the interests of workers. The research found a number of instances where personal assistants could be described as being disadvantaged by this such as their undertaking unpaid work for their employer. I argued that in terms of user-controlled support generally this could be just the *tip of the iceberg,* with many situations where direct employers could abuse their 'employer power' to take advantage of workers. This conflict of interests presents a dilemma for as Shakespeare (2000:68) argues: it would be deeply unfortunate if the liberation of disabled people from dependency [via personal assistance] contributed to the exploitation of another disempowered section of the population'.

Equalising the balance of power in the direct employment relationship to give personal assistants greater ability to achieve their interests would be controversial. In their campaign disabled activists placed emphasis on altering the distribution of power in the relationship to favour disabled adults, seeing direct employment of workers as a means of achieving this (Barnes 2004). It would also be problematic, given differences in the ability of the two groups to act to make their voice heard in the political arena. Disabled activists are well versed in this, whilst personal assistants have yet to operate collectively as a pressure group. This imbalance can clearly be seen in the ability of disabled activists to have the research focus on direct payment placed squarely on disabled people's rather than workers' concerns. One way of achieving greater power for personal assistants may be through the involvement of trade unions. Unions such as Unison have warned of some of the risks for direct employees, but are yet to be proactive in developing methods to support and protect them. Significantly none of the personal assistants in the study were members of a trade union, and as such lacked both the protection and the power of belonging to a group of organised workers.

Findings from the study revealed differences in other forms of support available to workers, for instance from managers and colleagues. Personal assistants reported having to rely on their employer or employers' relatives for support, whilst most homecare workers said they had good support networks in place. Personal assistants reliance on their employers is likely to be problematic where a conflict of interests arises in the relationship. The development of networks of support for personal assistants may help them to

achieve a more equal power dynamic, especially where their interests are at variance with their employer.

Another method that could help to redress the imbalance of power in the relationship is the registration of direct employees. In chapter 2 I described the move from the late 1990's to modernise social care, including reform of the regulatory and inspection services. In accordance with this homecare workers will be required to register with the General Social Care Council (GSCC) from early 2008, and this will involve the requirement for training and formal qualifications (www.gscc.org.uk). Personal assistants employed by direct payment users however will be exempt from regulation, and this discrepancy contrasts strongly with the trend towards a more skilled care labour market. It follows from the powerful argument made by disabled activists that compulsory regulation of workers would fetter the ability of disabled adults to employ workers of their choice, as many choose to employ untrained and unqualified workers (Campbell 2006; National Centre for Independent Living).

The notion of an untrained, unqualified personal assistance workforce is at the centre of the debate about whether care is a skilled job or unskilled 'women's work'. However excluding personal assistants from registration and training could compound their disadvantage, for as Williams (2001:482) suggests: 'the argument that untrained personal assistants demonstrate better the attributes necessary for good support, because they have not been inculcated with professional attitudes of paternalism, is important. But it overlaps dangerously with arguments that have kept women workers low paid for generations- that they bring with them skills which are natural and need not be valued'.

Exclusion could create a two-tiered care workforce, with an elite of qualified and registered homecare workers, and a second-class workforce of unregistered directly employed personal assistants. A deskilled, deprofessionalised workforce is not in a good position to protect its own interests or enhance the quality of its work.

9.3 Recommendations

The research investigated the effect of money and direct employment of support workers on the care relationship. It adopted a qualitative approach that enabled exploration of the understandings, imaginings, and experiences of the people who took part, and a consideration of the ways in which social processes, institutions and relationships work. It offers insights for the future direction of social care and reveals challenges for both direct and non-direct employment of workers.

In common with other studies, the method of supporting disabled adults used by the local authority, the task-based approach was found to be not only unfulfilling and stressful for workers, it was also disempowering and disliked by homecare users, some of whom were stressed by it. Correspondingly, a report reviewing homecare services for older people in England, argues that limiting homecare support to a prescribed list of tasks does not make practical sense, is not consistent with what people want, and that a more holistic approach is needed (Commission for Social Care Inspection 2006). This leads to the conclusion that a method of providing care that is dissatisfying for all concerned should not continue to be in widespread use amongst local authorities.

The findings from my research indicate the influence of cash in determining the nature of the care relationship, and I would recommend that funding for the support of disabled adults should be increased, as suggested by the Wanless (2006) report. The extra funding could help local authorities to develop a more personalised homecare service, where homecare users have dedicated chosen workers, with more time to develop closer relationships, and both users and workers having greater power to determine the nature and boundaries of their relationships. Greater funding could allow local authorities to pay direct payment rates which ensure direct employers have the ability to offer workers a reasonable salary with good conditions, including training and pension provision for their old age. Better pay and conditions for personal assistants would increase their status, and benefit direct employers too, as their ability to recruit suitable workers would be enhanced.

The government's proposed alternative to traditional service delivery, the provision of cash and direct employment of workers, is consistent with trends towards individualism and the exercise of choice. It is a market-style solution to the demographic 'problems' of providing care. However the research in this thesis raises concerns about the expansion of a system based on the widespread direct employment of support workers. In the local authority researched, direct employment operated to serve the interests of disabled adults, and despite what appeared to be personal assistants' greater satisfaction, held profound disadvantages for an already vulnerable group of workers. Consequently, if this is being replicated in other authorities, it raises the question of whether society should be moving towards a system of support that may (or may not) be cheaper, because it relies on reducing the

pay and conditions of an already lowly paid workforce, and places the bureaucracy on the shoulders of disabled adults.

The power in the direct employment relationship was firmly in the hands of employers, and I would recommend that it should be more equally shared with personal assistants. Whilst this would be controversial and difficult to achieve, unions could open their membership to direct employees and develop methods of supporting them in the workplace. Trade union membership helps workers to operate collectively, to present a united front, and offers the chance to network with others. Unions also provide legal advice and representation in case of disputes with employers, access to education for work based qualifications and information on work issues. In the study many personal assistants lacked basic information about their employment conditions, such as their right to sickness pay, and unlike homecare workers, they had few qualifications and lacked the opportunity to gain these through their employment. At the time of writing personal assistants are not eligible to join Unison, however the union is considering amending this, and is working to develop good practice terms and conditions for people employed through direct payments (Community Care 2006c, 2007).

Another method of supporting personal assistants to achieve a more equal share of power in the relationship could be through the development of networks of support. Carers' organisations such as Carers UK, Princess Royal Trust for Carers, and Crossroads Caring for Carers appear ideally placed to do this and I would recommend this development. Support networks could include: information giving, peer support meetings, 24-hour phonelines, provision of training, newsletters and so forth. At the time of writing there

appears to be nothing of this kind in existence, as numerous phone calls, emails and a comprehensive search of the internet for support for personal assistants was unsuccessful.

I would also recommend that to redress the balance in the relationship, the requirement to register with the General Social Care Council and abide by the National Codes of Practice, should be extended to personal assistants. Registration confers a status on workers (Orme 2001), which would help them in negotiating their interests in the relationship. Registration is associated with training and formal qualifications, providing workers with more options for employment, and thus greater bargaining power with their employers. A national register of personal assistants could also offer the facility to enable workers to organise into a position of collective strength. Based on this research I would also recommend that local authorities amend direct payment schemes, so that they are less onerous and stressful to direct employers. These changes may help to more evenly balance the power within the direct employment relationship, so that it becomes a truly reciprocal, interdependent relationship, which more equally benefits both personal assistants and disabled adults.

9.4 Suggestions for Future Research

The research has highlighted a number of areas where further research would be useful. In chapter 8 I suggested that one of the limitations of this study is that it provides a snapshot picture of the support relationship rather than a longer-term perspective. Research to look at the nature of the direct employment relationship and how it endures and changes over time would be of great interest. Also research to examine the affect of the direct employment

of personal assistants where employers have a cognitive impairment such as Alzheimer's disease or learning disabilities would further develop our understanding of the support that is needed to personalise care in this way.

I conclude my thesis with the same quote used to start the introduction. It was spoken by one of the direct employers in the study when she talked about the relationship with her personal assistant and it prompted the title of this thesis. For me it embodies all of the elements of power, control and autonomy that I found in this research and that are at the heart of cash payments:

I'm the piper, I pay the money

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Appendices

Appendix 1

Eligibility for a Direct Payment

To be eligible for a direct payment an individual must meet one of the following criteria:

1. Be a disabled adult and be assessed as needing

- a community care service within the meaning of section 46 the NHS and Community Care Act (1990); or

2. Be a carer of a disabled adult or have parental responsibility for a disabled child and be assessed as needing a service under section 2(1) of the Carers and Disabled children Act (2000)

3. Be a carer of a disabled adult or have parental responsibility for a disabled child and provide or intend to provide substantial and regular care to a disabled individual or child who needs

- a community care service within the meaning of section 46 the NHS and Community Care Act (1990) or

- a service under the Children Act (1989) section 17

4. Be a disabled young person aged 16/17 years assessed as needing a service under the Children Act (1989) section 17

Individuals must also

- Consent to a direct payment and

- Be able to manage the payment either alone or with assistance and

- Not be subject to certain criminal justice or mental health legislation (see box 1).

Box 1
Mental health/ criminal justice exclusions from direct payments

Direct payments cannot be made to the following people:

1. Patients detained under mental health legislation on leave of absence from hospital;
2. Conditionally discharged detained patients subject to Home Office restrictions;
3. Patients subject to guardianship or supervised discharge;
4. People receiving aftercare or community care as part of a care programme under a compulsory court order;
5. Offenders serving a probation or combination order subject to a requirement to undergo treatment for mental health, drug abuse or alcohol dependency;
6. Offenders released on license subject to an additional requirement to undergo treatment for a mental health condition or for drug or alcohol dependency; and
7. People subject to equivalent Scottish mental health or criminal justice legislation.

Cited in Leece (2003a): sources: 'Direct Payments Guidance: Community Care Services for Carers and Children's Services (Direct Payments) Guidance England 2003', and the Health and Social Care Act 2001

Appendix 2

Numbers of direct payment users in England

Council	3341 30th September 2002	3341 30th September 2003	3341 30th September 2004	3341 30th September 2005
TOTAL	**7,882**	**12,585**	**21,912**	**26,216**
Barking & Dagenham	25.0	22.0	60.0	155.0
Barnet	98.0	145.0	179.0	157.0
Barnsley	22.0	20.0	39.0	78.0
Bath and North East Somerset	17.0	22.0	48.0	64.0
Bedfordshire	46.0	65.0	116.0	163.0
Bexley	14.0	20.0	54.0	75.0
Birmingham	140.0	175.0	345.0	366.0
Blackburn with Darwen	22.0	32.0	73.0	116.0
Blackpool	31.0	43.0	79.0	81.0
Bolton	32.0	67.0	119.0	161.0
Bournemouth	17.0	30.0	77.0	108.0
Bracknell Forest	2.0	6.0	11.0	29.0
Bradford	37.0	50.0	125.0	124.0
Brent	26.0	26.0	39.0	60.0
Brighton & Hove	36.0	78.0	106.0	136.0
Bristol	98.0	113.0	175.0	195.0
Bromley	5.0	9.0	54.0	150.0
Buckinghamshire	40.0	70.0	97.0	348.0
Bury	6.0	16.0	80.0	24.0
Calderdale	29.0	38.0	70.0	87.0
Cambridgeshire	95.0	193.0	187.0	238.0
Camden	66.0	120.0	165.0	170.0
Cheshire	128.0	250.0	402.0	483.0
City of London	0.0	3.0	9.0	9.0
Cornwall	55.0	102.0	952.0	484.0
Coventry	35.0	99.0	196.0	223.0
Croydon	69.0	74.0	205.0	175.0
Cumbria	120.0	200.0	267.0	339.0
Darlington	18.0	35.0	65.0	68.0
Derby	48.0	100.0	148.0	155.0
Derbyshire	103.0	153.0	252.0	285.0
Devon	83.0	120.0	180.0	270.0
Doncaster	30.0	53.0	69.0	79.0
Dorset	58.0	100.0	152.0	212.0
Dudley	8.0	16.0	72.0	113.0

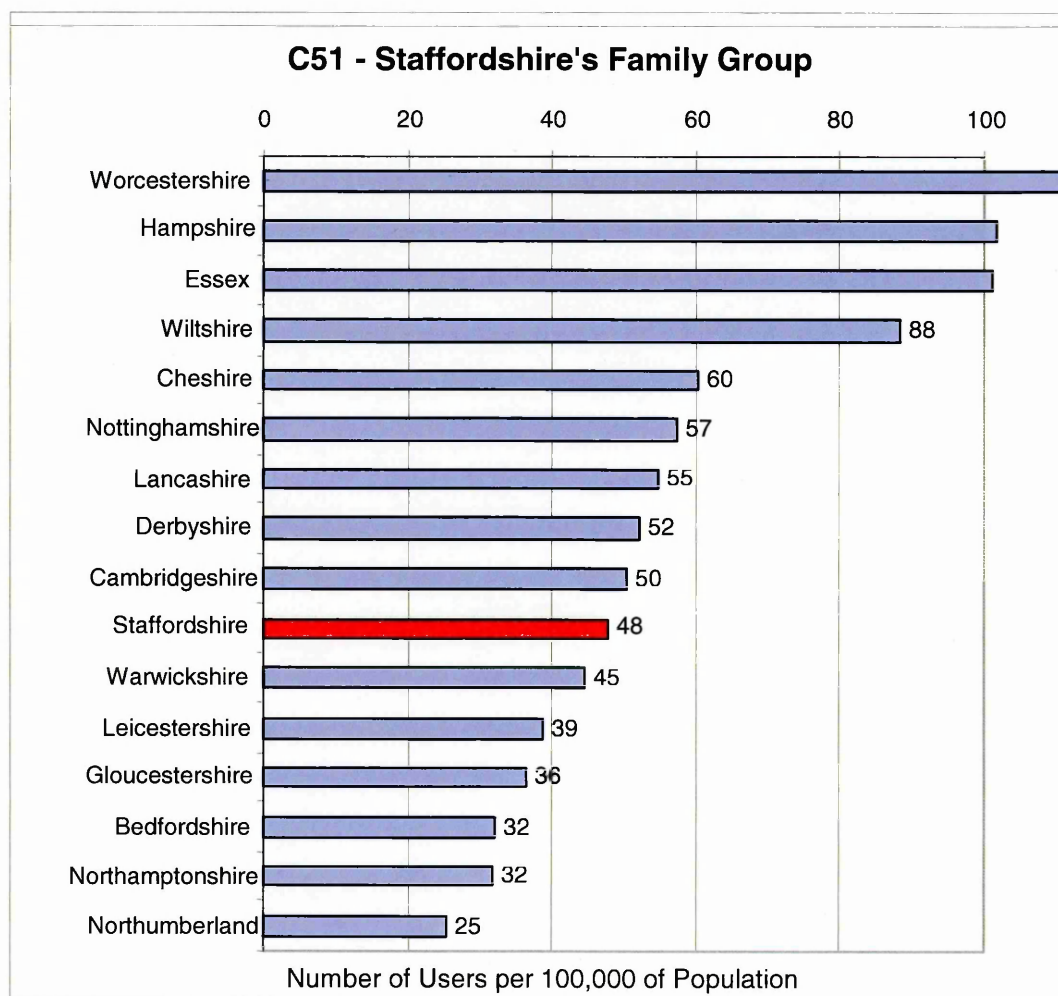|				
Durham	138.0	258.0	341.0	287.0
Ealing	29.0	33.0	62.0	268.0
East Riding of Yorkshire	18.0	71.0	162.0	241.0
East Sussex	92.0	117.0	168.0	158.0
Enfield	21.0	38.0	35.0	100.0
Essex	598.0	816.0	1095.0	1263.0
Gateshead	33.0	67.0	76.0	75.0
Gloucestershire	82.0	97.0	119.0	180.0
Greenwich	92.0	115.0	193.0	223.0
Hackney	26.0	31.0	46.0	96.0
Halton	24.0	61.0	143.0	205.0
Hammersmith & Fulham	27.0	41.0	75.0	103.0
Hampshire	619.0	656.0	751.0	1061.0
Haringey	28.0	51.0	82.0	107.0
Harrow	17.0	31.0	67.0	64.0
Hartlepool	11.0	15.0	21.0	39.0
Havering	3.0	9.0	17.0	39.0
Herefordshire	51.0	56.0	71.0	71.0
Hertfordshire	85.0	161.0	553.0	601.0
Hillingdon	80.0	103.0	147.0	184.0
Hounslow	10.0	90.0	134.0	142.0
Isle of Wight	21.0	41.0	72.0	110.0
Isles of Scilly	0.0	0.0	0.0	0.0
Islington	11.0	35.0	93.0	149.0
Kensington & Chelsea	19.0	25.0	59.0	57.0
Kent	80.0	140.0	371.0	374.0
Kingston upon Hull	9.0	38.0	86.0	113.0
Kingston upon Thames	79.0	81.0	99.0	119.0
Kirklees	87.0	176.0	243.0	237.0
Knowsley	16.0	39.0	65.0	91.0
Lambeth	47.0	73.0	110.0	99.0
Lancashire	137.0	239.0	470.0	646.0
Leeds	61.0	456.0	483.0	165.0
Leicester	63.0	76.0	113.0	220.0
Leicestershire	84.0	128.0	178.0	261.0
Lewisham	32.0	35.0	53.0	76.0
Lincolnshire	124.0	138.0	213.0	213.0
Liverpool	76.0	99.0	185.0	234.0
Luton	12.0	18.0	106.0	84.0
Manchester	137.0	163.0	183.0	269.0
Medway	31.0	47.0	77.0	79.0
Merton	22.0	35.0	44.0	84.0
Middlesbrough	17.0	33.0	36.0	68.0
Milton Keynes	57.0	60.0	67.0	76.0
Newcastle upon Tyne	71.0	91.0	129.0	170.0

Newham	13.0	22.0	41.0	95.0
Norfolk	175.0	362.0	584.0	769.0
North East Lincolnshire	31.0	32.0	48.0	50.0
North Lincolnshire	22.0	24.0	30.0	43.0
North Somerset	41.0	46.0	86.0	98.0
North Tyneside	7.0	11.0	32.0	84.0
North Yorkshire	17.0	33.0	128.0	169.0
Northamptonshire	71.0	66.0	105.0	209.0
Northumberland	10.0	25.0	55.0	102.0
Nottingham	39.0	58.0	93.0	111.0
Nottinghamshire	116.0	237.0	373.0	330.0
Oldham	22.0	53.0	113.0	173.9
Oxfordshire	95.0	145.0	308.0	482.0
Peterborough	17.0	23.0	38.0	44.0
Plymouth	11.0	14.0	41.0	89.0
Poole	19.0	25.0	32.0	83.0
Portsmouth	104.0	84.0	84.0	110.0
Reading	9.0	14.0	27.0	31.0
Redbridge	36.0	40.0	82.0	113.0
Redcar & Cleveland	13.0	28.0	74.0	108.0
Richmond upon Thames	36.0	65.0	115.0	117.0
Rochdale	21.0	56.0	81.0	83.0
Rotherham	20.0	27.0	63.0	207.0
Rutland	3.0	3.0	13.0	17.0
Salford	31.0	63.0	102.0	100.0
Sandwell	12.0	40.0	149.0	67.0
Sefton	32.0	65.0	110.0	136.0
Sheffield	111.0	86.0	143.0	260.0
Shropshire	73.0	95.0	146.0	160.0
Slough	2.0	7.0	32.0	53.0
Solihull	19.0	23.0	60.0	70.0
Somerset	179.0	214.0	288.0	307.0
South Gloucestershire	44.0	63.0	87.0	119.0
South Tyneside	4.0	9.0	102.0	210.0
Southampton	187.0	234.0	258.0	214.0
Southend-on-Sea	22.0	38.0	42.0	55.0
Southwark	31.0	36.0	81.0	85.0
St Helens	15.0	33.0	97.0	121.0
Staffordshire	86.0	133.0	293.0	342.0
Stockport	26.0	77.0	183.0	199.0
Stockton-on-Tees	22.0	30.0	89.0	121.0
Stoke-on-Trent	89.0	115.0	176.0	186.0
Suffolk	49.0	112.0	290.0	329.0

Sunderland	3.0	14.0	382.0	145.0
Surrey	0.0	401.0	516.0	448.0
Sutton	12.0	41.0	53.0	96.0
Swindon	34.0	32.0	48.0	56.0
Tameside	24.0	48.0	83.0	84.0
Telford & the Wrekin	31.0	145.0	184.0	272.0
Thurrock	10.0	21.0	32.0	53.0
Torbay	27.0	25.0	56.0	71.0
Tower Hamlets	11.0	16.0	58.0	85.0
Trafford	29.0	45.0	89.0	85.0
Wakefield	24.0	51.0	94.0	150.0
Walsall	9.0	22.0	55.0	96.0
Waltham Forest	49.0	65.0	92.0	113.0
Wandsworth	10.0	25.0	52.0	57.0
Warrington	31.0	43.0	74.0	106.0
Warwickshire	88.0	113.0	176.0	172.0
West Berkshire	9.0	18.0	39.0	53.0
West Sussex	165.0	162.0	223.0	234.0
Westminster	53.0	70.0	92.0	92.0
Wigan	42.0	85.0	115.0	122.0
Wiltshire	77.0	120.0	222.0	262.0
Windsor & Maidenhead	11.0	19.0	28.0	28.0
Wirral	35.0	100.0	236.0	300.0
Wokingham	7.0	14.0	25.0	42.0
Wolverhampton	10.0	16.0	44.0	58.0
Worcestershire	60.0	58.0	275.0	549.0
York	3.0	2.0	35.0	54.0

Council's Delivery and Improvement Statement data 2005/06 Commission for Social Care Inspection www.csci.org.uk

Appendix 3

Staffordshire's Family Group

C51 - Staffordshire's Family Group

County	Value
Worcestershire	
Hampshire	
Essex	
Wiltshire	88
Cheshire	60
Nottinghamshire	57
Lancashire	55
Derbyshire	52
Cambridgeshire	50
Staffordshire	48
Warwickshire	45
Leicestershire	39
Gloucestershire	36
Bedfordshire	32
Northamptonshire	32
Northumberland	25

Number of Users per 100,000 of Population

2004-05 Benchmarking against Staffordshire Indicator of Performance Family Group (Staffordshire County Council 2006)

Appendix 4

Identifying Relevant Literature in the Literature Review

Literature searches were directed towards studies reporting findings about social care and the support relationship. Searches were conducted via the internet databases: the Bath Information and Data Service: International Bibliography of the Social Sciences and Social Care Online: the Electronic Library for Social Care Institute for Excellence for the period 1990-2005. The following key words were used:

Care relationship, funding care, direct payments, personal assistants, personal assistance, individualised funding, independent living, care relationship, support relationship, cash payments, cash and care, commodification and care, cash and support, homecare, home care, domiciliary care, homecare relationship, home care workers, homecare workers, domiciliary care workers, domiciliary care relationship, nannies, domestic work, nursing relationship, power and care relationship, power and support relationship, independence and support, independence and care, stress and job satisfaction, boundaries and care, boundaries and relationship, boundaries and support, autonomy and care, autonomy and support

The databases generated 9,543 references, although many of these were the same and abstracts revealed that many were not relevant. Documents were obtained for studies reporting research pertinent to the research question. Literature was obtained in my capacity as a commissioning officer working in the direct payments arena. The literature in this thesis thus includes material from all these sources: books, reports by government and other organisations, research articles published in journals, unpublished reports and research articles from internet sites.

Appendix 5

Research Studies Involving Personal Assistants

UK Studies
1. Ungerson (1999) Investigates power and boundary setting in the care relationship. In-depth interviews with 7 personal assistants, no disabled employers involved. Respondents recruited from Centres for Independent Living. A pilot study. Funding body not stated.
2. Glendinning et al (2000a,b,c) Explores whether direct payments have a role to play in overcoming the division between health and social care. Semi-structured interviews with 42 direct payment users (under 65 years), telephone interviews with 13 health and local authority managers, 3 focus groups with 13 personal assistants (some directly employed, some employed by an agency). Funded by DoH.
3. Ungerson (2004)- same study is also reported in Yeandle (2003) Cross national study in 5 countries (Austria, France, Italy, Netherlands, UK). under the ESRC Shifting Boundaries Between Paid and Unpaid Work- Future of Work Programme. Examines whether older people and their support workers are made independent by cash payments. In depth interviews of approx 10 older people and 16 personal assistants in each country- in UK 5 personal assistants were directly employed others employed by an agency. Funded by ESRC.
4. Flynn (2005) Examines how personal assistance is defined, what is currently expected of the role and its future in two areas in the north-west. Focuses on users not workers, discusses training needs of personal assistants. 14 personal assistants, only 6 of these were interviewed one-to-one, 16 users including people with physical disabilities, learning disabilities, older people and mental health needs. All interviewees were offered a fee of £25. Funded by OPARATE -a Skills for Care pilot project.
Other Countries
5. Eustis and Fischer (1991) US study to examine the nature and quality of relationships between homecare users and their professional workers- aim of study was to explore how worker/user relationships are associated with quality of care examined from a user perspective. 54 users, both older and younger people. 39 homecare workers (including 20 who were directly employed) in-depth interviews. Funded by the Blandin Foundation, the university of Minnesota.
6.Askheim (2003) Norwegian study to show how personal assistance is adapted to people with learning disabilities. 6 users with learning disability (aged 12-39 years) took part but were not interviewed due to communication difficulties. They were observed with their personal assistant. Parents of users or representatives were interviewed, as were 6 personal assistants. Study focused on users perspective. Funded by the Norwegian Research Council.
7. Rivas (2003) US study –aim not stated. 8 users with disabilities, 11 personal assistants, 2

former personal assistants interviewed. Funding body not stated.
8. Benjamin and Matthias (2004) US study to examine differences in work-life and worker outcomes in consumer-directed versus agency care as well as between family and non-family workers. Random sample of 618 workers, 253 directly employed and 365 employed by an agency- telephone survey of workers, analysed using factor analysis. No users involved. Funded by US Department of Health and Human Services.
9. Dale et al (2005) US study to describe the experience of workers hired under consumer direction. Compared directly hired workers with those employed by an agency. 391 directly employed workers and 281 agency workers. Maximum time directly employed workers were employed was 9 months most had only been employed for 6 months. Workers had a 20 minute interview. No disabled employers involved or interviewed. Funding body not stated,

Appendix 6

Interview guide: disabled adults

1. So would you tell me a bit about yourself?

   How long you have lived here?
   What is/was your job?
   Ethnic origin

2. Would you describe to me what you do in a typical week

3. And the support you receive from……. What exactly does that involve?

   How many hours of care do you receive each week in total?
   How often do you see your worker?
   What tasks do they do for you?
   Do they do any healthcare tasks for you? (e.g. injections, manual bowel evacuations, physiotherapy)
   Does……. have enough time to do the work?
   Does ……lift you? How do they do this (lift or hoist)?
   Do you sometimes go on holiday? How do you manage for support then?

4. Would you tell me what you like best about the care provided?

5. And what you like least?

6. Moving on to your relationship with…   How would you describe this relationship (friendly, like family, professional)?
   Does……………. tell you his/her worries and concerns?
   Do you share your worries and concerns with ………?
   Does……………..do any jobs for you in their own time?
   Do you do any jobs for ………?
   How are social times managed, if family or friends visit you whilst ……is here:
   - Do you introduced them?
   - Does…….. sit and talk with your family or friends or would you keep them separate?
   - Would……. eat a meal or have a cup of tea with your family and friends?
   If your partner is present would………..
   - Sit and talk with them?
   - Go into a different room and wait to be called if help is required?
   What involvement do you have with …………… family/friends?
   Would you exchange birthday or Christmas cards or presents with………
   Do you ever contact……..at his/her home?
   If there was an emergency with regard to your support whom would you contact?
   Would you describe to me what effect money has in the relationship. Would you for example:

- Buy things from her/his catalogue?
- Borrow or lend money?
- Give or receive gifts of money?
- Buy or sell things to each other?

Would you like ....to provide support in an invisible way, unobtrusively waiting to be called to give assistance? How do you feel about this?

Would you describe to me any aspects of the relationship, which make you make you feel stressed?

What would you say are the good things and bad things about the relationship?

If there are any problems with your relationship with................ how are these resolved?

People often talk about independence, what does independence mean to you?

If a disabled adult were to go out with their partner or friend for a meal, and a homecare worker (or personal assistant) went with them to help, perhaps by cutting up food or assisting them to the toilet. The disabled adult may ask the worker (or personal assistant) to sit elsewhere until needed, so that the disabled adult could talk privately with their partner or friend. What are your views about this?

Who do you think is in control in the relationship?

Why is that?

Do you think the relationship is that of a master and servant with the disabled people being the master and the worker being a servant? What do you think about that?

Have you ever felt concerned for your safety in the relationship?

Is there anything else you would like to say about your relationship with........?

7. Job

Could you describe to me how you see your home care workers/personal assistants job?   High or low status?

8. Future

And moving on to the future could you tell me how you see your future?

Have you ever wanted................to stop providing support for you?

Would you feel able to tell him/her to stop/leave?

Do you feel any personal responsibility towards........?

Do you worry about him/her leaving?

Interview guide: workers

1.Would you tell me a bit about yourself and how you have come to working for...........?

How long have you worked for ....?

How long have you worked as a personal assistant/ homecare worker

What previous jobs have you had?

What made you choose this job?

Age

Qualifications

Ethnic origin

2.Would you describe to me a typical working week?
How many people do you support in total in a week?
How many hours do you work in a week (overall and with this person)?
How often do you see ....?
What support does your employer provide in this job?
Do you do any healthcare tasks for .... (injections, manual bowel evacuations, physiotherapy)?
Have you been trained for all of these tasks?
What training opportunities are there?
What training have you done in this job?
Is there anything you do that you do not feel happy about?
Is there enough time to do all this work?
Do you lift .... how do you do this (lift or hoist)
Do you go on holiday with..................?
If you needed any help/advice in your work, whom would you ask?
Do you feel isolated at all in your job?

3.Would you describe to me what you like best about your job?

4.And what you like least?

5. Moving on to your relationship with........How would you describe this relationship? (friendly, like family, professional)?
Does............. tell you his/her worries and concerns?
Do you share your worries and concerns with ....?
Do you do any jobs for .... in your own time?
Has.......ever asked you to do any jobs for him/her that are not strictly part of his/her job?
How are social times managed if family or friends visit whilst you are there:
- Are you introduced to them?
- Do you sit and talk with them or would you sit separately?
- Would you eat a meal or have a cup of tea with them?
If .... partner is present would you
- Sit and talk with them?
- Would you go into a different room and wait to be called if help is required?
- What involvement do you have with .... family?
What involvement does........have with your family and friends? Would you invite........to your family social occasions?
Would you exchange birthday or Christmas cards or presents with.........?
Does........ever contact you at home?
If there was an emergency regarding...........support whom do you think she/he would contact?
Would you describe to me what effect money has in the relationship? Would you for example:
- Buy things from her/his catalogue?
- Borrow or lend money?
- Give or receive gifts of money?

- Buy or sell things to each other?

How do you feel about providing support in an invisible way, unobtrusively waiting to be called to give assistance?

Would you describe to me any aspects of the relationship or job, which make you make you feel stressed?

What would you say are the good things about the relationship?

And what are the bad things about the relationship?

If there are any problems with your relationship with................ how are these resolved?

Would you describe to me anything you would change about the relationship?

People often talk about independence, what does independence mean to you?

If a disabled adult were to go out with their partner or friend for a meal and a homecare worker (or personal assistant) went with them to help, perhaps by cutting up food or assisting them to the toilet. The disabled adult may ask the worker (or personal assistant) to sit elsewhere until needed, so that the disabled adult could talk privately with their partner or friend. What are your views about this?

Who do you think is in control in the relationship?

Why is that?

Do you think the relationship is that of a master and servant with the disabled people being the master and the worker being a servant? What do you think about that?

Have you ever felt concerned for your safety in your work?

Is there anything else you would like to say about your relationship with........?

6. Future

Moving on to the future, could you tell me how you see your future?

Have you ever wanted to change your job?

Would you feel able to leave the job?

Do you feel any personal responsibility for..........?

Do you worry about losing job or job security?

Appendix 7

Job Satisfaction Questionnaire

Please read this carefully;

I would like you to tell me how satisfied or dissatisfied you feel with each of these features of your present job. Please answer ALL the questions simply by underlining the answer which you think most nearly applies to you.

1. The physical working conditions	I'm extremely dissatisfied	I'm very dissatisfied	I'm moderately dissatisfied	I'm not sure	I'm moderately satisfied	I'm very satisfied	I'm extremely satisfied
2. The freedom to choose your own method of working	I'm extremely dissatisfied	I'm very dissatisfied	I'm moderately dissatisfied	I'm not sure	I'm moderately satisfied	I'm very satisfied	I'm extremely satisfied
3. Your fellow workers	I'm extremely dissatisfied	I'm very dissatisfied	I'm moderately dissatisfied	I'm not sure	I'm moderately satisfied	I'm very satisfied	I'm extremely satisfied
4. The recognition you get for your job	I'm extremely dissatisfied	I'm very dissatisfied	I'm moderately dissatisfied	I'm not sure	I'm moderately satisfied	I'm very satisfied	I'm extremely satisfied
5. Your immediate employer	I'm extremely dissatisfied	I'm very dissatisfied	I'm moderately dissatisfied	I'm not sure	I'm moderately satisfied	I'm very satisfied	I'm extremely satisfied
6. The amount of responsibility you are given	I'm extremely dissatisfied	I'm very dissatisfied	I'm moderately dissatisfied	I'm not sure	I'm moderately satisfied	I'm very satisfied	I'm extremely satisfied
7. Your rate of pay	I'm extremely dissatisfied	I'm very dissatisfied	I'm moderately dissatisfied	I'm not sure	I'm moderately satisfied	I'm very satisfied	I'm extremely satisfied
8. The opportunity to use your ability	I'm extremely dissatisfied	I'm very dissatisfied	I'm moderately dissatisfied	I'm not sure	I'm moderately satisfied	I'm very satisfied	I'm extremely satisfied
9. Relations between the bosses and	I'm extremely dissatisfied	I'm very dissatisfied	I'm moderately dissatisfied	I'm not sure	I'm moderately satisfied	I'm very satisfied	I'm extremely satisfied

the workers							
10. Your chance of promotion	I'm extremely dissatisfied	I'm very dissatisfied	I'm moderately dissatisfied	I'm not sure	I'm moderately satisfied	I'm very satisfied	I'm extremely satisfied
11. The way your employing organisation is managed	I'm extremely dissatisfied	I'm very dissatisfied	I'm moderately dissatisfied	I'm not sure	I'm moderately satisfied	I'm very satisfied	I'm extremely satisfied
12. The attention paid to suggestions you make	I'm extremely dissatisfied	I'm very dissatisfied	I'm moderately dissatisfied	I'm not sure	I'm moderately satisfied	I'm very satisfied	I'm extremely satisfied
13. The hours of work	I'm extremely dissatisfied	I'm very dissatisfied	I'm moderately dissatisfied	I'm not sure	I'm moderately satisfied	I'm very satisfied	I'm extremely satisfied
14. The amount of variety	I'm extremely dissatisfied	I'm very dissatisfied	I'm moderately dissatisfied	I'm not sure	I'm moderately satisfied	I'm very satisfied	I'm extremely satisfied
15. Your job security	I'm extremely dissatisfied	I'm very dissatisfied	I'm moderately dissatisfied	I'm not sure	I'm moderately satisfied	I'm very satisfied	I'm extremely satisfied
16. Now taking everything into consideration how do you feel about your job as a whole	I'm extremely dissatisfied	I'm very dissatisfied	I'm moderately dissatisfied	I'm not sure	I'm moderately satisfied	I'm very satisfied	I'm extremely satisfied

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nferNelson
understanding potential **GENERAL HEALTH**

QUESTIONNAIRE

GHQ 12

Please read this carefully:

We should like to know if you have had any medical complaints, and how your health has been in general, *over the past few weeks*. Please answer ALL the questions simply by underlining the answer which you think most nearly applies to you. Remember that we want to know about present and recent complaints, not those you had in the past. It is important that you try to answer ALL the questions.

Thank you for your co-operation.

HAVE YOU RECENTLY:

1– been able to concentrate on whatever you're doing?	Better than usual	Same As usual	Less than usual	Much less than usual
2 – lost much sleep over worry?	Not at all	No more than usual	Rather more than usual	Much more than usual
3 – felt that you are playing a useful part in things?	More so than usual	Same As usual	Less useful than usual	Much less useful
4 – felt capable of making decisions about things?	More so than usual	Same As usual	Less so than usual	Much less capable
5 – felt constantly under strain?	Not at all	No more	Rather more	Much more

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		than usual	than usual	than usual
6 – felt you couldn't overcome difficulties?	Not at all	No more than usual	Rather more than usual	Much more than usual
7 – been able to enjoy your normal day-to-day activities?	More so than usual	Same As usual	Less so than usual	Much less than usual
8 – been able to face up to your problems?	More so than usual	Same As usual	Less able than usual	Much less able than usual
9 – been feeling unhappy and depressed?	Not at all	No more than usual	Rather more than usual	Much more than usual
10– been losing confidence in yourself?	Not at all	No more than usual	Rather more than usual	Much more than usual
11– been thinking of yourself as a worthless person?	Not at all	No more than usual	Rather more than usual	Much more than usual
12– been feeling reasonably happy, all things considered?	More so than usual	About same as usual	Less so than usual	Much less than usual

Appendix 9

Approval by the OU Ethics Committee for the Research

TheOpen University

M E M O R A N D U M

HUMAN PARTICIPANTS AND MATERIALS ETHICS COMMITTEE

FROM:	John Oates, Chair, HPMEC	**Email:**	**j.m.oates@open.ac.uk**
To:	Janet Leece, part-time p/g student	TEL:	52395
CC:		DATE:	21 June 2006
SUBJECT:	**Review of :** Paying the Piper and Calling the Tune: A Study to Consider How the Opportunity to Pay Workers Using Cash Payments Affects the Support Relationship.	Ref:	HPMEC/06/#212/1

This memorandum is to confirm that the ethical protocol that was followed for this research project has been reviewed and found to be in general compliance with the principles and policies of the Open University Human Participants and Materials Ethics Committee

John Oates
Chair, OU HPMEC

Appendix 10

AGREEMENT TO PARTICIPATE AND CONSENT TO USE INFORMATION GIVEN IN THE INTERVIEW

Name of Research Project: A study of the relationship between disabled people and the workers paid to provide their support.

Name of Institution: The Open University

Name of Researcher: Janet Leece

Contact Telephone Number: 01782 631527

Contact Address:10 The Glade, Westbury Park, Clayton, Newcastle, Staffordshire, ST5 4NG

I have been given information about the research project and the way in which my contribution will be used. It has been explained to me how the transcript of the interview will be kept confidential unless I give permission for my name to be used.

My contribution will be kept safely and securely with access only to those with permission from the researcher.

I understand that I can withdraw my consent at any time by simply saying so.

If I wish to complain about any aspects of my participation in this project I can contact the Associate Dean (Research) at: The Open University, School of Health and Social Welfare, Walton Hall, Milton Keynes, MK7 6AA. Telephone 01908 274066

I understand that the researcher may need to disclose certain information if it is revealed that a person is at risk of serious harm.

I give permission for the interview, which I am about to give/have given for the above project to be used for research purposes only (including research publications and reports) with strict preservation of anonymity.

I herby assign the copyright in my contribution to Janet Leece.

Signed---

(Interviewee)
Date---

Signed---
(Researcher)
Date---

Appendix 11

Statement read to each respondent

I am a part time PhD student with the Open University and I also work part time for Staffordshire County Council as a Commissioning Officer. The research I am undertaking is a study of the relationship between disabled people and the workers paid to provide their support.

I would like to interview you as part of this study. The interview will be tape recorded and then transcribed, that is everything on the tape will be typed out into written format. The tapes and transcripts will be kept in a locked filing cabinet. Information will be entered into my computer for analysis and this will be protected by a password.

At the end of the interview I will ask you to sign a form to say that you agree to participate in the study and that you consent to information given in the interview being used for research purposes, such as a research dissertation and research publications.

Your contribution will be kept anonymous and your name will not be identified. Your name will not be revealed in any publication.

The form will also ask you to assign the copyright of your contribution to me, as when an interview is recorded the person who speaks the words owns the copyright. By assigning the copyright to me it means that I will have the sole right to use material from the interview for research purposes.

Appendix 12

Letter to possible respondents

Dear

Research study

I am a part-time PhD student with the Open University and also work part-time for Staffordshire County Council. For my PhD study I am researching the relationship between disabled people and the workers employed to provide their support/care.

For this study I wish to interview people receiving homecare/direct payments from Social Services and also a homecare worker/personal assistant employed to provide their support/care. I am able to offer a small thank you to each person interviewed. This will be a £10 shopping voucher (from the shop of your choice) or £10 in cash.

The interviews will take approximately 60-90 minutes each and will be tape recorded. They could take place in your own home or a mutually convenient place. Material from the interviews will be used to produce a research thesis and publications in academic journals. People's identity will be kept anonymous in these.

I want to assure you that your choice either to take part in the study or not will have no affect on any services which you receive from Social Services.

If you are interested please return the attached form in the pre-paid envelope or telephone me on 01782 631527 or email <u>DLeece@aol.com</u>

I look forward to your reply
Yours Sincerely

Form for reply

I am interested in taking part in the Open University PhD research study.

Name...
........................…..

Address...
....
....

....
....
....
....
....

Contact phone number...

Email
address...
....

Appendix 13

Letter to consumer researchers

Dear Researcher,

Consumers as Researchers Course- Staffordshire University

I do hope you don't mind me writing to you. I am a part-time PhD student with the Open University and also work for Staffordshire Social Services. For my PhD study I am researching the relationship between disabled people and the workers they employ to provide their support/care. The research will focus on disabled people who receive a direct payment from Social Services.

I am very keen to involve user/consumer researchers in the development and design of my study, as I feel this will make it far more effective. I am aware that you have recently attended a Consumer's as Researchers Course at Staffordshire University and would like very much to discuss my study with you to gain your views. This would involve my explaining the study and discussing the proposed research methods and interview schedule with you, for your comments.

I'm not able to make any payment for this unfortunately, as my study is entirely self-funded. I would be most grateful for your help. If you are interested please contact me at the above address or telephone 01782 631527 or email DLeece@aol.com

We can then arrange the best way to proceed. I could visit you at home, or discuss my study on the telephone or by email.

I look forward to your reply

Yours Sincerely

Mrs Jan Leece

Appendix 14

Letter for developmental study

Dear

Research study

I am a part-time PhD student with the Open University and also work part time for Staffordshire County Council. For my PhD study I am researching the relationship between disabled people and the workers employed to provide their support/care.

I am at present piloting this study. I wish to interview people receiving homecare from Social Services and also a homecare worker employed to provide their support/care. I am able to offer a small thank you to each person interviewed. This will be a £10 shopping voucher (from the shop of your choice) or £10 in cash.

The interviews will take approximately 60-90 minutes each and will be tape recorded. They could take place in your own home or a mutually convenient place. Material from the interviews will be used to produce a research dissertation and publications in academic journals. People's identity will be kept anonymous in these.

I want to assure you that your choice either to take part in the study or not will have no affect on any services which you receive from Social Services.

If you are interested please return the attached form in the pre-paid envelope or telephone me on 01782 631527 or email <u>DLeece@aol.com</u>

I look forward to your reply
Yours Sincerely

Mrs Jan Leece

Appendix 15

Pen Pictures of Respondents

Brief details of respondents are detailed below. All the information was gained during the interview. Respondents are placed in their pairs with users followed by the worker supporting them.

Direct Payment Users and Personal Assistants

Karen (DP User)

Karen has been a widow for 3 years. She previously had her own catering business, which she ran with her late husband, but had to give this up when he died. She has 5 children and was diagnosed with M/S some years ago. Karen has received a direct payment for 22 hours of support each week for one year. She employs one PA whom she has known for a number of years to support her. They met whilst taking their children to school.

Joy (PA)

Joy is Karen's PA, she lives with her partner and children. Joy's employment background is in domestic cleaning and working in a residential home for older people.

Linda (DP User)

Linda works as a qualified panel member for the disability appeals service 2 days a week and undertakes range of voluntary work. Linda was born with cerebral palsy, and is a wheelchair user; she also has unclear speech. Linda married 2 years ago and has been receiving direct payments for 2 years to employ 4 PA's. The direct payment is for 23-25 hours each week.

Sue (PA)

Sue is one of Linda's four PA's. On the day I interviewed her she was leaving employment with Linda to be a healthcare assistant to increase her working hours. Sue also works evenings as a homecare worker for Staffordshire social services. Sue first met Linda 8 years ago in her capacity of a homecare worker employed by an independent agency. She has provided 6 hours of support each week for the last two years.

Gemma (DP User)

Gemma was born with cerebral palsy. She is a wheelchair user and has unclear speech. She works one day a week as a clerical assistant at a college. Gemma employs four PA's to provide 24-hour support 7 days per

week, funded partly by the ILF and partly by a direct payment. Two of the PA's work 48-hour shifts and two work 24-hour shifts. This includes sleeping at Gemma's home. She has her own car, which the PA's drive.

Mim (PA)

Mim is one of Gemma's four PA's. She was made redundant some years ago from her position as a sales demonstrator, and got a job supporting people with learning disabilities leaving residential care to live in the community. Mim worked there for about four years and then applied for the job with Gemma where she has worked for five years. Mim works two 13-hour shifts and two-sleep-ins. She works from 19.00 hours on Monday through to 19.00 hours on Wednesday. Mim lives with her husband who is retired

James (DP User)

James had an accident 5 years ago, which left him unable to walk or stand. He uses a wheelchair. James is divorced with 3 children. He looks after his youngest child during school holidays and after school. James had his own scaffolding business, but had to give this up after the accident. He started receiving direct payments 2 years ago, and uses them to employ his aunt. He usually has 8 hours of support each week.

Dot (PA)

Dot has worked as James' PA for 2 years, and presently is employed for 13 hours per week over 7 days. She previously worked as a cook in a social services nursery and retired from this 2 years ago. Dot is married with a number of grandchildren and great grandchildren. One of her sons is a wheelchair user.

Freda (DP User)

Freda has used direct payments for two years. Prior to this she employed her PA's privately after deciding that social services homecarers were not supporting her as she wanted. Freda now has 10½ hours direct payment per week and pays for some care herself, employing 3 PA's. Freda had brain surgery about 20 years ago and now has difficulty standing or walking. She is registered partially sighted and is hard of hearing. Freda lives with her husband.

Liz (PA)

Liz is employed by Freda for 15 hours per week, 6 of which are funded by the direct payment and 9 are paid for by Freda herself. Liz works for 3 hours each morning Mon-Fri and been employed for 18 years after responding to an advert. Liz previously worked in Boots and had no experience in care work other than caring for children. She does no personal care for Freda, but does gardening, cooking, cleaning and shopping. Liz is married with 3 grown-up daughters who live away from home.

Wanda (DP User)

Wanda employs 3 PA's. She had Parkinson's disease for 20 years and was diagnosed with breast cancer a year ago. Wanda lives alone following the break up of a 30-year relationship. She has moved around the country and run a wool shop, a restaurant and 6-bedroomed pub; she is now retired. Wanda has 2 sons, but she sees them rarely following an argument. Two of Wanda's PA's provide sleep-in cover between them and some support during the day, and the other (Win) works 5 mornings a week.

Win (PA)

Win is one of Wanda's PA's. She previously worked as a store detective for 23 years and then as a civilian in the police for 12 years. Win retired when she was sixty, but said she was bored. She applied for the job with Wanda and has been employed for about a year. She is divorced and lives alone.

Harry (DP User)

Harry had an accident 5 years ago when he fell from a hotel balcony where he was staying on holiday with his parents. He sustained severe head injuries and now has vision problems, unsteady mobility and impaired use of his left arm. At the time of the accident Harry was 18 and taking his A-levels. He is now attending university doing a BSc in computer science. Harry receives a direct payment for 16 hours per week.

Tom (PA)

Tom is a university student who works for Harry. They met whilst studying the same foundation course for their degree and became friends. Tom helped Harry informally without pay during the foundation course, and started to work for him formally two months before my study took place. He is paid for 16 hours supporting Harry by taking him to university, carrying books, helping him to get about the university, some note taking and help with course work. Tom has a partner and 14 month-old-daughter for whom he also provides some care. Tom has worked previously in shops, petrol stations, factories and warehouses.

Peter (DP user)

Peter was diagnosed as an insulin dependent diabetic 22 years ago. Six years ago the condition worsened, and sometimes he becomes unconscious, which could be fatal if he does not receive the correct treatment. Peter has poor mobility and uses a wheelchair, although he owns and drives a car. Peter was recently diagnosed with cancer of the bowel. He has 24-hour care and employs two PA's, one of whom lives-in (Ian), and the other works from 10.00-16.00 3-days a week as respite for Ian. Peter received a direct payment and ILF to fund his support for the last 2 ½ years.

Peter previously worked as a barrister. After becoming disillusioned with the legal system he worked as a journalist (court reporter) for various newspapers in Fleet Street, which led him into publishing, where he owned a publishing company and also worked as a management consultant. He retired 6 years ago. He has been married and divorced three times.

Ian (PA)

Ian provides live-in support to Peter and does not have a home of his own. Previously he worked supporting people with M/S and in a daycentre. Ian was unemployed when he met Peter; they became friends and he began helping Peter without payment. Ian does the cooking, shopping, laundry, pet care, laying coal fires, domestic cleaning as well as helping with personal care. He provides sleep-in care during the night. His family live abroad although he does have a sister in this country who visits him with her children.

Homecare Users and Workers

Brenda (Homecare user)

Brenda worked as a police officer until 1994, when she had a nervous break down. She then did an access course, a degree in integrated astrophysics and later a masters degree. She is studying for a PhD, however 9 months after she started Brenda had a road accident, spending 3 months in hospital. She returned to university and in February 2003 had a stroke. Following the stroke she is completely paralysed down her left side and is in pain. She is a wheelchair user. Brenda receives 2 hours of support per day 7 days a week. This is delivered by four 30-minute visits, although sometimes the assessed amount of care (14 hours per week) is not enough, and she has to pay a surcharge for extra care.

Jane (HCW)

Jane worked as a housewife until her son started work. She then worked in a care home for 2-3 years, and joined social services as a homecare worker 5 years ago. She works part-time 18.5 hours per week in the evenings helping people into bed. She has provided support for Brenda for about 5 months, for about 2½ hours per week.

Jackie (Homecare user)

Jackie lives with her second husband. Between them they have 7 adult children. She was diagnosed with MS in 1991 and uses a wheelchair. Prior to her illness she worked as an engraver and a fork lift truck driver. Jackie has unclear speech and her husband was present at the interview to help her to take part. She receives homecare of 10 hours per week over 5 days Mon-Fri. Her husband retired early in 2003to care for her. Jackie attends a social services daycentre 5 days a week and goes to a respite home run by the M/S society 6 times a year.

Tess (HCW)

Tess has been working for social services for the last ten years as a home care worker. She works part-time 20-25 hours and has been supporting Jackie (5 hours a week) for the last 2 years. Tess worked previously as a school dinner supervisor and cleaner. Tess also cares for her husband whom she described as in the early stages of Alzheimer's disease.

Rachel (Homecare user)

Rachel lives with her second husband and 15-year old son. He no longer attends school, as he was bullied; he provides some care for his mother. Rachel worked in the pottery industry for 12 years, but had a back injury causing her to leave work. The clay dust has affected her lungs resulting in bronchitis and asthma also arthritis and joint pain. Rachel uses oxygen from a cylinder at night and a wheelchair on occasions. She receives homecare usually by 3 regular workers; one visit 7 times a week of varying time depending on the support provided. She receives 5 ½ hours of care per week.

Jill (HCW)

Jill worked as a qualified chef in various restaurants, a children's home and for in a care home for older people. She became bored and volunteered to become a counselor, joining social services in January 2004. She hopes to become a social worker eventually. Jill lives with her husband and three daughters. She works part time 20-25 hours per week. Jill has been providing support to Rachel for 2½ months, visiting 3-5 days per week.

Trevor (Homecare user)

Trevor was injured in a diving accident in Spain twenty-two years ago. He worked as a sheet metal worker before the accident, but has not worked since. He has spinal injuries and uses a wheelchair. He lives alone in a bungalow and receives some of his support from district nurses (bowel care and help to bed) and 15½ hours of care per week from social services. Homecare workers help him to wash, dress, shower, help out of bed, prepare meals and hot drinks.. He has 5/6 main workers, but many others visit to provide support. He has known Beth for a few years.

Beth (HCW)

Beth lives with her husband and children. She has worked in a factory making wires for cars and part-time evening work in a shop. She also looked after her mother who had Parkinson's disease. Beth has worked for social services for the last 4 years. She works part time 15-20 hours, and provides about 5 hours of support each week over 5 days for Trevor.

Jeanne (Homecare user)

Jeanne lives with her husband and has two grown up children living nearby. She worked in the pottery industry and in a snack bar part-time. Jeanne was diagnosed with M/S 22 years ago, and had a minor stroke in 2003. She is a wheelchair user. She has 11½ hours care provided by social services each week. Jeanne's husband retired early to help his wife; they also pay a domestic cleaner privately. A district nurse visits on occasions as Jeanne has a catheter.

June (HCW)

June worked in the pottery industry for 6 years, and did a counseling course, as she was bored with her job. She got a part-time job with a private care home, and then left to work for social services where she has worked for 6 years. She lives with her partner and young daughter. She works 25-30 hours per week. June has known Jeanne for 6 years and been one of her main workers for the last 3 years. She visits her 5-7 days a week depending on the shift pattern and provides 3½ -4½ hours of support each week

Sandra (Homecare user)

Sandra has had rheumatoid arthritis for the last 18 years. She uses a wheelchair, and can walk short distances. Before her illness Sandra was a book-keeper for the business she and her ex-husband started. She is divorced with 3 children who live nearby. She attends a daycentre twice weekly. She receives 3 homecare visits a day, seven days a week. These are two 15-minute calls and a 1¼ hour call at lunch time. In total she receives 12½ hours care per week.

Lucy (HCW)

Lucy has worked for social services for 22 years. Prior to this she worked for the post office and at a hospital. She is presently working full time. Lucy has known Sandra for years and has been a regular worker for her for about 18 months; she provides 3¾ hours of support over three days a week. Lucy is separated from her husband and lives alone. She has a daughter who lives nearby.

Daniel (Homecare user)

Daniel worked at British Steel in quality control until he had an accident on a motorcycle in 1988. This left him paralysed from the neck down and he uses an electric wheel chair. He has not worked since. Daniel married 18 months after the accident, and lives with his wife in a bungalow. His wife works full time. From Monday to Friday he has 4 visits a day of ½ hour to provide and help him drink a hot drink and empty his catheter bag, then one visit of ¾ hour to make a sandwich and drink at lunchtime. Daniel's wife provides all other support for him. During the week he stays at home watching sport on TV or goes into his garden.

Anne (HCW)

Anne has been working for social services for ten years. Previously she worked in a bakery for six years then four years in a nursing home. Anne lives with her husband and works part-time (20-25 hours per week). She provides support to around five different people each week. Anne has been supporting Daniel for 8-9 years.

Mathew (Homecare user)

Mathew was diagnosed with motor neuron disease eight years ago. He is unable to use any of his limbs, and uses a wheelchair and voice recognition computer. He lives with his wife, who provides some care, and an adult son. Mathew is a retired teacher. He has received help from social services for four years and has 21 hours of homecare a week. He has three visits per day, two of these are 30 minute 'toileting' visits where just one worker helps him. Two workers help Mathew wash, and he has a 'sitting service' one afternoon a week for 3 hours to enable his wife to go out.

Jess (HCW)

Jess has been working as a home care worker for 11 years. She worked prior to this as a 'dinner lady', 'lollipop lady' and a childminder. Jess works 25 hours per week. She has been supporting Mathew for about 2 years, visiting him for 8¼ hours per week over 5 days. She helps him out of bed, operating the hoist with the help of his wife and assists him to the toilet. She returns later with another worker to help Mathew to shower. Jess occasionally sits with Mathew for 3 hours whilst his wife goes out.

Appendix 16

Conditions of Employment

Please answer the following questions by underlining the answer that applies to you.

Do you receive sick pay?	Yes	No	Don't Know
Do you receive holiday pay?	Yes	No	Don't Know
Do you have access to a pension scheme?	Yes	No	Don't Know
Are you a member of a trades union?	Yes	No	Don't Know
Do you get compassionate leave?	Yes	No	Don't Know
Do you receive extra payments for working unsociable hours?	Yes	No	Don't Know
Are your hours of work guaranteed?	Yes	No	Don't Know
Do you receive paid travelling time?	Yes	No	Don't Know
What is your hourly rate of pay?	£..............per hour		

Appendix 17

Thank you letter sent to respondents

Dear

Research Study

Thank you very much for taking part in my research study. I am very grateful for your contribution, which is enormously valued. It was very good of you to spare the time to talk with me.

I also enjoyed meeting you very much!!

Thank you very much for your help.

Yours sincerely

Jan Leece

Appendix 18

Letter sent to people who had offered to take part

Dear

Research Study

Thank you very much for offering to take part in my research study. The response to my request was very high and I have now completed this section of the study. I will therefore not need to interview you. However it was very kind of you to offer and I am most grateful.

Thank you very much.

Yours sincerely

Jan Leece

Appendix 19

Words associated with boundaries

Words associated with boundaries used by direct employment sample				
Direct Payment users			**Personal Assistants**	
Word Searched	**Number of Relevant Times Used**	**Number of respondents using word and amount of Times used**	**Number of Relevant Times Used**	**Number of respondents using word and amount of Times used**
Boundary/ies	2	(Linda, James) 2	1	(Sue) 1
Line/s	3	(Peter, Gemma) 2	0	
Limit/s	0		0	
Rule/s	1	(Gemma) 1	0	
Allow/ed	0		1	(Sue) 1
Regulation/s	0		0	
Distance/s	0		1	(Win) 1
Attach/ed	0		3	(Ian) 1
Total number of times used	6		6	

Words associated with boundaries used by non-direct employment sample				
Home Care users			**Home Care Workers**	
Word searched	**Number of Relevant Times Used**	**Number of respondents using word and amount of Times used**	**Number of Relevant Times Used**	**Number of respondents using word and amount of Times used**
Boundary/ies	0		2	(Jill) 1
Line/s	2	(Trevor, Sandra) 2	9	(Anne, Jane, Jill, Beth) 4
Limit/s	1	(Trevor) 1	2	(Beth) 1
Rule/s	0		3	(Tess, Jane, Jess) 3
Allow/ed	16	(Daniel, Brenda, Rachel, Jackie) 4	10	(Anne, Lucy, Jane, Jill, Beth, Tess) 6
Regulation/s	0		0	
Distance	1	(Trevor) 1	2	(Anne, June) 2
Attach/ed	0		7	(June, Jill, Beth) 3
Total number of times used	**20**		**35**	

Appendix 20

Words associated with infantilising language

Words associated with infantilising language				
Personal Assistants			**Homecare Workers**	
Word Searched	**Number of Relevant Times Used**	**Number of Respondents Using Word**	**Number of Relevant Times Used**	**Number of Respondents Using Word**
Boy	0		1	(Anne) 1
girl	0		1	(June) 1
normal	0		3	(Anne) 1
naughty	0		3	2 (Anne, June)
child	0		0	
children	0		1	(June) 1
demanding	0		9	(June, Jill, Beth) 3
baby	0		0	
babies	0		1	(June) 1
Total number of times used	**0**		**19**	

Appendix 21

Words associated with workers low status

Table 1	Words associated with workers' low status			
Personal Assistants			**Homecare Workers**	
Word Searched	Number of Relevant Times Used	Number of Respondents Using Word	Number of Relevant Times Used	Number of Respondents Using Word
girls	2	(Sue) 1	52	(Anne, Lucy, Tess, June, Jane, Jill, Jess, Beth) 8
girl	2	(Sue) 1	9	(Anne, Lucy, Tess, June, Jane, Jill) 6
Total number of times used	**4**		**61**	

Table 2	Words associated with workers' low status			
Direct Payment Users			**Homecare Users**	
Word Searched	Number of Relevant Times Used	Number of Respondents Using Word	Number of Relevant Times Used	Number of Respondents Using Word
girls	5	(Linda) 1	26	(Brenda, Jeanne, Trevor, Sandra, Rachel, Jackie) 6
girl	1	(Linda) 1	4	(Daniel, Brenda, Rachel) 3
Total number of times used	**6**		**30**	

Appendix 22

Words associated with stress and dissatisfaction

Words associated with stress and dissatisfaction				
Personal Assistants			**Homecare Workers**	
Word Searched	Number of Relevant Times Used	Number of Respondents Using Word and amount of times used	Number of Relevant Times Used	Number of Respondents Using Word and amount of times used
Stress	1	(Tomx1) 1	0	
Stressful	3	2 (Tomx2)(Ianx1)	3	2 (Janex2)(Annex1)
Pressure	2	2 (Mimx1)(Ianx1)	0	
Anxious	1	(Mimx1) 1	0	
Anxiety	0		0	
Worry	11	4 (Mimx1)(Tomx5) (Ianx4)(Suex1)	6	4 (Lucyx1)(Tessx1) (Janex2)(Jillx2)
Worried	4	2 (Ianx2)(Lizx2)	4	2 (Jillx3)(Bethx1)
Hassle	0		0	
Strain	0		0	
Upsetting	0		1	(Annex1) 1
Upset	0		9	5 (Jillx2)(Lucyx2) (Tessx1)(Junex1) (Janex3)
Concern	0		0	
Concerned	0		1	(Janex1) 1
Total number of times used	**22**		**24**	