

Social Relationships and Disabled People: the impact of direct payments

Sarah Lesley Woodin

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Abstract

This thesis investigates how and why social relationships develop in circumstances where disabled people employ personal assistants to help with aspects of daily living. The concept of public and private spheres of action are used as an analytical tool in recognition that while houses are places for living for disabled people, they are workplaces for personal assistants, and because policy initiatives have sought to influence home living arrangements.

Several underresearched areas are investigated. Family Studies has overlooked disabled peoples' experiences as members of families, in favour of an emphasis on 'care'. Disability Studies has ignored the family and interpersonal relationships in favour of identifying and challenging social barriers to public sphere participation by disabled people. Consequently important oversights have been made. An understanding of how disabled employers, personal assistants, family members and friends organise daily life in practice may inform the commentaries that have been offered on how personal assistance arrangements ought to be made.

Relationships between disabled people and family members and friends improved substantially as a consequence of direct payments, as both disabled people and family members were able to exercise choice about the degree and nature of their association.

Personal assistance relationships were reciprocally influenced by structural relationships within families and households. In particular, the relative amount of autonomy exercised by disabled people within their homes had a large bearing on whether personal assistants were characterised as 'paid friends' or employees. The construction of personal assistants as either friends or employees is shown to be a purposeful management strategy for many rather than a personal failing, with decisions being made in the structural context of family life and the public understanding of Independent Living.

Abbreviations

BCODP	British Council of Disabled People
CIL	Centre for Independent Living
DLA	Disability Living Allowance
DP1	Disabled Peoples' International
ILM	Independent Living Movement
NCIL	National Centre for Independent Living
P.A.	Personal assistant
U.K.	United Kingdom

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Chapter 1

Introduction

This thesis is about direct payments and the arrangements that disabled people make with personal assistants on a daily basis. It illustrates what personal assistance means for disabled people's social relationships with family members and friends and why people take particular courses of action. Direct payment is a policy initiative that shifts resource allocation from workers employed by local authorities to the provision of cash grants to people using social services. The effect of this is to allow disabled people and others to choose their own staff (personal assistants), who are then employed directly by people receiving the help. Because the base for personal assistants is their employers' homes, and because the intention is to assist employers with their daily lives, there is the potential for the paths of assistants and family members / friends to cross, and even when not directly in contact with one another, personal assistance may impinge on or influence social relationships with other people. These are the issues discussed in this study. The focus is on the lived daily lives of disabled people, their family members, friends, and the personal assistants who are employed after payments have been received, and the differences made to social relationships over time.

Why Direct Payments and Social Relationships?

This research covers new ground in two main respects. Firstly, the subject area has not been covered adequately before. There is a growing volume of work concerned with direct payments but authors have tended to approach the subject area from one particular vantage point only, resulting in an incomplete picture.

One body of research has considered how national and local government policies have developed in response to a variety of influences and the way that directives have been implemented in practice by local authorities. The present study has relevance to these social policy concerns. Good social relationships have been linked to personal well-being and health (Acheson, 1998; Black, 1988) and social inclusion of people who are or may become marginalized is a focus for New

Labour intervention. Direct payments (also sometimes termed individual budgets) is a key area of policy development, and government guidance contains an expectation that social inclusion will be strengthened as a result of the measures (Department of Health, 2000b). Furthermore, the intention is that direct payments will become more prevalent and for a larger number of users (Mandelstam, 2004). Local authorities are now compelled to offer direct payments, a provision of the 2001 Health and Social Care Act that came into effect from April 2003. Studies about policies and practice (e.g. Glasby & Littlechild, 2002) represent just one angle on how direct payments are working out for recipients. In the absence of information on how disabled employers use direct payments in daily life, some commentators have made judgements about how relationships with personal assistants *should* be (Department of Health, 2004; Vasey, 1996). This study provides information on what is happening in daily life in practice.

This research has relevance for the increasing numbers of people receiving direct payments and those who may become recipients. Disabled people have lobbied hard for increased control over the manner in which services are provided as indeed have organisations representing the interests of family members. Ultimately such measures only make sense if they are translated into perceived improvements identified by the people involved.

It may seem obvious to say that social relationships involve more than one person, but within sociology at least studies have rarely considered the perspective of more than one of the parties involved. Some have studied the perspectives of disabled people only (e.g. Watson, 2002), and others the points of view of personal assistants only (e.g. Mears, 2005; Ungerson, 1999). There are also a large number of studies that consider family and social relationships, from which disabled people and personal assistants are largely absent (e.g. Williams, 2004). Often these separate projects do not reflect the way that disabled people actually live their daily lives as part of social and work groups. Respondents in the present study took into account one another's circumstances, and the decisions people took were profoundly affected by those made by others.

Disability Studies scholars have pointed out that family and community affiliations form a central point of reference for many disabled people, as they do for most of the population (e.g. Priestley, 1995; Watson, 2002). However, this acknowledgement has been tangential to other concerns. Disability Studies has important links with the Independent Living Movement (ILM), which seeks to improve the circumstances of disabled people in society. As such there has been much debate about where the focus of campaigning should be and correspondingly, the focus for academic study (Oliver, 1992). It is difficult to know what a campaign based on social relationships would look like and the degree to which it would be appropriate. Ambivalence surrounding these concerns has meant that the study of social relationships has received scant attention in Disability Studies, with family and social relationships placed in the category of personal experience, despite the fact that family and living arrangements may also be viewed as societal structures. As a result of this, at times the social affiliations of family and friends have almost been portrayed as if they are counterpoised to political participation. In consequence, the study of social relationships has largely been left to medical researchers and academics who share that perspective.

Studies concerned with domestic employment have often emphasised the low status of working conditions for poorly paid, working class, mostly female workers (e.g. Ungerson, 1997; 2003). This research also has its counterpart outside academia, even if the link is not explicit. The agenda here is about improving the working conditions for people doing 'caring' work, whether this is paid employment or that which takes place as part of the gendered division of labour within households, where women do most of the work (Holzhausen, 2002). There may be a purposeful blurring of the distinction here between paid and unpaid work. Because of this, these studies share some ground with Family Studies research. Disabled people have been largely absent in both Family Studies research and that into the working conditions of domestic workers, except as the recipients of 'care' (Ungerson, 2003). Due to this focus, social relationships between disabled people, family members and paid workers have been omitted as an area of concern from these areas of research.

Therefore both Disability Studies and Family Studies, for different reasons, overlook the study of social relationships, kinship and friendship with regard to disability. This thesis will address the omission in the context of direct payments.

Secondly, the research is important in its own right: the findings shed new light on unexplored areas of social and work life. As will become apparent during the course of the thesis, knowledge about direct payments and personal assistance is not readily available to all people in the course of daily life. This is because the location of personal assistance is often in the home, a space that is essentially private to the people living there, and because personal assistance may be presented in different ways in various social contexts. Another reason why personal assistance arrangements are not readily apparent to observers is because of the range of different forms that they may take. Diversity as well as similarity is characteristic. Knowledge of one instance is not enough to give a full picture of the broader dynamics which shape this form of assistance.

Key Questions, Themes and Issues

The questions asked in the study (see also the following chapter) look at social relationships in several ways. Changes and continuity in employers' relationships with family and friends over time, the relationships between personal assistants and employers, and the relationships between all three parties are discussed. While much of the thesis has to do with relationships based in and around the home, how relationships are shaped by different social contexts outside the home provides a broader perspective on the topic.

Relevance to Debates

This study engages with some key debates. Firstly an issue has centred on who should receive cash grants/direct payments. While initially funding was made available to people with physical impairments, in recent years provision has been expanded to more user groups, including 'carers' who provide help to disabled people. At the time of writing there remain flashpoints for disagreement over how disabled people should manage direct payments (e.g. regarding the need for

formalised structures and agreements with personal assistants) and what the money may be spent on. This thesis relates to these debates in that it points out the variation in how payments were made in different areas and the differences between official policy and implementation. Further questions are raised about policy, such as the extent to which measures should legitimately be concerned with shaping home life.

Secondly, issues about the nature of 'care' are raised. Importantly there tends to be an assumption in much of the Family Studies literature that 'care' is essentially benign in nature. This thesis shows that this cannot be assumed, and that 'care' can be either outright abusive or pernicious in its ability to undermine social connectedness, as well as helpful and supportive. The term is therefore used in inverted commas, to denote its contested meanings. Questions are raised about the continued casting of disabled women and also some men, as passive recipients of assistance in the light of the large amount of helping they do for other family members and friends, especially when in receipt of direct payments. Given that someone may only be defined as a 'carer' if there is someone else who they 'care for' this brings into question how meaningful clear distinctions between the two parties are and the degree to which they overlap with reciprocity characteristic of kinship and friendship, at least for some employers, including those who participated in this study.

Disabled parents have not always been recognised as 'carers'. Disagreements about the relative rights of parents and 'young carers' have diminished in recent years in the sociological literature at least, but insecurities about support for parenting were evident from the accounts of parents who participated in this study. Personal assistance arrangements took particular forms, for lone parents in particular, where they felt their custody of their children was not as definite as they would have liked.

Thirdly, the discussion also makes a contribution to debates about the overlap and distinction between work and 'care' (e.g. Ungerson, 1999). In the thesis some of the processes by which that boundary is negotiated are explored, with consequences for the conclusions drawn. As a particular form of domestic work,

personal assistance has been compared with other employment that has the home as its base, such as the hiring of servants and *au pairs*. The study adds to this literature and draws some important distinctions and comparisons with the situations of these other workers. Class and social status as well as the influence of external regulation, boundary maintenance and personal circumstances are shown to have additional relevance here. The findings bring into question the degree to which all domestic work can be seen as essentially the same.

Fourthly, the distinction between public and private spheres is used in the thesis as an ideal type for analysis. Often these terms are used unproblematically in the sociological literature, obscuring the relationships of power that lie behind the ability to define certain areas as one or the other. In the context of direct payments the thesis shows how relationships and spaces come to be defined as either public or private and how and why particular contexts may be different for different people, according to their social position. As such it explains how the public and private are shaped and defined.

Fifthly, another issue within Disability Studies concerns commonality and difference and the social model of disability. The thesis is concerned with these debates because many of them rest on a tacit but unstated assumption that there is common agreement about what is personal and what is public. Sometimes the distinction between impairment and disability is mapped onto public and private spheres of life, and the consequence of this, it is argued here, is that a private sphere is not safeguarded, with disability in the private sphere remaining unchallenged.

Other Sociological Debates

Some areas of discussion have not been followed up and might have been in other circumstances.

There is currently much debate about questions of identity. The concept occupies an important place within sociology at present, meant in the sense that identity provides a sense of belonging with and difference from other people, as well as

intersecting with social relationships (Bradley, 1996). MacInnes argues that the reason for this has to do with the collision of assertions of equal moral worth stemming from liberal Enlightenment and the existence of “enduring, vast, empirical inequalities of *status*.” (2004: 532) As an analytical tool identity calls for a conflation of individual agency and social structure and the approach needs to focus on how people come to construct their social identities and take action from this (MacInnes, 2004). Perspectives on understanding origins of identity have tended to emphasise either essential biological characteristics, or the social construction of difference.

Interest in identity and social relationships has been strengthened by the work of Giddens (1992) and Beck and Beck-Gernsheim (1995; 2002) who argue that forms of intimacy are changing in present day conditions of late modernity. They assert that people are now more actively engaged in the construction of their own identities and that traditional ties of affinity are losing their grip as evidenced by such things as increased rates of divorce, while ironically people also seek greater fulfilment and self-expression through personal relationships. Beck and Beck-Gernsheim’s (2002) arguments for the existence of increased fluidity and mobility in social relationships have been influential in the field. One difficulty with their thesis is the assumption that the construction of social identity is under the control of people as individuals. While not suggesting that people have a complete free choice in the matter, the inference is that choices may be made between a range of possible identities, in ways that have not been possible in the past. There is ample evidence that this is simply not the case from the point of view of disabled people. As Hughes et. al (2005) describe the situation:

‘A personal project of self-identity might help a disabled person to multiply their identities but such a project would be spitting in the wind with respect to social organisation.’ (2005: 6)

A large volume of medical work tends to assume that diagnosis determines identity and may explain the subsequent experiences of disability. While disabled people may reject such stereotypes (Beart, 2005; Watson, 2002) others may accept such accounts. Bradley (1996), for example, distinguishes between three levels of identity – passive, active and politicised. Much sociological writing concerning

identity has tended to uncritically accept medical model frameworks, ascribing negative identities to disabled people on the basis of impairment. Studies consider (e.g. Boden & Strunin, 2004; Lyons et al., 1995) how people feel about themselves following the onset of particular impairments, making assumptions that low self esteem results from impairment. Conversely, authors writing from a social model perspective strongly challenge this work by breaking the link between impairment and disability, as does disability culture outside of an academic perspective.

Disability studies accounts emphasise, for example, the pernicious effects of internalised oppression when faced with disablism as an alternative interpretation.

While identity represents an important possible point for analysis, it suggests rather too isolated a position to have been used here as the central part of the discussion. The focus of attention would have been removed from reciprocal social relationships *between* people in favour of the *effects* of relationships on one or more group(s) of people. Positioning identity as a central point of concern would have therefore necessitated a different set of research questions. Nevertheless the findings presented in this study have implications for the study of identity and might in other circumstances have been followed up.

Citizenship, and political concerns about rights and responsibilities also do not figure prominently until the end of the thesis, although the latter is briefly mentioned in Chapter 3. This is because they did not figure prominently in the accounts of respondents when talking about personal assistance and social relationships. Political concerns did arise as an issue when considering policies implemented in the administrative areas, primarily with regard to access to payments – getting agreement from fund holders and assessors. However this study is mostly concerned with the arrangements that took place after access to resources had been secured. Citizenship is also rather a narrow concept for the discussion here. It is one aspect of a possible four components of the public and private divide as used in the thesis. While the concept of citizenship is important, it is not sufficiently broad for this discussion.

A more central issue has to do with the concept of work and employment.

Employment represents access to money, which may typically be freely spent on

items of one's own choosing, even if decisions are often made in association with others such as partners / spouses, children etc. Employment is unequally distributed in society, with jobs that pay well being particularly scarce. Work, a rather broader concept, defined here as 'action involving effort or exertion' (The Little Oxford Dictionary, 1974: 660) is also unequally distributed, and although employment and work overlap, they are not equivalent in terms of who does each and where they are done. Authors have pointed out that if working as a personal assistant represents being employed for money, then managing a personal assistant represents work for no pay for disabled people (see Barnes, 2000). One issue that became apparent during the course of this study is that many of the disabled people interviewed resented their exclusion from paid employment and most would have welcomed increased opportunities to work for money. This is an important but rather broader issue than that posed by the research questions. An issue in this study was the way that people made sense of personal assistance in a variety of contexts. Starting out with a focus on the dimensions of work and employment, while relevant, would have made an assumption that this was in fact the way that employers, personal assistants and family members / friends defined the situation. As became apparent, people expressed a range of views on the subject. Work and employment therefore are discussed in this thesis but are not the starting point.

Finally, it may be noted that the concept of control features strongly in the Disability Studies literature and concerns about choice and control have been the driving force behind the campaign by disabled people to secure direct payments. These themes have not been developed in this thesis because they did not feature in the accounts of respondents with regard to their social relationships. Although they did feature in accounts of experiences of receiving assistance from agency staff, that part of the discussion forms a comparison with direct payment arrangements and is not the central part of this study. Respondents used other concepts to describe relationships with family members, friends and personal assistants and these are explained during the course of the thesis.

The Research Questions

The following questions guided the research process:

- What influence does employing a personal assistant (P.A.) have on the personal and social relationships of disabled employers and what are the implications of this? How do the changes in circumstances affect people's relationships both in terms of their composition and the ways they develop? Are there different implications for different kinds of relationships? (e.g. acquaintances, intimate relationships, friendships etc).
- Do existing relationships change, and if so how? (E.g. frequency of contact, activities that form part of relationships, reciprocity, etc.?) Do disabled employers form new relationships, and/or reduce contact with older friends? Are there changes in the balance of voluntary and involuntary ties in people's social networks? Are there differences and/ or similarities, for example, according to gender, ethnicity, age and household composition?
- Does employing a personal assistant lead to disabled employers being seen and treated differently by others? If so, what are the differences? Are there changes in the way disabled employers see themselves?
- What views do personal assistants hold with regard to the social relationships of their employers? Do they mediate social relationships and if so, how?
- How do disabled employers manage social relationships between P.A.s and other people inside and outside the home? Does managing a personal assistant free up more time, take it up, or is there a trade-off between several aspects?
- How are the experiences of managing personal assistance and social relationships interconnected?

Outline of the Thesis

Public or Private?

Chapter 2 gives a background on the relevant literature and the theoretical perspectives that are used as a lens for analysis. In each of the sections a central concept used is the dichotomy of public and private domains of life. In employing and working as a personal assistant these domains meet – the role of householder and that of employee, and the space of home and work. The concept is used in two ways. On the one hand it is employed as an ideal type during the course of the discussion. On the other, the arrangements made in people's daily lives can then be used to shed light on the nature of shifting boundaries of public and private spheres themselves.

Social relationships are an important focus. While some authors (Roseneil & Budgeon, 2004; Weeks et al., 2001) have pointed to a merging of friendship and kinship relations, using the concept of 'families of choice', these relationships have been kept distinct here. This is because there are different expectations about what friends and family might be expected to do. Family members may expect to and often do provide practical help to other kin in a way that friends are less likely to, and this element of relationships has particular relevance for disabled people. A further reason for retaining the distinction is because family relationships are often the site of policy interventions or attempted interventions, and disabled people are often implicated in these, as well as specific policies concerning disability. While there is a private dimension to practical and interpersonal assistance there is also a public face due to debates on 'care'. Friends, conversely, are largely seen as being outside the sphere of formal intervention: they cannot be legislated for and are generally not seen as legitimate targets for policy interventions.

Developments and tensions surrounding direct payments are the subject of Chapter 3. The emergence of direct payments through the efforts of the Independent Living Movement is considered here in an historical context. Other influences on policy are also discussed; such as the political priorities of the government of the time, as well as the ways that measures have been implemented in practice.

At the core of this thesis is an empirical study involving disabled people, their family members and friends, and personal assistants. The research questions, the rationales for the use of methods, details of procedures followed, as well as the limitations and issues that arose in the course of the fieldwork are discussed in Chapter 4. Brief details about the people taking part may be found in Appendix 1, and information about methods is provided in Appendix 2.

Home or Workplace?

The local context in terms of previous support arrangements is the subject of Chapter 5. This formed the basis for comparison for most disabled respondents with personal assistance relationships. All respondents spoke of instances of abusive treatment by staff from private agencies, questioning the notion that poor quality ‘care’ may be attributed to a few ‘bad apples’. It also forms a low baseline for positive comparisons. There was clear evidence that disabled people preferred direct payments to alternatives such as assistance provided via agency staff. A consideration of assessment procedures and the extent to which employers are seen by local authorities and see themselves as employers highlights concerns about control over assistance.

Chapter 6 outlines the key distinction made, in the words of respondents, between personal assistants as employees or paid friends. Correspondingly, a comparison is made between the house as a place of work and home as a space for living. Reasons why relationships took the form they did and well as the ways relationships developed over time are discussed here. Subsequent chapters, which provide further explanations for why relationships took particular forms, rest on these fundamental distinctions. The accounts of respondents are an important part of this and the following three chapters.

‘Carer’ or Family Member?

Of course arrangements between disabled people and personal assistants did not exist in a vacuum. Chapter 7 discusses relationships between disabled people and

their families and friends over time in relation to direct payments. The discussion therefore situates personal assistance in a social context. How disabled people, family and friends felt about direct payments, the impact it had had on their own lives and the nature and quality of their relationships raise questions about the intersection of 'care' and social relationships.

Different Relationships – Different Places?

In Chapter 8, the focus is on the ways that disabled people, personal assistants and family members / friends organised their lives on a day-to-day basis. The discussion allows clarification of the nature of paid friendship as it compares with other notions of friendship and kinship relations. If employers expressed preferences (agency) for particular forms of associations with personal assistants, then they were also powerfully influenced in that preference by their personal relationships and vice versa (structure). Particular issues arose when intimate relationships changed and for disabled parents with young children.

One of the most important aspects of personal assistance is that it has opened up the lives of a large number of disabled people, meaning that people are able to participate in a much wider range of activities at times of their choosing. Chapter 9 considers the issue of managing personal assistance in a range of different, mainly public contexts, from the points of view of all parties. Again, the explanations of respondents shed light on the reasons for decisions made with regard to personal assistance. Different decisions were made in different circumstances and by way of example, the contexts of dealing with professionals, with members of the public, in work, education (schools) and in service user groups are compared. This comparison allows the central importance of context to appear and raises again issues of disablism and how people managed this.

In Chapter 10 the thesis concludes by returning to the research questions and considering the ways that they have been answered. Research findings are related to broader issues of sociological theory, especially those concerning the nature of the public and private divide, kinship and friendship, employment, and the nature

of agency and self-determination. Broader relationships to society and the welfare state are considered.

Conclusion

This introduction has set out the broad parameters of the study in terms of its content and boundaries. Key themes have been described and the relevance to contemporary debates highlighted. Because the study intersects with a broader body of research, a review of this forms the subject of the following chapter.

Chapter 2

Background to the Study

Introduction

This chapter will review a range of studies, theoretical positions and reflections relevant to the research questions. In the course of this thesis I will draw on this literature to make comparisons with the data from this study. Some studies connect more immediately than others. The omissions in Disability Studies and Family Studies research mentioned in Chapter 1 are apparent, especially with regard to personal assistance and direct payments. The most immediately relevant material, on social relationships and personal assistance, is discussed at the end. At least some of that work is anecdotal rather than academic – accounts of personal experiences rather than rigorous studies. They have validity in that they raise issues and concerns echoed in this thesis even if they are not able to establish broader social patterns.

The discussion in the chapter will move from the more abstract to the more concrete. Four main areas of knowledge are discussed: theoretical accounts, studies on social relationships, characterisations of personal assistance and social relationships between disabled employers, assistants and family / friends.

Who Are Disabled People?

This section is concerned with definitions and it provides a brief outline of the way that terms are used in the thesis. Disability, gender and ethnicity were an explicit focus of the study. Because these concepts have been used extensively in recent studies, brief definitions are provided here and issues are woven into the discussion in the course of the chapter. Class has been a less central concern in sociology recently, but it was an important factor in understanding the data at various points. A longer explanation about how class and social stratification is understood in the thesis is provided in this section.

Defining Impairment and Disability

In sociological and disability studies literature the term disability is used ambiguously and authors may conflate impairment and disability (Thomas, 1999). The problem of definition is complicated by confusion in the meaning of terms used in everyday communication and literature, due both to differences in perspectives and the complexity of the concepts (Altman, 2001). Terminology is important in that socially accepted definitions may influence the perception of disability by family members, friends and colleagues (Wendell, 1996). Definitions matter in that they make visible the ways that impairment and disability are understood. The debates reflect underlying values, assumptions and beliefs about disabled people, their place in society and the nature of their relationships with other people.

Much disability studies literature has used the concepts of impairment and disability as defined by Disabled Peoples International, and which has been associated with the social model of disability.

‘IMPAIRMENT: is the functional limitation within the individual caused by physical, mental or sensory impairment.

DISABILITY: is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers’ (DPI 1982, cited in Oliver, 1996a :41)

This definition reflects DPI’s dilemmas in terms of reaching agreement about definitions on a global scale. It draws on an earlier formulation by the Union of the Physically Impaired Against Segregation (1976), which referred to disability as,

‘the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from the mainstream of social activities.’
(cited in Oliver, 1996b :22)

Associated with these definitions is the location of the problem in society rather than the individual: rather than rehabilitation, the emphasis is on removing social barriers that prevent disabled people from participating in everyday life. This forms the basis of the social model: disability is conceptualised as a relationship between individuals and the structures of wider society. While definitions of impairment have been relatively uncontested (although the significance has not), the meaning of disability has been the topic of lively debate in recent years (for a detailed discussion see Barnes & Mercer, 2003).

Both the definitions outlined present difficulties here. The UPIAS definition refers only to physically disabled people, a reflection of the point in history when it was developed and the priorities of the group involved in formulating it. The DPI definition of disability also presents difficulties in that it suggests what Thomas terms a 'property of the person with impairment' (1999: 40). This, she argues, suggests that all restrictions of activity equate to disability and that they are caused by social barriers. Attributing some (non-social) restrictions to impairment effects, she proposes instead a social relational model of disability:

'Disability is a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being.' (Thomas, 1999: 60)

Positioning disability as a social relationship has an advantage in that there is a potential for resolving the difficulties it causes for disabled people. It also addresses the concerns of medical sociologists and disability scholars with regard to impairment (see Barnes & Mercer, 1996). From the point of view of this thesis it allows disability to be examined as an integral part of the social relationships of people participating in the study. Thomas points out that there are several dimensions to her definition, and calls for renewed theorising of these: political economy, psycho-emotional dimensions of disability, theorising difference and impairment and impairment effects (Thomas, 2004). Equal weight is not accorded to these in this thesis. The focus here is on social relationships although other dimensions are readily apparent in the accounts given by respondents.

Definitional problems should be borne in mind when reading this thesis. Not all authors and respondents used the concepts with meanings as defined here and their original wording has been retained. The term ‘employer’ is used in this thesis to refer to disabled people who receive direct payments. (For further discussion of the rationale for this, see Appendix 3).

Defining Gender

Gender may be thought of in terms of socially constructed differences that are mapped onto biological distinctions, although authors writing within the perspective of queer studies have challenged these distinctions (e.g. Butler, 1990). Much research on gender has been done by and focussed on women; traditional sociology and disability studies in the past have assumed a white, male subject.

Defining Ethnicity

An ethnic group has been defined as;

‘A named human population with myths of common ancestry, shared historical memories, one or more elements of common culture, a link with a homeland and a sense of solidarity among at least some of its members.’
(Hutchinson & Smith, 1996: 6)

Where early studies did not distinguish between ethnic minority groups, differences in culture both between different ethnic groups and also within different groups are now recognised.

Defining Stratification and Social Class

Class may be defined as:

‘a nexus of unequal lived relationships arising from the social organisation of production, distribution, exchange and consumption.’ (Bradley, 1996: 46)

Due to disproportionate exclusion from the workplace, some authors have concluded that disabled people form part of an ‘underclass’ – that set of persons

who are absent from the labour market and form a low strata of the dispossessed in society. While this aspect of systematic disadvantage of disabled people in relation to non-disabled people has been well documented (Barnes, 1994, 2000; Barnes et al., 1998; Palmer et al., 2005), most research about disability and class has centred on inequalities in health and physical well-being. Attention is drawn to the fact that people who are more economically disadvantaged are more likely to experience impairment (Heyman et al., 1990; Mir et al., 2000) reflecting medical rather than social concerns. Employment data used to measure class points to clear disparities in life chances but does not allow differentiation between people who are unemployed.

Other authors, noting that the collation of stratification data on the basis of economic criteria leads to the exclusion of a majority of the population who do not engage in paid employment, have sought to devise alternative measures of social inequality that include social and cultural concerns. An example of this is an approach which considers class and stratification as formed through the associations and personal networks of social actors (Bergman & Joye, 2001; Bottero & Prandy, 2003). This approach is incorporated into the analysis of class in this thesis, while not utilising all components of the system. An analysis of class and disability presents particular problems in that disabled people face financial disincentives to retain paid employment, rendering measurement on the basis of paid employment alone insufficiently detailed. (Only four disabled respondents were in paid employment at the time of interview, but people had differing social backgrounds and associations). Using associational networks to measure differences between respondents not in paid employment offers a more nuanced understanding of relative differences in the sample population.

Two main issues may be identified here. On the one hand this approach makes comparison between disabled employers and a cross section of the population problematic, although this kind of analysis is outside the scope of the study. On the other hand, the use of associational connections obscures relations of power and exclusion. Bottero and Prandy (2003) for example, tend to treat social networks as unproblematic, assuming that relationships are self-selected between consenting participants. There is ample evidence that for disabled people and probably for

many non-disabled people that this is not the case, particularly with regard to the formation of new relationships (see for example, Keith, 1996; Lyons et al., 1995). With these caveats, a rough distinction between middle class and working class respondents is drawn, using the criteria of economic position and social associational connections.

Public and Private

The concepts of public and private are used here as a way of thinking about the intersection of personal assistance (paid work, conventionally seen as a public relationship) and home life (unpaid and conventionally private). This dichotomy represents a tool for analysing how respondents made sense of personal assistance arrangements in everyday life.

The distinction has been used as a framework for understanding spheres of action and social divisions since classical antiquity with a brief exception in the middle ages (Slater, 1998). Weintraub (1997) argues that the distinction between public and private is currently used in different ways and the differences between these formulations are not well understood or acknowledged; therefore debates between tend to ‘talk past’ one another. He suggests as ideal types four different uses of the concepts that are related to one another and also overlap. These are summarised as:

1. ‘The liberal-economistic model, dominant in most “public policy” analysis and in a great deal of everyday legal and political debate, which sees the public / private distinction primarily in terms of the distinction between state administration and the market economy.
2. The republican – virtue (and classical approach), which sees the “public” realm in terms of political community and citizenship, analytically distinct from *both* the market and the administrative state.
3. The approach, exemplified for instance by the work of Ariès (and other figures in social history and anthropology) which see the “public” realm as a sphere of fluid and polymorphous sociability, and seeks to analyse the cultural and dramatic conventions that make it possible...
4. A tendency, which has become important in many branches of feminist analysis, to conceive of the distinction between “public” and “private” in terms of the distinction between the family and larger economic and political

order – with the market economy often becoming the paradigmatic “public” realm.’ (Weintraub, 1997: 7)

While, as is acknowledged, these distinctions are simplistic, they serve as a reminder of the different ways in which the concepts have often been used. As will be apparent, the meanings adopted in this thesis also shift according to the context of the discussion. The main focus here is on the ways in which people construct and make sense of private and public spheres in a context where lines are not clearly drawn, as will be explained below.

In Chapters 3 and 5 the focus is on public and private in the liberal – economist sense (definition 1) and on the distinction between the household and the larger political and economic order (definition 4). In Chapters 6, 7 and 8 the emphasis is on the latter (4), and in Chapter 9 it is on the distinction in terms of 3 and 4. To reconcile these different meanings it is important to note that the 4th distinction – that between the family and the wider order - rests on a second distinction that goes beyond the first two definitions. As Slater (1998) points out, the modern public / private distinction is actually two distinctions. Firstly general and particular interests are separated as in Weintraub’s 1st and 2nd definitions. Neither of these recognise the existence of the household and family sphere. Women and children are mainly confined to the ‘private’ domestic realm. This realm is seen as being the site of intimate and personal relationships, ‘of relationships which are to be defended from public scrutiny or interference, of values which cannot or should not be experienced in public life’ (Slater, 1998: 140) A second distinction is therefore made (as in definition 4) which describes both the state and civil society, including the world of work, as a public sphere from which women have largely been excluded.

The distinction between public and private is not unproblematic. Many authors have spent time trying to determine what exactly falls into each category, a contested endeavour that has not met with resounding success due to the slippery nature of the concepts. Within the broad parameters of the above definitions, authors have disputed where lines should be drawn and what should be included in each category (see for example, J. Bailey, 2000; Ribbens & Edwards, 2001). This

applies to both liberal and feminist traditions (Pateman, 1987). Meanings shift according to historical time, place and according to the power of those involved (Lister, 1997) and the valuation of each of the spheres changes over time. Moral imperatives influence these discussions of the public and private. While historically the public sphere has been highly valued, the private realm is increasingly seen as more significant. The distinction between public and private domains therefore only makes sense when the terms are related to one another (Weintraub, 1997). Rather than as fixed categories, the divide is better conceptualised as a shifting ground where parties strive to legitimate or disallow actions and concerns.

Furthermore other authors have noted the gradations and nuances within public / private spheres – for example Lohan (2000) argues that within the home, the second – order private sphere, private spaces are created out of parts that are more public. Others have described the divide in terms of modes of thinking (Steinberger, 1999) or conceptualised each part of the divide as possessing pockets of the other part within it (Fahey, 1995). These approaches seek to understand the divide as being socially constructed, reflecting a greater role for agency, but as Lister (1997) points out, some people have more power than others in this regard. Disabled people have not been present in these debates.

Public, Private and Gender

The situation of disabled people shares ground with feminist analysis. Feminist authors have argued that the public / private divide is unhelpful because it serves to obscure oppressive patriarchal social relations.

Women have traditionally done, and still do much of the work of maintaining personal relationships in the private sphere: in the household and between households, as well as supporting men's participation in the public, economic sphere (Crow & Allan, 1994). The exclusion of women from work and the public sphere, and the exploitation and abuse of women in the home, is hidden by virtue of the home being seen as different in quality: nature versus culture (Pateman, 1987). The slogan the 'personal is political' underscores this point.

However women are increasingly participating in higher education and employment (Walby, 1997). The persistence of occupational segregation is marked, with women disproportionately employed in work that reflects their unpaid roles, such as providing 'care' for others, and which attracts lower rates of pay (MacEwen Scott & Burchell, 1994). Such changes have led some to assert that patriarchal relations are shifting from a private to public gender regime, with differences opening up between women according to age (Walby, 1997); younger women being more advantaged by new opportunities. There is evidence that increased participation in employment has not led to a dramatic shift in household responsibilities. Women continue to perform most housework and maintenance of the well being of others in the home, despite working (Hochschild, 1997).

It has been asserted that disabled men find it easier to secure assistance for daily living because of gendered expectations about unpaid responsibilities within households and families (Rae, 1993). With women expected to provide 'care' for others, securing personal assistance may be more difficult, and their role in providing assistance to others may not be recognised. The challenges faced by disabled women seeking to become parents are discussed below. The intention behind personal assistance is to increase the personal autonomy of disabled people, but as this literature shows, expectations of men and women, and the opportunities open to them within the home and outside it are different.

Feminists have in the past rejected the public private distinction because it has been seen as a means of justifying oppression. This having been said, there is a more current move within feminist studies to reinstate the divide as having some use, with a rather more sophisticated and complex analysis. Impetus has also been given to this by Black feminists who have argued that the family may represent a place of support in a racist environment (Collins, 1989; hooks, 1984). Lister (1997) notes, to further her argument in favour of women's citizenship, that most feminists would now argue for a rearticulation of the divide. This would involve dissolution of the gendered nature of the divide rather than the divide itself, recognition of the many ways the two spheres impact on one another and acknowledgement of changing boundaries.

Public, Private and Ethnicity

Common ethnicity can provide a sense of cohesion and identity and also be the basis for conflict where two or more ethnic communities co-exist within a territorial area. The divide between public and private has powerfully influenced the study of 'race' and ethnicity and its intersection with liberal democracy, particularly in relation to the concept of equality. As Modood et. al. (1997) note, equality should mean,

'not having to hide or apologise for one's origins, family or community but expecting others to respect them and adapt public attitudes and arrangements so that the heritage they represent is encouraged rather than contemptuously expected to wither away.' (Modood et al., 1997: 358)

They note two conceptions of equality. One posits that there should exist a right to assimilate to the dominant culture in the public sphere, but that difference in the private sphere should be tolerated. The other conception asserts recognition of difference in both public and private spheres. These issues are politically charged and currently have a particular salience for Muslims. While multiculturalism may be thought of as a descriptive term denoting the existence of groups that have different and distinctive cultural practices within a nation state, the term is also used to refer to policy measures that tolerate or encourage expressions of difference. Policies that question multiculturalism have been given more prominence in recent years (e.g. Phillips, 2005), and the implications of this are that questions about life in the private sphere may also raise questions about willingness to 'integrate.' Identity and citizenship have particular salience with regard to ethnicity. Authors (Hussain & Bagguley, 2005; Werbner, 2004) have written of 'hybrid identities' characteristic of ethnic minority groups as people assimilate aspects of Western culture while retaining those of their 'home' culture. There may also be gradations in the public sphere in this respect, with some activities more or less visible. Differences of cultural and political expression between South Asian groups in the public sphere along religious lines and age rather than inter-ethnic differences may be the primary focus, adding complexity to the picture (Werbner, 2004).

As Young (1989) points out however, this conception of equality has limitations in that it does not recognise structural inequality. People from ethnic minorities are more likely to be substantially disadvantaged; to live in inner-city areas, in substandard housing, and to face discrimination in education, employment and access to service provision.

There is evidence that members of ethnic minority groups receive less assistance from statutory services and of a lower quality (Harper & Levin, 2005; Katbamna et al., 1998). This may be rationalised by service workers on the basis that minority ethnic groups 'look after their own' (Social Services Inspectorate, 1998) although such assumptions may not always be justified, as geographical separation due to migration and the increasing influence of 'western' ideas on children born in the UK may exert influence on the capacity and willingness of family members to provide assistance (Harper & Levin, 2005). Barriers to the receipt of statutory assistance include the inability of service providers to provide information other than in English, the provision of culturally inappropriate or inflexible services and attitudinal barriers among service providers who may be poorly informed or racist (Chamba et al., 1999; Fazil et al., 2002; Hussain et al., 2002; Katbamna et al., 1998; Mir et al., 2000). Furthermore, authors have argued that ethnic minority disabled people have been marginalized in the disabled people's movement (Ali et al., 2001) and may seek support from members of their ethnic group rather than the disability movement (Hill, 1994; Priestley, 1995). Disabled people who are members of refugee and asylum-seeking communities may be at an even greater disadvantage with regard to lack of information and resources and because of dispersal policies which compound geographical dislocation (Harris, 2003; Roberts & Harris, 2002).

From this it follows that actions that involve scrutiny into household arrangements by outsiders may present particular problems for ethnic minority disabled people. Both assessment procedures by 'public', most probably White officials, and the recruitment of personal assistants who are supportive of living arrangements from a smaller pool of possible applicants, are likely to present difficulties with regard to direct payments.

Public, Private and Disability

Discussions of the public / private divide with regard to disability often focus on the intersection with public policy and the allocation of resources. Fawcett (2000) argues that disabled people have largely been relegated to the private sphere (conceptualised in terms of social roles and relationships; the public being employment, and citizenship the dividing line). The disabled people's movement has fought to gain access to the public sphere and access to resources to allow freedom of movement and operation have been seen as essential to this (Barnes, 1994; Campbell & Oliver, 1996). Beckett and Wrighton (2000) point out that an achievement of the disabled people's movement and the social model has been to place the responsibility for resource allocation from the private to the public sphere. (Here the private refers to the home and social relationships within it, and the public refers to local government). In defining resource allocation as a public issue, the irony is that those resources become more difficult to secure. Receiving assistance is dependent on acknowledging a model of disability as an individual deficit, and this process has implications for identity as well as forming the justification for disrespectful and dehumanising treatment (Gillman et al., 2000). However, public action (here participation in wider society) depends on the need for this individual assistance; therefore access to the public sphere is problematic. In the process the private sphere is invaded and contested. Beckett and Wrighton argue that:

‘policy or practice that prevents disabled people from protecting a private sphere, and controlling identification and recognition within that sphere, also creates fundamental personal and social oppression. Until disabled people share rights to both social privacy and social action there will be key barriers to achieving equality in social categorisation.’ (2000: 998-9)

Disabled feminists have also found the public / private distinction useful to their analyses (most notably Morris, 1992; 1996; Thomas, 1999) and some of their concerns with regard to the political underpinnings of ‘private’ concerns have been mentioned above. They have pointed out that when emphasis is placed on inclusion and participation in the public sphere, oppression in the private domain may be

overlooked. This, they argue, has been due to the domination and overrepresentation of men in the leadership of the disability movement, as well as reluctance to discuss personal experience on the basis that it is difficult to counter disabling professional and medical discourse.

Despite the fact that public and private and impairment and disability are often presented as binary oppositions, I would argue that the concepts do not map onto one another in a straightforward fashion. Building on the discussion so far, it follows that impairment and disability can be and are present in both public and private domains, regardless of how the latter are defined. Within the disability movement and its academic arms there remain disputes with regard to appropriate spheres of action but these do not stem from the definitions of impairment and disability or the social model, even if they have been framed at times in this way.

The Meaning and Significance of Home

In line with an increased sociological interest in the private sphere, there is a developing literature on the meaning of home. Here the home is singled out for discussion because it is the physical base for disabled employers and personal assistants and often for the social relationships of kinship and friendship. As such it is the place where public and private relationships meet. The home, its form and associated relationships are historically and culturally variable and the meanings associated with it are diverse. The emergence of the home as a private place is often attributed to the separation of home and work that accompanied industrialisation and urbanisation, with the middle-class home becoming more private through the marking of physical boundaries in the earlier part of the 19th century; this development later spreading to working class households. The link between household privacy and respectability remains strong (Allan, 1989).

Mallett (2004) notes how meanings can range from the notions of the ideal home, the real or remembered home, the notion of home as a haven and as a journey. Meanings of home are further related to self and gender. The meaning that most closely relates to conceptions of public and private distinctions is that of the home as a haven and a central place of reference in life. The home as a haven is seen as a

place of refuge from a potentially hostile world and as offering freedom from surveillance and control. In contrast to earlier historical arrangements the home has come to be seen as a place for relaxation and self-expression. While it is centrally bound up with the family, it is more than just a place for domestic organisation as it increasingly becomes a place for socialising with others (Allan, 1998). Therefore the home has a central place in maintaining important social connections.

The notion of the home as a haven has been challenged on the basis that it sets up binary oppositions, as well as obscuring exploitative and violent relationships (Mallett, 2004). However this idea of the home has been shown to be of particular relevance to people who live alone. People living on their own derive more benefits from the home as a source of autonomy than people who live with others (Hochschild, 1997; Kearns et al., 2000), and space can become a focus of conflict where people working from home live with others (Sullivan, 2000).

Certain expectations commonly accompany homes with regard to visitors, in particular that occupants will exercise control over who comes into the home and what basis. It is accepted that certain rooms will be out of bounds – some spaces within the home are more private than others to household members and visitors. Cultural norms regarding access are often determined by the relationship of visitors to home occupants (Allan, 1989).

For disabled people homes may present certain structural difficulties and professionals may not take into account important aspects with regards to what is important in their home when designing adaptations (Hawkins & Stewart, 2002). Receiving visits from service providers is disruptive of the relationship between the self and the home; people may become subject to the regime of service providers who ironically may have the intention of helping people to keep a sense of meaningful place in their homes (Angus et al., 2005) – at least in comparison with residential service provision. These issues are taken up in Chapter 5. Finally, homes may be associated with profit: a place to store wealth and assets, which may lead to ‘NIMBYism’ - the exclusion of people perceived to be outsiders due to desire to maintain property prices (Gleeson, 1997).

Work-Life Balance and the Overlap Between Spheres

While these studies show the home as an essentially private space, in recent years authors have also pointed to the ways in which the space between home and employment is becoming less distinct. Although the division between the home and the outside world has always been shifting and fluid (Crow & Allan, 1994; Mallett, 2004), the argument is that paid employment is increasingly encroaching on the home due to the changing nature of the employment market including job instability, different gendered work participation rates (Crompton, 1999; Llewellyn & Walker, 2000), efforts to maintain work – life balance in the context of the life course (Ammons & Markham, 2004) and the increasing use of technology which enables flexibility of location (Llewellyn & Walker, 2000; Montgomery et al., 2005). While paid working from home has increased in recent years, there are cross-cutting issues related to gender, ethnicity, occupation and employment status which paint a more complex picture of developments (Felstead et al., 2001). It may be noted here that these studies refer to changes in work – home life balance that concern individuals rather than the juxtaposition of people working and those considered not to be, as is the case for personal assistants and employers. Nevertheless personal assistance brings these questions to the fore.

There are a range of other occupations which cut across the public / private divide as commonly conceived (Fahey, 1995). Confessional priests, doctors, therapists, bank managers, solicitors etc. all commonly have access to information deemed to be private to the people for whom they work. As Fahey notes, relationships are often tightly governed by codes of practice relating to confidentiality of information and there are often implications for the client's close contacts in the sense that the professional gains information about others and the client gains information that may help them to renegotiate relationships with other people.

Accounting for finances used for paying personal assistants is a requirement stipulated by local authorities, and while there are increasing numbers of support organisations who might take on this work for disabled employers, many opt to do this work themselves. It has been described as an interface activity between the public and private (Llewellyn & Walker, 2000), with accountability being the

relationship between persons. Llewellyn and Walker make a distinction between control over finances and management of them. Accounting, while apparent to local authority managers who are obliged to conduct audits, is in this instance mainly a hidden activity and as such attracts less recognition than if it were publicly visible. The practice serves to maintain a boundary around the home (Llewellyn, 1994). As an interface activity, it represents a way that disabled employers can protect from the private sphere by managing, if not exercising control over, the boundary with the public.

What Kind of Work is Personal Assistance?

Personal assistants (P.A.s), as the term is used here, are people who are directly employed by disabled people to assist with aspects of daily living. The relationship is often considered to be a formal one, involving a contract of employment, agreement about roles and financial payments by disabled employers.

Arrangements are most frequently mediated by social service departments, through a process of assessment of disabled people and from this the hours worked and the kinds of assistance offered are stipulated. Disabled people are thereby subcontracted to manage the employment of an assistant, although they may not have total control over the broader duties that the assistant is to carry out. Personal assistance is based in employers' homes although may not be confined to it.

There is a long history of domestic service to wealthy individuals (Ungerson, 1999) and personal assistants are classed as domestic servants for employment purposes (Shakespeare, 2000). Domestic work is highly gendered and women carry out almost all of this, although the picture has varied historically. Spaces used by domestic servants in the earlier part of the 19th century were often tightly controlled (Taylor, 1976) and alternative forms of employment for women were restricted to ensure an adequate labour supply to wealthy households at this time (Beddoe, 1989; Walby, 1990). Following a decline in the intervening period, there has been resurgence in domestic labour as more women have entered paid employment and wealth inequalities have increased.

Studies of domestic labour have noted the importance of class, ethnic and gendered patterns of employment. As Twigg (2000) points out, the fact that assistance work is gendered means that it is viewed in contradictory ways. On the one hand it is seen as low-level work; on the other it is seen as being special, involving love and 'care' for the person receiving assistance. Recently increased attention has been paid to the recruitment of ethnic minority female migrants who form a growing sector of workers in domestic service (Lutz, 2002; Phizacklea, 2000) and who might also become personal assistants (Ungerson, 1999, 2003). Several authors note the vulnerabilities of personal assistants in that pay and conditions of work are poor, there is opposition to credentialism from disabled employers and career prospects are very restricted (Shakespeare, 2000, Ungerson, 1999). With an awareness of the need for personal assistance to be seen to be working well, disabled authors have called for employers to show responsibility and to treat personal assistants well (Rae, 1993; Shakespeare, 2000), a point emphasised by respondents interviewed by Glendinning et. al. (2000).

The status of personal assistants does not map easily onto a model of servanthood in relation to disabled employers. While the literature on servants discusses power imbalances between employer and employee, Twigg (2000) points out that where physical assistance is needed, there is a profound power imbalance in relationships between the people giving and the people receiving help, with the person receiving help disadvantaged in relation to the assistant. As Ungerson (1999) notes, there are some important differences in that disabled employers are not supported by social distance and deference as were nineteenth century landed gentry, but socially constructed in demeaning ways and potentially at risk in their relationships with personal assistants (Hendy & Pascall, 1998; Saxton et al., 2001). According to Morris (2005), choice and control over how this type of assistance is given has the potential to address the 'vulnerability created by this unequal power relationship' (Morris, 2005: 10).

There are also some other important differences in the circumstances of many present day domestic labourers and personal assistants. The literature on domestic labour highlights this work as a feature of the globalised economy, with female migrants increasingly recruited from less economically advantaged countries. Lack

of certainty about workers' immigration status may exercise a downward push on wage levels, and workers may have few social networks that might act as a source of support. In the case of *au pairs*, it is a specific expectation that they should live as part of the host family and a token payment is given in return for meals, lodging and household work. Conversely, with personal assistants the employment relationship is open to scrutiny from local authority managers and auditors, who ensure that minimum wages at least are offered. Personal assistants are less likely to be disconnected from their own social networks due to the fact that living in the employer's house is not an expectation for most, they are likely to be older than *au pairs* in particular, and to be in a stronger position in the labour market with regard to the legality of their work.

This having been said, it is important not to overstate the advantaged position of personal assistants in relation to other domestic workers. They are likely to earn minimum wages, while at least some nannies might expect to earn substantially more (Nannytax, 2005). Other domestic workers such as interior designers and trades people might again expect much more substantial wages.

Studies have also discussed relationships between domestic workers and their employers. For example, while nannies might be spoken of as being part of the family (although in practice limited by exclusion from many aspects of family life), cleaners are accorded more autonomy to offset the low status and demeaning nature of the work (Gregson & Lowe, 1994). Personal assistants may object to being characterised as cleaners (Mears, 2005), viewing their work as more demanding and varied than this, and involving a range of interpersonal skills. Cox and Narula (2003), in their study of relationships in households employing *au pairs* also note the recurring theme of 'false kinship' that is characteristic of situations where employment takes place in the home. By false kinship what is meant is:

'mobilising the rhetoric and practices of familial relations to shape interactions, responsibilities, and degree of intimacy between employers and domestic workers.' (Cox & Narula, 2003: 333)

As they note, family relationships are usually hierarchical and false kinship is not benign in its effects. It may not be a relationship of equal benefit to both parties

and may not be subscribed to by both. Rather, it can be a way of exerting moral pressure on employees to do more work and reducing their resistance to this on the basis of affective relationships. Furthermore, they argue, the emphasis on family membership has the effect of making it more difficult for people working in these circumstances to leave their employment. These findings are taken up in more detail at a later point.

Social Relationships

Social relationships are fundamental to human existence and they hold great significance in people's lives. Relationships with others influence the actions and life directions people take and how people think and feel about themselves. There is evidence that social support is connected to personal well-being and health (Acheson, 1998; Black, 1988) although studies have been criticised on methodological grounds (Pahl, 2003). The form and significance of social relationships varies according to stages in the life path, birth cohorts and generations (Priestley, 2003; Ridge & Millar, 2000) and the circumstances in which they take place. Social relationships may be characterised by unconditional positive regard, ridden with conflict, be somewhere in between, or characterised by both positive and negative features (Duck et al., 1997). Relationships may be of great help or act as a constraint at times of transition and change. While ties between people can act as a source of social identity and cohesion, the formation of groups can also be the basis of social division and maintain patterns of inequality. Three main distinctions have been drawn in the kinds of ties which characterise people's social relationships; friendship, kinship and intimate/marriage relationships, although some distinctions have increasingly come to be seen as blurred or overlapping. Disability studies literature has also been concerned with relationships with strangers, and a discussion of this is included in the next section.

Kinship and Family

Kinship may be contrasted with friendship ties in that these relationships are not voluntary but given. Changes in family forms, both historically and between societies, present authors with particular problems in trying to define the family,

and these may be conflated with moral judgements about ideal living arrangements. There has been much discussion about the proliferation of non-nuclear families in recent years (Carvel, 2001a, 2001b) and the implications of this.

Authors have pointed to contemporary changes in the nature of family relationships, such as the growing incidence of co-habitation, divorce and re-constituted families (e.g. Family Policy Studies Centre, 1997; McRae, 1999; Ribbens McCarthy et al., 2003; Williams, 2004). Attention has also been drawn to the increased numbers of people who now live on their own and in same-sex relationships or families of choice (Roseneil, 2000). Reasons for these changes include the fact that people are living longer, making long-term commitments harder to sustain, and an increase in the numbers of women working. It is argued that the latter, combined with a decline in stable full-time male employment, is reducing women's economic dependence within families. (Crompton, 1999; General Household Survey, 2000; Irwin, 2000; Walby, 1997; Williams, 2004), giving women alternatives to remaining in unsatisfactory relationships.

Ethnic minority households may show different familial patterns. The experience of migration can be a source of physical division in households, although people may retain strong ties with kin overseas and kinship may itself have a role in facilitating migration. Kin relationships and friendships may also be important in providing a source of support in a hostile, racist environment. Households can take different forms; Afro-Caribbean kinship structures, for example, tend to be matrifocal, due in part to a larger number of female-headed households (Goulbourne, 1999), and some Asian families may have joint households (Allan, 1996).

Giddens (1992) argues that there is an increased importance attached to love and intimacy apparent through the search for a pure relationship: intimacy that is based on an enjoyment of each other's unique qualities and the sustaining of trust through mutual disclosure. Individualisation driven by the labour market (Beck & Beck-Gernsheim, 1995) has also been cited as a cause, together with the changing position of women in society resulting in women seeking more meaning from personal relationships. These theories have been very influential within sociology

but have also attracted criticism on several grounds. Empirical studies, for example, have pointed to lived life experiences as encompassing more complex patterns of commitment than the pure relationship, and to the persistence of inequality (Jamieson, 1998, 1999). Doubts have been cast on the grounds of the persistent gendered nature of household task allocation, differences with regard to class and ethnicity and wider structural constraints and context, including position in the family (Smart & Neale, 1997, 1999).

According to political and theoretical perspectives the changes in family arrangements have been viewed as either signalling moral crisis, evidence of increasing individualisation, democratisation, continuity in the sense that they reflect earlier patterns (McRae, 1999), simply changes, or a combination of these (Cheal, 1998; Gillies, 2003; Wright & Jagger, 1999). Furthermore, particular definitions have often been associated with political and moral perspectives on forms that the family *ought* to take (Jones et al., 1995).

Due to changing forms, concepts of kin and family present particular problems of definition. Early studies that charted the existence of extended nuclear family forms (e.g. Willmott & Young, 1960) have been challenged with assertions that the conventionally conceived nuclear family "is so rare as to render the whole idea of the nuclear family entirely redundant." (Bernardes, 1997: 10). Some authors have suggested instead the concept of personal community as 'active ties with friends, neighbours and workmates, as well as kin' (Wellman, 1988: 131) and a focus on how relationships fit into social structures without having to formally name relationships. Others point to a convergence in the kinds of roles taken by family and friends (Pahl, 2000, 2002b). Bearing in mind these ambiguities, in this thesis I use the definitions given by respondents, rather than try to identify features or categories. The concepts of family and friends (and other relationships such as neighbours etc.) are important everyday terms that people use to describe relationships with others and these will be explored here. People usually distinguish sharply between family and friends (Wellman & Wortley, 1990) and largely have different expectations of each.

Much of the sociological literature on the family has been concerned with expectations and obligations that members have of one another and the questions of reciprocity and 'care' are considered below.

Social Support: Reciprocity and 'Care'

The fact that people are embedded in networks of social relationships has led to an expanding literature on social support. Although there is not a consensus on the meaning of social support, Llewellyn & McConnell (2002) note two main formulations: social support as information that contributes to feelings of being accepted, valued and capable, and social support as a commodity, that is an exchangeable good or service. This distinction may be related to help that is commonly conceived as existing in the private sphere, unregulated and informal, and that which could be seen as existing in the public domain, where it is formally contracted and paid for by one source or another. Changes in the balance of this in recent years, stemming from efforts made by the disabled people's and feminist movements and government policies mean that this is contested ground (Morris, 1991, 1997a, 2001a, 2005; Pijl, 1994; Ungerson, 1997, 1999, 2003). With regard to the following discussion it may be noted that reciprocity and 'care' overlap: while reciprocity usually refers to the mutual exchange of small favours, 'care' involves more substantial assistance.

Reciprocity

Wellman (1999) maintains that most community ties are specialised, with network members in western societies usually only offering a few kinds of social support. Therefore people have to maintain an active 'portfolio' of ties on whom they can call, in order to make sure they have access to all the help they need. This is all the more so, because personal communities are usually sparsely knit and loosely bounded, i.e. networks tend to be fragmented, particularly in urban areas. People living in rural areas are likely to have more connected social worlds, or denser networks (Jamieson, 1998).

Exchange theory (Blau, 1964) is one of a number of formulations which have sought to understand the nature of social interactions (see also Homans, 1961; Kelley & Thibaut, 1978). Blau argued that people are attracted to others through an expectation that they will gain through the association. Processes of social attraction then lead to social exchange, defined as:

'voluntary actions of individuals that are motivated by the returns they are expected to bring and typically do in fact bring from others' (1964: 91)

Where people are not able to reciprocate, they are faced with three alternatives – either to force the other person to help them, to get the needed help from another source, or to find ways of getting along without the help. Where a person is not willing or able to do this, then the only course of action is to subordinate oneself to the other person, and comply with their wishes, so rewarding the other person with power over them as an inducement for supplying the needed help. In this way, he argues, power differentials emerge.

Jamieson (1998) notes that exchange theory arose at a particular point in time and no longer holds as much influence as it once did. Nevertheless, most researchers recognise that an element of exchange or reciprocity is an important part of social relationships, even if it is best considered long-term over the life course (Pahl, 2000) and as being more nuanced than straightforward exchange of goods and services. Pahl cites the perception of 'persistent high maintenance without reciprocity' (2002: 8) as one of grounds cited by respondents for ending a friendship.

Linking reciprocity and 'care', another body of literature points to the lack of clear agreement on what actions family members should take with regard to supporting relatives – even though this is work that is mainly carried out by women. In comparison with friendship, large favours and financial assistance are more readily sought and given by family members, particularly between parents and children. While family members may not agree on specific courses of action with regard to family responsibilities, there is more agreement on how decisions should be

reached (Finch & Mason, 1991; 1993) within the parameters of a general obligation to help. Obligations are contingent and negotiated.

Rae (1993) maintains that disabled people are disadvantaged by the way society works, because relationships have an element of reciprocity or equality of exchange as a component. She argues that because disabled people are often not in a position to reciprocate the help they receive, they are disadvantaged. This point is underlined by Galvin (2004) who notes the constraining effects of shame, frustration and gratitude experienced in situations where disabled people have to depend only on informal assistance. She describes how disabled people employing assistants did not feel diminished by the help they received, were more in control of their lives and less disabled, impairment notwithstanding, than people relying on informal assistance.

'Care'

Many family members of disabled people provide assistance with aspects of daily living and although this arrangement may form part of a close relationship and be welcomed by people involved, it may also cause difficulties and stresses between partners due to the hard work and ties it involves (Lyons et al., 1995; Parker, 1993). The relationships of disabled people with others have been most frequently defined in terms of the need for 'care' in literature concerning the family. Similarly, people with whom disabled people have often had most close relationships have frequently been designated as 'carers'. A large body of writing has been generated around the concept, which has been a flashpoint for disagreements between disabled people, policy makers and others such as organised bodies of some informal 'carers' such as the Carer's National Association, where the argument has primarily been about the control of resources and autonomy. In academic work the concept has been used in a variety of ways and its meaning and use has been similarly contested.

There appear to be three main ways that the term 'care' is used and there may be more. Firstly, Graham (1999) describes the feature of 'care' in the British policy context as being: provided for others, non-institutional, unpaid, arising through

bonds of kinship, typically by relatives and concerned with individuals who have a long-term need for help and support, and Pijl (1994) distinguishes 'caring' from voluntary work on the basis of the personal relationship involved.

Secondly, an alternative use of the concept of 'care' has sought to broaden it to a way of thinking about social relationships in general. Tronto (1993) argues that caring involves four ethical elements which are part of life: attentiveness, responsibility, competence, and responsiveness, while recognising that these aspects may involve conflict. She argues that an 'ethic of care remains incomplete without a political theory of care' (1993:155). Sevenhuijsen (2000) uses Tronto's work to argue that caring can be 'conceptualised as a social process and as a daily human activity' (1999: 13) It is a moral obligation, a public virtue and set of values that can guide human agency in a variety of fields and Williams (2001; 2004) argues in favour of an ethic of care, meant in this sense, to balance the ethic of work prominent in current British social policy. Therefore this concept has been picked up and developed as a way of expanding what have been termed private values and placing them into the public sphere.

Against this, Gleeson (1997) argues in favour of retaining the boundary between public and private as a means to seek recourse to justice in the public sphere and Silvers (1995) argues against the position of moral ethicists on the basis that an ethics of 'care' removes attention from 'the repression of those already marginalized' (1995: 31), and in favour the reconciliation of both equality and difference. Shakespeare (2000) has sought to bring the emphasis on civil rights, independent living and personal assistance emphasised in the disability studies literature together with the concept of care as used by Tronto, Sevenhuijsen and other moral ethicists. He argues for a separation between physical and social aspects of help for disabled people, a concept that he uses in preference to 'care'. Thereby, he argues, both perspectives can be usefully brought to bear on the issues.

Finally Morris (2001a) emphasises the importance of separating means and ends, arguing that the issue is not what 'care' is, or how it is delivered that is important, rather whether the result is to allow all people to express their common humanity.

She argues for the recognition of human rights as an outcome rather than a focus on means such as the form and shape of means, such as 'care'.

Thirdly, 'care' is also used to refer to paid workers who do work which can include assistance for disabled people in the public sphere (Hugman et al., 1997). Here there may or may not be any particular feeling of well-being for people who receive assistance.

From a disability studies perspective, Wood (1991) rejects the usefulness of the concept of 'care' in favour of choice and control to enable people to maintain independence over their lives, and Finkelstein (1998a) contrasts the notion of 'care' as used by paid service professionals with the concept of support which he sees as characterising the informal assistance provided to disabled people by family members. The concept of 'care' is seen as being of little use therefore, and symbolic of the ways in which disabled people have been and are oppressed (Hunt, 1966). From an historical perspective, disabled people have persistently experienced social exclusion and segregation. Institutional life experienced by many has offered a bleak existence (French, 1996; Goffman, 1975), and Hunt describes the experiences of being seen by others as 'unfortunate, useless, different, oppressed and sick' (1966: 146), or as being described by social work researchers as socially dead (Hunt, 1981; Miller & Gwynne, 1972). Segregation and marginalisation have been maintained by the existence of administratively separate services (Priestley, 1999) staffed by professional workers who have built careers from removing disabled people from society (Finkelstein, 1981a, 1990). While this situation is changing due both to the efforts of the disabled people's movement and the reluctance of governments to fund expensive service provision, segregation can persist on a smaller scale.

The concept of care has therefore often been used to signify diametrically opposed actions in terms of the meaning for receivers of 'care'. In the literature, often all three meanings may be conflated.

Direct payments and personal assistance have been seen as the way out of these dilemmas. Galvin (2004), for example, describes how disabled people employing

personal assistants did not feel diminished by the help they received and were more in control, feeling less disabled than people relying on informal help from others. McLoughlin & Glendinning suggest the development of a notion of ‘de-familialisation’ (1994: 23) in relation to payment for ‘care’, arguing that this allows the focus to be shifted on to social relationships rather than a one-sided relationship that is implicit to the feminist concept of ‘care’. The intersection between ‘care’ and social relationships described here and by Finkelstein (1998a) is examined in this thesis, and the questions raised in the debate above will also be picked up again in the conclusion.

Disabled People as Part of the Family

Disability studies literature has tended to steer clear of the family and home life, with some important exceptions, although much of the medical and professional literature has highlighted it. There is a considerable body of research in the latter that documents the problems caused within families when one or more member is impaired. This will not be reviewed here as it lies beyond the scope of the study but some general points are relevant. In particular, emphasis is placed on stress caused by impairment and resulting distress and dysfunction within the family (e.g. Boden & Strunin, 2004; Forbat, 2002; Kearney & Griffin, 2001; Lyons et al., 1995). Child development norms are said to inform parents’ experiences of grief and mourning for the loss of the ‘perfect child’ when a baby is born with, or a child develops, an impairment. Kearney and Griffin argue that the uncritical acceptance of child development theories by professionals can lead to parents being labelled as dysfunctional and pathological when they do not show the ideals of ‘acceptance’ and ‘being realistic’ (Kearney & Griffin, 2001: 583).

Other perspectives take a more critical approach and point to discrimination and exclusion experienced by disabled children and their families (Russell, 2003). Families may experience a courtesy stigma in the sense that negative attributions are attached to them through their relationship with their disabled relative (Goffman, 1968) together with financial hardship, impoverished living conditions and reduced opportunities (Beresford, 1994, 1995; Roberts & Lawton, 1999; Ward, 1999).

A smaller body of literature considers interpersonal family relationships. Kearney and Griffin (2001) characterise parents' experiences as including both joy and sorrow, noting that the positive aspects were due to their relationships with their disabled children. While children's accounts have been largely omitted in sociology in the past, more recent studies give a voice to disabled children (Morris, 2001b, 2003) and provide a more balanced account in comparison with early negative findings. In their study on sibling relationships, Stalker and Connors (2004) found that relationships were characterised by ordinariness. Disabled siblings might be described as 'playmate, teacher's pet, annoying little brother, helper – and relationships could be good, bad or indifferent at times' (2004: 228). Parental support is a major influence in helping disabled young people to negotiate the experience of transition to adulthood and to succeed subsequently (Pascall & Hendy, 2004; Shah et al., 2004). Such accounts present a more optimistic account of family life in comparison with the large number of studies emphasising stress and hardship.

There is evidence that disabled people may more strongly identify themselves by reference to their relationships to family and friends than as people who have impairments (Priestley, 1995; Watson, 2002). Relationships of affinity, as noted above are strong reference points in life.

Disabled Parents

In the past decade there have been considerable controversies surrounding disabled parents. Concerning pre-natal screening and abortion, the demands associated with a woman's right to choose have been experienced as a eugenic threat by disabled people because impairment is considered a prime justification for abortion (Rock, 1996). There is also evidence that medical professionals exert pressure on women to abort fetuses where impairment is suspected (Kallianes & Rubinfeld, 1997). These issues are beyond the scope of this thesis but they form an important backdrop for this paper and are of particular relevance for disabled parents. Concerns about disabled parents relate to commonly held beliefs that impairments are passed on to children genetically, despite the evidence to the contrary (O'Toole

& Doe, 2002). There is also controversy about ‘designer babies’ and much publicity has been attached to instances where parents have chosen to give birth to impaired babies (Teather, 2002) or to select certain genetic characteristics for future offspring.

Notions of ‘good parenting’ have an important place in discussions of children and family life, and a whole series of social ills may be blamed on ‘inadequate’ parents, in particular lone parents and absent fathers. Studies have questioned the ability of disabled parents to care adequately for their children by virtue of the fact that they would not be able to perform certain actions seen as integral to being a parent (Campion, 1995; Wates, 1997; Watson, 1999). There is evidence that disabled parents, particularly mothers with learning difficulties, experience lack of social support and isolation, especially when they do not have a partner (Llewellyn & McConnell, 2002) and are more likely to have their children taken away from them (Booth & Booth, 1998). This fear may make mothers go to great lengths to show others that they are managing and they may not ask for help when they need it (Grue & Tafjord Laerum, 2002; Thomas, 1997; Wates, 1997). Disabled people are discouraged from becoming adoptive parents (O’Toole & Doe, 2002; Wates, 2002) and face discrimination in legal disputes concerning child welfare (Pfeiffer, 1994; Swain & Cameron, 2003; Wates, 2002).

Concerns about disabled parents have been most recently voiced in the discussion about ‘young carers’. Defining ‘young carers’ has been problematic for a variety of reasons but broadly the term refers to children who provide what has often been termed ‘excessive’ assistance to a, or several, disabled family members. Early debates often revolved around the respective rights of children and of disabled parents (Aldridge & Becker, 1996; Keith & Morris, 1995) although there is now more emphasis on a whole family approach (Aldridge & Becker, 1999; Olsen & Clarke, 2003). Authors have pointed to negative implications for young carers, including effects of physical work, decreased opportunities for social contact that can lead to isolation, the emotional stresses of the work and reduced participation in schooling with consequences for future adult life and well being (Aldridge & Becker, 1999; Dearden & Becker, 2002; Thomas et al., 2003). Reports about these issues have led to the proliferation of services designed to support young people

(Dearden & Becker, 2004) as well as criticism on the basis that such services have not been proven to help families but to undermine the position of disabled parents (Newman, 2002). Evidence of the degree to which children of disabled parents undertake extra work is unclear, with children reporting both negative and positive effects (Banks et al., 2001). Another issue is poverty: disabled parents are more likely to be poor and child deprivation has been linked to this. Some authors have argued that material disadvantage has more to do with disadvantage of families where parents are disabled than with the incidence of impairment (Banks et al., 2001).

There is a growing literature that describes the positive aspects of parenting written by disabled women (Finger, 1990; Kent, 2002; Mason, 1992b; Prilleltensky, 2003, 2004; Wates & Jade, 1999). Motherhood has been seen as an important marker of adulthood for disabled women, which contrasts with the role of passive recipient (Barron, 1997). Challenges have been mounted to the Loughborough studies on 'young carers' on several accounts. Referring back to the problems of definition, disabled women note the difficulties of teaching empathy, care for others and self to children in the context of these parenting responsibilities being cast as reliance on 'young carers'. Young people have reported positive benefits from their experience, including 'increased understanding of disability, closer family relationships, enhanced maturity and practical skills. Parents drew attention to greater sensitivity, sharing, empathy and independence' (Banks et al., 2001: 805).

There is scant evidence regarding the influence of direct payments. Prilleltensky (2004) notes that disabled mothers appreciated having personal assistants who they employed but expressed worries about possible future cuts to services.

Friendship

Friendship has been characterised as a relationship between equals. While a relationship may be characterised by difference, and it may not be the case that people are equals in the eyes of others, the important point is that in friendship each party has a sense of being of equal social worth (Allan, 1996). Voluntary social relationships are often seen as being the product of people's free choice; an

expression of personality, choice and free will, but they are also shaped by external factors (Adams & Allan, 1998), including the historic social and economic context and people's structural positions in society. Friendships therefore develop in contexts. There is evidence that ideas about what constitutes friendship may vary between societies and over time, although the degree to which this is significant is contested (Eve, 2002; Pahl, 2002a). Changes in circumstances, such as divorce and work moves may lead to changes to friendships by virtue of the changed circumstances and opportunities for contact with others (Allan, 1998; Oliker, 1998; Pahl, 2000; Terhell & van Groenou, 2004). Friends are rarely formally dumped (Pahl, 2000). While some friendships may last a lifetime, more commonly they will wax and wane (Allan, 1996). Wellman et. al. (1997) found that, in the personal communities (encompassing both kin and friends) of two-thirds of the people from Toronto they studied, there was a gradual turnover of network members such that over ten years nearly three quarters of intimates were people who had not been there previously. Ties that were likely to persist over this time were those that were strong, were between kin, and those where people were part of densely knit networks.

On an interpersonal level, friendships also develop in particular contexts. The contextual basis may remain static or may change; interactions may remain limited to one place, or may be broadened to other circumstances and occasions. The wider the contexts in which the relationship takes place, the more likely the relationship is to be described as a friendship. This is particularly so when the context is widened to include people's homes, which are increasingly used for socialising (Allan, 1996). Authors have also drawn attention to 'mateships'; social relationships bounded by one context only, i.e. they are limited to only one location and arise from participation in the context rather than through deliberate arrangement (Allan, 1996). An example might be relationships formed by men in pubs but which do not extend beyond it.

Different kinds of friends and acquaintances often provide different kinds of assistance. People will typically gain most of their support, including companionship, from a small number of strong ties (Pahl, 2000; Wellman & Wortley, 1990). However weak ties or relationships with acquaintances have been

shown to be effective in some circumstances such as getting a job (Granovetter, 1974), gaining information useful to operate effectively in work-related circumstances (Kadushin, 2000) and gaining access to new resources (Wellman, 1999).

The discussion on friendship above has important implications for disabled people, particularly when well-documented problems of access are borne in mind (Barnes, 1994). If forming and strengthening friendships relies on access to particular physical contexts then this suggests that limitations on access will adversely influence relationships and that personal assistance may be expected to have some influence on this.

Friendship and Disability

The literature on disabled people's friendships is sparse. Most attention has been paid to the friendships of people with learning difficulties who are particularly likely to be socially isolated (e.g. Chappell, 1994; Lutfiyya, 1991). For people with acquired impairments there is evidence that friendship circles decrease markedly following the onset of impairment (Lyons et al., 1995). Studies of the friendships of physically disabled people tend to consider the situations of younger people, often students (Ash et al., 1997; Bunch & Valeo, 2004) and the context in which relationships take place (e.g. Seymour & Lupton, 2004). Because several of these are concerned with personal assistance, they are discussed below, following a discussion on acquaintances.

Acquaintances

With the possible exception of one's parents and immediate family, each new personal tie at any stage of a person's life develops from a relationship formed between strangers outside the immediate home environment. Acquaintances and strangers may therefore represent potential friends and intimates.

Goffman (1968) examined relationships between people he considered to possess stigmatising characteristics and people who were not so perceived. He maintained

that people who possessed ‘discredited’ or ‘discreditable’ identities were viewed by ‘normal’ people as being not fully human, and that stigmatised individuals had to use a variety of means to manage the way they were seen and treated by others. Keith (1996) follows a broadly similar line of thought, while noting that Goffman’s work has been criticised on the basis of its language and the fact that he appears to place blame on the stigmatised person for having unwanted attributes. She points out that, in relation to non-disabled people:

‘Their smiles, questions and comments reinforce the feeling that whatever image we might have of ourselves, society imposes a negative identity upon us and much of our social life is a struggle against this. Strangers do not let us forget that their perception of us is dominated by the ways in which we are different’ (1993: 75)

Keith suggests that the negative perceptions of the general public concerning impairment may override other indicators of disabled peoples’ social status. Citing by way of example, the experience of a colleague returning from a business meeting encountering demeaning remarks from a taxi driver, she maintains that members of the public overlook all roles, social standing and achievements in life in favour of a focus on impairment, resulting in an ambiguous encounter. There are implications for a person’s self – esteem. Where disabled people internalise others’ negative views, so they may devalue themselves, and question their own self-worth as well as that of other disabled people. This in turn has negative effects on people’s social relationships in comparison with people not seen in this way (Mason, 1992a; Morris, 1991; Rieser, 1990).

Impairment Effects

Most studies note commonalities of experience across impairment groups but some differences in experiences are also discussed. Following the onset of impairment, Lyons et. al. (1995) found that disabled people with spinal cord injury were more able to restructure their social relationships than were people who had strokes or multiple sclerosis. People who had chronic tiredness, bowel or bladder, mobility and fine motor co-ordination impairments were also reported as being lonelier. However these effects were also influenced by other factors. Those who had been

less involved in activities outside the home prior to the onset of impairment, younger and older people were more likely to feel isolated. Therefore social isolation cannot be attributed to impairment in a straightforward way. While impairments that carry more social stigma may be related to isolation, attitudes and physical barriers as well as internalised oppression may influence social relationships.

Employers, Personal Assistance and Social Relationships

Research has consistently documented that disabled people have felt their lives to have been enhanced by personal assistance, in ways that have a bearing on social and personal relationships. However, beyond stating that employers felt that this was the case, the literature here is patchy. More has been said about some areas than others, and some of what is available concerns the experiences of individuals. Three areas of work are discussed here, to correspond with the questions asked: relationships with personal assistants, with family and friends and with wider networks of people.

Employer – Personal Assistant Relationships

Studies have consistently pointed out that both employers and personal assistants value highly the close relationships they have with each other (Adler, 1993; Glendinning et al., 2000; Mears, 2005; Spandler, 2004; Yamaki & Yamazaki, 2004). Writing from the perspective of working as a personal assistant in Canada, Adler (1993) argues that the relationship between employer and employee is the most important aspect of the job, and that intimacy is essential to a satisfactory arrangement. Mutuality and negotiation rather than control are highlighted as important for resolving potential conflicts of interest. Vasey acknowledges that it is not possible to employ someone without some degree of liking for them, and talks of her ‘personal policy of blurring the boundaries and not treating personal assistants exclusively as staff’ (1996: 87).

Marquis & Jackson (2000) point out that relationships between people receiving assistance and helpers exist along a continuum, with mutually satisfactory reciprocal relationships at one end and violence and abuse at the other. Most studies document fulfilling relationships, backed up by the possibility of ending those which are deemed unsatisfactory, by virtue of the employment relationship involved in direct payments. However some authors record instances where abusive relationships can occur. Saxton et. al. (2001), in their study on abuse of disabled women, use a broader definition of personal assistance than the one used here, but 56% of their sample were women who received their main form of assistance from people who they employed. Social and personal boundary confusions, power dynamics, the difficulties of recognising abuse, the complexity of receiving help from family and friends and barriers to reporting are identified as key issues. Strategies for dealing with abuse identified include the importance of long experience in managing personal assistants and access to supportive networks. The authors also note the dangers involved in this kind of experience, in that it might result in disabled women being seen as hapless victims who would be better served by receiving medically oriented supervision thereby undermining the independence offered by personal assistance services.

Lesbians, gay men and bisexual employers may face particular difficulties with regards to disclosure of sexual preferences to potential or existing personal assistants, an issue made more difficult by the ambivalent support within the disabled people's movement and the uncertainty of support in the neighbourhood (Killin, 1993).

Describing the relationships between employers and personal assistants has presented authors with some difficulties. Yamaki & Yamazaki (2004) identify four ways in which employers described assistants: as instruments, employees, companions and social assets. They argue that these descriptions reflect the dimensions of functionality (getting things done), socio-emotional aspects and a collective dimension (the relationship to society at large). Ungerson points out that the nature of personal assistance work gives problems with the maintenance of boundaries, particularly that between paid work and friendship. Glendinning et. al. (2000) likewise report that the personal assistants in their study welcomed the trust

and close relationships they developed with their employers, but both parties sometimes experienced difficulties in managing their relationship, particularly ‘balancing appropriate employer – employee relationships with the provision of ‘extensive and intimate personal assistance in the setting of a private home, over extended periods of time’ (Glendinning et al., 2000: 208) As a result of this, in some instances employers reported developing a sense of obligation towards their assistants, becoming less able to exercise control over the help they received. Some assistants felt that over time their situation became similar to that of a family member, with associated obligations, reflecting the theme of ‘false kinship’ discussed above.

Disabled employers have also acknowledged these problems. Vasey talks of there being ‘a received wisdom in the use of personal assistants which states that they should not be friends with the disabled user’ (1996: 85). While it is acknowledged that there is a need to feel comfortable with personal assistants (Brignell, 2001), people using direct payments are urged not to become too friendly with P.A.s on the basis that it can be devastating when people leave, because of the need to be able to ask assistants to do jobs - this being made more difficult by a relationship of friendship – and because of a need for privacy and confidentiality with regard to what assistants might tell other people (Pridmore, 2001). Marfisi (2002) discusses the context for employer – personal assistant relationships in terms of friendship and business relationships. She argues that there are powerful dichotomies and dilemmas posed by personal assistance. While employers’ social isolation may exert a push towards friendship, expectations and boundaries are easier to maintain when the emphasis is on the business side of the partnership. The situation is, Marfisi argues, made more complex by the context of personal assistance, where assistants are undervalued societally and economically, and where many other people do not support the concept of independent living.

Privacy has been highlighted. Vasey points out that receiving assistance can be claustrophobic at times. Employers have reported feeling that their house was no longer their own (Glendinning, 2000); Brignell (cited in Vasey, 2000) points to the stress involved in having other people in her home. Needing assistance makes it

impossible to shut the door on the outside world. She remarks that the effect is to feel one is on show at all times, and that this can make it difficult to relax.

Personal Assistants and Friends

Bailey (2000) notes that a major question is how to manage her relationship with a personal assistant so that she can get the help she needs and also have the space to be alone with friends. She remarks that having a P.A. sometimes made her lazy, in that she might take her assistant somewhere rather than invite friends, simply because it was easier. Other dilemmas concern managing the role of the personal assistant when with friends. On the one hand she notes that it feels uncomfortable to ignore a personal assistant in favour of talking to friends, and on the other, involving her assistant in conversation could be very tiring, and also lead to the assistant becoming party to a lot of personal information which she would prefer not to disclose.

A few authors also discuss how the perceptions of friends may alter when they become employers. Wallis (2000) argues that the relationship with a personal assistant is open to a wide range of different interpretations. Vasey (1996) mentions an occasion where a friend expressed resentment when asked for assistance, on the basis that she must be saving money from her care package. She notes that economic considerations can creep into everyday relationships with friends as a result of becoming an employer. Other examples include friends becoming annoyed when a personal assistant was not included in conversation, and where a friend saw the employer-employee relationship as one reminiscent of the servanthood characteristic of white/ Caribbean relationships (Vasey, 2000). Sparse though this literature is, the suggestion is that contact between personal assistants and friends may not be unproblematic.

Personal Assistants and Intimate Relationships

Bruce (2000) highlights the need for agreement with personal assistants about how sexual needs will be supported. This area remains controversial and personal assistants supporting disabled students may be more likely to define sex as a 'want'

rather than a 'need' (Earle, 1999). Personal assistants may vary in the degree to which they will support the expression of an employer's sexuality, and greater difficulties have been reported by gay and lesbian employers: outrage from personal assistants, personal assistants walking out or telling neighbours, leading to attacks on the house, etc. (Killin, 1993). Some authors have reported that the presence of P.A.s can lead to difficulties in social situations outside the home (see also below), where the employer – employee relationship is unclear or possibly not accepted. Such instances may include personal assistants making disparaging remarks in a lesbian bar or instances where other people refuse to leave a personal assistant alone (Vasey, 2000).

To further illustrate how personal assistants can disrupt personal relationships, Rae (1993) cites her own experience of being in relationship with a man who employed female personal assistants. She maintains that she was placed in a position of having to struggle against stereotypical images of sexually attractive womanhood. Her relationship came to an end when she was no longer able to support her partner, who enjoyed having a lot of female P.A.s around him:

‘..many disabled women with similar experiences also find that their partner’s P.A. undermined their authority, their assistance and their integrity’ (1993: 50)

Adler (1993), writing from the perspective of a personal assistant, also notes that he became employed as a result of his employer’s wife having left him for the previous personal assistant.

Again, these instances show that personal assistants may hinder or be problematic in relation to intimate relationships, either because of their presence or through their actions.

Personal Assistants and Wider Social Networks

Kestenbaum (1999) notes that despite personal assistance support services rarely being contracted for anything other than securing people’s safety in their own homes, in fact employers’ social lives are opening up because of the flexibility of

the payments and the acknowledgement of people's aspirations for independent living. Gaining access to more diverse settings is possible (Parker, 1999), because employers are able to purchase a wider range of flexible help, with better continuity, giving greater control and an enhanced quality of life (Glendinning et al., 2000) These advantages have been consistently noted, in comparison with circumstances where assistants were recruited through 'care' agencies (Glendinning et. al., 2000) or where employers experienced assistance controlled by statutory services, such as residential 'care' (Morris, 1993).

Discussing relationships formed at college, Parker (1999) notes that some disabled students felt that the presence of a personal assistant meant that they tended to be viewed by others as a pair, and that sometimes the employer and employee also saw themselves this way. One of the students Parker interviewed reported a friend giving instructions to his assistant rather than him, and another mentioned that former friends had backed off, becoming less close than they were when she did not have an assistant. These issues seemed to be resolved over time and with increased familiarity, although Parker does not say how this was done. Skar & Tamm (2001) report that disabled children and adolescents often socialise mainly with adults, generally lack friendships in relation to non-disabled peers, and that assistants could both help and hinder the formation of peer relationships. Helpful actions included giving the child or adolescent access to play areas and initiating enjoyable games in which the disabled young person could participate. Actions that hindered included their presence (as mentioned in relation to adult students above), substituting in play, not leaving children and adolescents alone with their friends and acting as if embarrassed to be seen with them in public. Clearly the situations of adults and children or adolescents are different; adults are expected to have and are usually accorded more autonomy, although disabled and older people have often been infantilised (Hockey & James, 1993). It is also not clear from Skar and Tamm's study how much opportunity the young people had to decide on who to employ as their assistant and on the roles they should take.

Some authors argue that access can be only partial. Parker (1999) points out that while having a personal assistant does enable entry into higher education, it 'does

not ensure full engagement in the range of the HE experience and high quality access to the whole curriculum' (1999: 489 – 9), this being for reasons of extra time needed to get things done, the availability of assistance, access problems with some buildings, or because of the presence of the assistant him/herself. She quotes Freda, a student at the college:

'I think I'd love to skip a class but I can't because Vera wouldn't be doing anything and it's not fair on her. A bit like having another conscience around. I have to allow myself to wish I could do something without considering the other person....lack of flexibility, unable to be neglectful....waste time...go for a beer...be a proper student. With Vera at my shoulder I feel I shouldn't be doing this as she is standing there doing nothing.' (1999:498)

The physical presence of a personal assistant may therefore act as a constraint on spontaneity, regardless of the actions of the P.A. Particularly where employers have limited hours of assistance available, there may be pressure to use the time doing something seen as productive. Disabled people's experience of higher education is not specifically addressed in this thesis but the main point remains that the presence of an assistant may have a bearing on what employers feel able to do in certain situations. Vasey (1996) talks of the importance of planning well in advance, even if she does not feel like it. The need to have support arranged beforehand means that it is difficult to take holidays, travel, to have a lie in bed, or more fundamentally, move to a new area, due to the potential difficulties of arranging a new support package.

There is very little data on personal assistants' relationships with other people in the public sphere. Adler (1993) raises the issue of how his work is perceived by other people in the sense that it attracts low status and is often viewed in medical terms, highlighting differences between public perceptions and his own experience. Beyond this, there is little information.

Despite these issues, direct payments have proved hugely popular with disabled people, and the consensus is that personal assistance opens up possibilities that were simply not available before. The trade off is between privacy and participation.

Conclusion

This chapter has taken a path through the most relevant knowledge about social relationships, personal assistance, disabled people and the question of social context, with regard to the research questions. It has presented definitions of the concepts used and elucidated the concepts of public and private as a classic dichotomy that will be used in the course of the thesis. There are evident gaps with regard to direct payments and personal assistance, highlighting the addition that this study makes to existing knowledge. The studies about direct payments do provide descriptive accounts of events and experiences but they do not explain how or why relationships develop, for example between employers and personal assistants. They are descriptions of situations at a given point rather than accounts of developments over time.

In the next chapter I will discuss the development of direct payments as a policy initiative. Receiving direct payments rests on the agreement of local authorities to fund personal assistance and to continue doing so. The historical influences shaping developments and the dilemmas resulting from differing agendas form a different but interrelated background to the study.

Chapter 3

The Policy Context

Introduction

Unlike domestic work that is contracted by private individuals using money from their own earnings, direct payments is a specific measure resulting from the lobbying efforts of disabled people to change national government policy. It is designed as an alternative to other forms of service provision with the intention of extending greater choice and control to people receiving payments. This chapter presents a brief historical picture of the early precursors to direct payments and an overview of the legislation and subsequent measures that extended the provisions. The shape of the legislation results from both government ideologies and pressure from the Independent Living Movement and while their agendas did not coincide there was sufficient coincidence in outlook, when combined with an emphasis on cost savings, for legislation to be passed.

This chapter draws attention to the tensions inherent in the agendas of governments and that of the Independent Living Movement. These tensions are relevant in that they impact on local provision in practice. As such this Chapter should be considered together with Chapter 5, where disabled people's experiences of statutory 'care' are discussed as well as the uncertainties surrounding continued provision of payments. These uncertainties, as will be shown subsequently, have ramifications for disabled people's relationships with family and friends and personal assistants.

The History of Direct Payments: Legislation and Welfare Provision

With the expansion of public services following the second world war, the poor law was finally abolished in 1948, to be replaced by a national system for paying social security benefits and legislation in favour of welfare services for older and disabled people (Glasby & Littlechild, 2002). Under the National Assistance Act (1948) Local Authorities were given the power to provide services but forbidden to

provide cash payments to welfare recipients (Hudson, 1994). This aspect of the legislation remained in place until the passing of the 1996 Community Care (Direct Payments) Act and its implementation in 1997. New provisions permitted local authorities to make cash payments in lieu of community care services to which disabled people were assessed as being eligible under the 1990 Community Care Act, but offering this was not mandatory until 2001. Regional variations existed, for example in Scotland the Social Work (Scotland) Act of 1968 allowed payments to be made in exceptional circumstances, where it was judged more cost effective to do so. However this provision was rarely used until 1997 (Pearson et al., 2005).

Early Forms of Payment

Before direct payments became legal there were various ways that money was siphoned to disabled people through third party arrangements. A few authorities made indirect payments either through trusts that recipients had set up for themselves or through organisations. A well-known early example of the latter was set up in the early 1980s in Hampshire, where a group of former residents of a Leonard Cheshire home received payments through that organisation to set up their own homes (Campbell, 1999; Evans & Hasler, 1996). Such indirect payments were initially mainly limited to a few of the conservative - governed southern counties of England, but became more widespread following the endorsement of Hampshire's work as an instance of innovative practice by the Audit Commission (Audit Commission, 1986; Glasby & Littlechild, 2002), albeit slowly due to questions of legality (Evans & Hasler, 1996; Mason, 1998).

Another precursor to direct payments legislation was the Independent Living Fund and this was national rather than local in approach. The ILF was launched following the passage of the 1986 Social Security Act because the Government was concerned that the measures in the Act might result in some disabled people going into local authority residential accommodation and this went against the push towards community care (Pearson et al., 2005). With a budget of £5 million, the fund was administered by a Trust and it was anticipated that the scheme would run for about five years. Aimed at assisting disabled people who did not have assistance from family members, the ILF allowed disabled people the opportunity

to employ personal assistants and while it emphasised personal care rather than support for social activities, it offered much greater flexibility than the alternatives (Kent, 1993; Kestenbaum, 1993).

The ILF attracted criticism from various disability groups and opposition M.P.s due to its discretionary nature but it proved very popular with disabled people (Zarb & Nadash, 1994). By the time it was closed down in 1992, the annual budget was over £97 million and there were 22,000 claimants (Hudson, 1994). The original Fund was replaced with the Independent Living Extension Fund for existing claimants and with the Independent Living (1993) Fund for new applicants. The latter was available to people under 65 who were eligible for at least £200 worth of local authority services per week. In this way grants were tied into local authority assessment procedures (Glasby & Littlechild, 2002) rather than being administered independently. A decline in the numbers of people taking up funding ensued (Kestenbaum, 1995).

Legislation and Eligibility

The Community Care (Direct Payments) Act was passed in 1996, coming into force in England, Wales and Scotland the following year, and two years later in Northern Ireland. The Act had several setbacks en route (Glasby & Littlechild, 2002) and was subject to various amendments and modifications. In the resulting legislation, people eligible for direct payments were defined as follows:

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

- All adults with physical impairments (including people with sensory impairments) who are able and willing to manage direct payments (with help if necessary), with no age limit. This does not exclude people who have both a physical impairment and another condition (such as learning disability).
- All disabled adults who are able and willing to manage direct payments (with help if necessary) with no age limit.
- All adults who are able and willing to manage direct payments (with help if necessary), with no age limit.'

(Community Care (Direct Payments) Act, 1966: pp 4-5)

The Secretary of State indicated that his preference was to limit payments to the first group, i.e. people with physical impairments aged under 65 although people with other impairments were not excluded under legal provisions. This was an attempt to limit eligibility (Glasby & Littlechild, 2002). Few local authorities made payments to people with mental health issues or people with learning difficulties, using the phrase 'willing and able' as an exclusionary clause. Close family members and partners could not be employed as personal assistants at this time, ostensibly to prevent exploitation of both parties but also as a means of continuing to make use of unpaid assistance to disabled people. Again, local authorities were given the power to give direct payments but not the duty to do so and there is continuing evidence that in the main professionals remain opposed to them (Clark & Spafford, 2002; Wistow et al., 2005; Witcher et al., 2000).

Many of the details of implementation were communicated later through additional guidelines. The Policy and Practice Guidance (Department of Health, 2000c) emphasised partnerships with disabled people, and the importance of support from Independent Living organisations. Local authorities were charged with ensuring that money was used effectively, costs monitored and that provision made was within their budgets. Direct payments could only be made available if they were at least as cost effective as directly provided services (Glasby & Littlechild, 2002).

Extending Direct Payments

Since the 1996 Act direct payments have been made more widely available. Restrictions on the 65 age limit were removed in 2000, payments were made available to ‘carers’, children aged 16 – 18 in 2001 and to families with disabled children (Department of Health, 2000a). Evidence suggests that payments have largely been restricted to white, physically disabled people (Glasby & Littlechild, 2002), although there have been and remain concerted efforts by some to extend the scope of payments to people with learning difficulties (Holman & Bewdley, 1999), people with mental health issues (Newbigging & Lowe, 2005; Rankin, 2005; Spandler & Vick, 2004) and older people (Clark et al., 2004). Concerns remain about groups who have limited information about and access to direct payments (Hasler & Stewart, 2004). However since 2001 it has been made mandatory for local authorities to offer payments where they are requested and people are eligible. The continued expansion of direct payments remains a priority in government policy (Prime Minister's Strategy Unit, 2005). Government data (Department of Health, 2005a) shows the number of people receiving direct payments to remain very small in comparison with the availability of home ‘care’ and professional support, although numbers have risen to 17,300 in 2003-4 compared with 9,600 in 2002-3.

The next section will consider the influence of the Independent Living Movement on the development of direct payments. As authors have noted, direct payments legislation arose as a result of rather disparate agendas and the contradictions between these have given rise to continuing tensions in how provisions are made in practice (Pearson, 2000; Spandler, 2004).

The Independent Living Movement (ILM)

Since the 1960s disabled people have mobilised around political issues and civil rights. Between 1981 and 1993 the number of organisations of disabled people grew from 16 to over 80 in the UK (Davis & Mullender, 1993). The British Council of Organisations of Disabled People reported 106 member organisations in 2005 (Pridmore, 2005) and campaigning has focussed on access issues, legislative

change and independent living. Personal assistance services have been a key concern, particularly for physically disabled people.

A major impetus for the development of the Independent Living Movement was the poor quality and often abusive nature of services provided to disabled people (Hunt, 1966, 1981). Numerous research studies have pointed to the ways that disabled people have been marginalized from daily life and activities that are taken for granted by non-disabled people (Barnes et al., 1999; Finkelstein, 1981b, 1990, 1991; Morris, 1993). Direct payments were seen as an alternative which offered recipients more choice and control (Carmichael & Brown, 2002). BCOBP's campaign to change the 1948 legislation on cash payments to welfare recipients was given impetus by an important piece of research which demonstrated that direct payments were 30 – 40% cheaper than directly provided services (Zarb & Nadash, 1994). This work was pivotal in terms of convincing politicians and policy makers who were keen to reduce costs as well as take less a less active part in welfare provision (Sharkey, 2000).

It should be noted that there were also broader challenges to the traditional ways of providing public welfare; in particular there was dissatisfaction with housing and other social 'care' services. The women's, Black people's and lesbian, bi-sexual and gay movements, for example, set up alternatives which emphasised collaborative work with service users, such as rape crisis centres, lesbian / gay helplines, advocacy schemes etc. and these often met needs that had not been acknowledged. New philosophies such as normalisation and social role valorisation challenged the value base on which traditional services were built and offered coherent alternatives (Beresford & Postle, 2005; O'Brien & Tyne, 1981). This gave rise to alternatives to institutional incarceration such as small-scale services that provided assistance with, for example, getting employment and places to live, especially for people with learning difficulties. All these developments formed part of a wider movement to challenge traditional provider preference in the delivery of services.

Self-Help

Centres for Independent Living (CILs) are mostly managed and run by disabled people on a self help basis and many have been established since the early 1970s, aiming to provide services to disabled people needing assistance. One of the earliest Centres, the Derbyshire CIL, articulated seven needs with regard to independent living: information, peer support, housing, equipment, personal assistance, transport and access (Davis & Mullender, 1993; Hasler, 2003).

Independent Living has also been renamed Inclusive or Interdependent Living to more clearly describe the intention behind the term. There have been a variety of definitions but all focus on the concepts of choice, control, freedom and equality (Hasler, 2003). The main points have been summarised as follows;

‘Independent Living’ means that disabled people want the same opportunities and the same choices in everyday life that their non-disabled brothers and sisters, neighbours and friends take for granted. That includes growing up in their families, going to the neighbourhood school, using the same bus, getting employment that is in line with their education and abilities, having equal access to the same services and establishments of social life, culture and leisure. Most importantly, just like everyone else, disabled people need to be in charge of their own lives, need to think and speak for themselves without interference from others.’ (Ratzka, 1996 p.1)

CIL.s and user-led organisations in the UK have argued for the implementation of direct payments and have supported people employing personal assistants (BCODP, 1995). User led services can have a vital role in helping people new to direct payments to gain confidence in both the practicalities of administrative tasks and the management of assistants and CILs have been pinpointed as the focus for future support of people using direct payments (Prime Minister's Strategy Unit, 2005).

User-led support organisations may be distinguished from user involvement (see Begum & Zarb, 1996, for a discussion of the latter) although areas of overlap may exist. Barnes et. al. (2003) further distinguish between self-help and user-controlled organisations on the basis that the latter are characterised by:

‘formal mechanisms to ensure: control by disabled people, high levels of accountability to members, employment policies that favour disabled paid and

voluntary staff, and a commitment to the social model of disability and independent living.’ (Barnes et al., 2003: 13)

The existence of user-led organisations has been shown to enhance the scope for empowerment of disabled people within a ‘care’ management system which by its nature limits it (Tanner, 1998). However the effectiveness of organisations may be compromised by difficult relationships with local authorities with regard to the intersection of funding, campaigning and referral issues as well as competition from other service providers. Capacity, financial stability and resourcing remain problematic in the long term (Barnes, Mercer et al., 2001; Barnes, Morgan et al., 2001) . While there is some debate with regard to the extent to which disabled people’s organisations ought to be closely allied to local authorities in the sense that this involvement can compromise the effectiveness of campaigning, the presence of user-controlled services has been shown to be a vital alternative support for disabled people in the context of problematic and unresponsive services (Davis & Mullender, 1993). Having been centrally involved in campaigning both nationally and on a local level for the implementation of direct payments, disabled people are well placed to offer relevant and appropriate assistance.

Political Priorities

The perspective of the ILM may be compared and contrasted with the prevailing political philosophy of the government in the mid 1990s and beyond. There were some important ways in which the priorities of the government and ILM coincided but their reasons for agreement differed.

Direct payments legislation and guidance rests on earlier community care legislation, and in particular the 1990 National Health Service and Community Care Act. The Conservative government promoted neo-liberal philosophies concerning the importance of individual choice and responsibility. Concerns were expressed about monolithic, bureaucratic services and the interference of the ‘nanny’ state in people’s lives. It was argued that services had been shaped by professionals to meet their own rather than service users’ needs, resulting in the creation of service users who were passive and dependent (Harris, 1999). There were attempts to curb the power of professionals through increases in managerial

power and a reduction in the public accountability of services through the setting up of appointed boards (M. Barnes, 1997).

Costs of service provision were a key concern. Firstly, the Government argued that better value for money could be obtained through the promotion of competition between private service providers. Grants were made available to voluntary organisations in order to promote their involvement in service provision rather than advocacy work. Secondly, it was argued that publicly provided services should be supporting 'families, friends neighbours and other local people' (Griffiths, 1988) instead of providing direct assistance. The emphasis was on individuals as actively involved in taking responsibility for their own welfare and that of their families. In these ways, the government sought to promote consumer-driven choice between a range of privatised services, which would result in decreased waste of resources (Beresford & Postle, 2005; Harris, 1999).

Policies have not altered dramatically since 1997 with the election of a New Labour government. There is less emphasis on privatisation in favour of a plurality of welfare provision, but the emphasis on individual consumer choice remains. People are expected to take responsibility for their own welfare, especially with regard to old age and there are attempts to persuade people that citizenship involves individual and mutual responsibilities rather than individual rights (Dwyer, 2002).

The promotion of choice and control by the ILM accords with these concerns. Both share a dislike of traditionally organised bureaucratic services and embrace the notion of the 'active welfare subject' (Williams, 1999 p.667). Some have argued that the disability movement's campaign for direct payments colluded with neo-liberalism on the basis that it opened the door to the privatisation of services (Morris, 2005). Ratzka's statement (above) echoes traditional liberal concerns about freedom from interference from others, for example. The American ILM has been seen by some as overly-influential in arguing for the importance of consumer power and in the U.K. the ILM did make important compromises over the issue of costs in order to gain government agreement to direct payments.

Critics of government measures have pointed to key differences on outlook. Mason has expressed profound scepticism about government motives:

‘Direct payments are not independent living because Direct Payments are a local government provision which meets central government legislative needs and nowhere in our country does legislation contemplate the enabling of equal opportunity through the provision of personal assistance. Our dream was that disabled people would be enabled to become active citizens at work, rest and play thereby fulfilling their roles in terms of taking the opportunities society offers and meeting the responsibilities society requires. We believed that direct payments would offer this but that is not so. What has happened is that Direct Payments is just another means of providing social welfare. At the basic level it is seen in the same category as attendance at the Day Centre, an auxiliary nurse getting you up and putting you to bed or two weeks in a respite home.’ (Mason, 1998 p.4)

Given these concerns, it is worth reiterating that the developments have represented an important success for the disabled people’s movement in the UK (Barnes, 2002). Despite the drawbacks, there is consistent evidence (Kestenbaum, 1999; Zarb & Nadash, 1994) that disabled people prefer direct payments to previous arrangements.

Getting Hold of Direct Payments

Fundamental to the 1990 Act legislation was the separation of service purchasing and provision, with care managers responsible for determining applicants’ needs and arranging relevant services following an assessment. To be eligible for a direct payment, applicants had to show that they were eligible for a service that the local authority had responsibility for. Switching from receiving a service from a private agency to a direct payment represented a dramatic change for many recipients but the gateway to securing services remained the same.

In theory at least, services provided should be based on people’s needs, rather than already existing services, and based on risks to independence (Davis et al., 1997; Department of Health, 2002). The Social Services Inspectorate has suggested that ‘need’ is:

‘a shorthand for the requirements of individuals to enable them to achieve, maintain or restore an acceptable level of independence or quality of life, as defined by the particular care agency or authority.’ (Department of Health et al., 1991 p.12)

Since the 1990 Act much effort has gone into designing eligibility criteria (M. Barnes, 1997) tailored to the limited financial resources of local authorities. ‘Care’ managers are asked to consider need in the light of available budgets.

More recently there has been increased emphasis on working in partnership with disabled people and on their ‘active participation’ in the assessment process (Department of Health, 2002). Person centred planning is advocated as an appropriate focus for making services more responsive to individuals seeking help (Department of Health, 2005b; Wistow et al., 2005). Disabled people have also argued in favour of an approach that takes their interests as primary (Barnes et al., 1995; Department of Health, 2002; Morris, 1993), despite different definitions of requirements. While care managers are likely to see needs in terms of functional limitations caused by impairment and available services; disabled people are more likely to think of needs in terms of access to education, employment, access, transport etc. (Barnes, 1994; Davis et al., 1997). For disabled people therefore, direct payments and other services are a means to an end rather than an end in themselves.

Harris et. al (2005) report on an action research study into assessment procedures that involved switching to a focus on outcomes instead of needs as an attempt to circumvent this problem. Outcomes were defined in terms of disabled peoples’ personal comfort, autonomy, and social and economic participation. They report that attempts to implement the change encountered a number of difficulties, including professional concerns for power, lack of understanding of the social model of disability and unwillingness to implement new procedures (Harris, 2004) although in some instances staff welcomed the change, as did disabled applicants themselves (Harris et. al. 2005).

As well as needs-led assessments and re-focussing on outcomes, disabled people have made some efforts to introduce self assessment, that is, where people define their requirements for themselves (Barnes et al., 1995; Priestley, 1999) .

Central government stipulations with regard to access to ‘care’ services have been widely publicised on local authority web sites and written information packs.

While the stated Government aim is for services to be offered on a more consistent basis across the country, room is left for flexibility in terms of the shape of the provision. In making judgements about eligibility, local authorities are asked to band people’s needs into four groups as follows:

‘Critical – when

- Life is, or will be threatened; and/or
- Significant health problems have developed or will develop; and / or
- There is, or will be, little or no choice and control over vital aspects of the immediate environment; and / or
- Serious abuse or neglect has occurred or will occur; and / or
- There is, or will be, an inability to carry out vital personal care or domestic routines; and / or
- Vital involvement in work, education or learning cannot or will not be sustained; and / or
- Vital social support systems and relationships cannot or will not be sustained; and / or
- Vital family and other social roles and responsibilities cannot or will not be undertaken.

Substantial – when

- There is, or will be, only partial choice and control over the immediate environment; and / or
- Abuse or neglect has occurred or will occur; and / or
- There is, or will be, an inability to carry out the majority of personal care or domestic routines; and / or
- Involvement in many aspects of work, education or learning cannot or will not be sustained; and / or
- The majority of social support systems and relationships cannot or will not be sustained; and / or
- The majority of family and other roles and responsibilities cannot or will not be undertaken.

Moderate – when

- There is, or will be, an inability to carry out several personal care or domestic routines; and / or
- Involvement in several aspects of work, education or learning cannot or will not be sustained; and / or

- Several social support systems and relationships cannot or will not be sustained; and / or
- Several family and other social roles and responsibilities cannot or will not be undertaken,

Low – when

- There is, or will be, an inability to carry out one or two personal care or domestic routines; and / or
- Involvement in one or two aspects of work, education or learning cannot or will not be sustained; and / or
- One or two social support systems and relationships cannot or will not be sustained; and / or
- One or two family and other social roles and responsibilities cannot or will not be undertaken.’

(Department of Health, 2002 pp.4-5)

These guidelines therefore relate the provision of assistance to the circumstances of individuals seeking help. They call for judgements to be made about the relationships between people and their environments and the ways that well-being and social connectedness will be compromised by lack of support or enhanced by its provision. Local Authorities are charged with making these judgements while also being subject to budgetary constraints (Department of Health, 2000b), in particular the stipulation that direct payments should not cost more than equivalent directly provided services.

While details about how direct payments are being implemented in practice are continuing to emerge, there is some evidence that a variety of contextual factors impinge on the actions of gatekeepers. Various reasons for the opposition of social service professionals to direct payments have been suggested, including that care managers want to safeguard their control over service users and ultimately their jobs (Davis et al., 1997; Riddell et al., 2005; Rummery & Glendinning, 1999) and this was deemed to be the main reason by the employers taking part in the study. Local authority personnel had expressed concerns that money would be used irresponsibly, and this has been noted in other studies (Glasby & Littlechild, 2002). ‘Care’ managers have also been found to be worried about how to offer provisions, concerned about applying the criteria of ‘willing and able’, balancing empowerment and exposure to ‘risk’ and maintaining fairness to all while meeting

individuals' needs flexibly (Clark & Spafford, 2002). A more deliberate approach to obstruction has also been suggested, in that these reasons have been used by social workers as justification for their wish to 'police' their clients (Sapey, 2001), and some social workers have been portrayed as essentially in favour of payments, but constrained by structural factors (Stainton, 2002). In their study on widening access to direct payments for mental health service users, Spandler and Vick (2005) note for example that the need to safeguard resources continued to exert a restraining influence on assessors. Other concerns were with risk management, the safety of recipients and worries that money might be spent on the wrong things. Consequently, assessors tended to select people they thought might be suitable for payments rather than offer the option to all who might want it. This and related work (e.g. Harris, 2004; 2005) suggests that there are discrepancies between public policy, which implies that resources are allocated according to need, and the actual practice of determining eligibility.

Conclusion

This brief outline has discussed the contradictory and conflicting priorities of disabled people, national governments and local authorities, while noting the areas of overlap. Where different priorities exist, it may be expected that differences will re-surface at various points. With reference to the questions posed in this thesis, improving and strengthening social networks was not an explicit outcome of direct payments as stated by national government. Social inclusion is a priority for New Labour but this is couched in rather general and individualistic terms and without acknowledgement of a connection between 'care' and social relationships. The means for effecting inclusion is largely considered to be via employment.

There is an expectation that services, whether provided through direct payments, by social service departments or intermediary agencies should not be a substitute for assistance that is provided on an unpaid basis by kin and friends. This point will be taken up in Chapter 5, where issues regarding service – led and outcome / needs –led provision are discussed together with local authorities' expectations about what family members ought to be doing. The issues also relate to Chapter 7, where the experiences of employers and family members over time are discussed.

Because these sections document the views of respondents in the study, the methodology used to generate data is the subject of the following chapter.

Chapter 4

Methodology

Introduction

This study initially arose from a much smaller piece of research carried out as part of an MA in Disability Studies at the University of Leeds that considered the relationships between disabled employers and personal assistants. In turn this arose from the substantial interest shown by disabled people in securing direct payments as an alternative to other more traditional forms of 'care' and from concerns expressed about managing personal assistants (Vasey, 2000). Following discussions with and guidance from colleagues, an expanded research proposal was developed. Funding was secured from the ESRC for a three-year study.

Rationale for the Use of Methods

A qualitative research strategy was used, employing semi-structured interviews and an interpretive analysis.

Employing a personal assistant is a relatively recent experience for many disabled people, as is working as a P.A. for people who take up this job. While a few disabled people have employed assistants directly for many years, (Evans, 2000; Morris, 1993), their numbers are small. It is only in the past few years that these arrangements have become more widely available. At the time of this study direct payments were being made available to more people in many areas as local authorities were increasingly being compelled by central government to extend provision (Glasby & Littlechild, 2002) and under pressure from disabled people to make these available. There are new implications for family members and friends of disabled people and people doing assistance work. Not much is known about the social impact of direct payment arrangements on disabled people, their family members, friends and personal assistants. A qualitative research strategy has the potential to provide a more flexible context in which to explore nuances and complexities, in contrast to a quantitative approach. Using semi-structured

interviews permitted asking further questions as issues and pertinent points arose during interviews. On the other hand using the same basic structure for all the interviews allowed the generation of data that was largely comparable. The schedule of questions asked is provided in Appendix 2. A qualitative approach allows the expression of respondents' interpretations in ways that are less available through quantitative analysis (Barnes, 1992; Blaikie, 2000) The subject matter of the study was sensitive in that it involved intimate and personal relationships and how these were developing over time. Personal contact between the interviewer and respondents, together with the flexibility of the interview schedule allowed these issues to be discussed in a setting judged to be more comfortable for respondents.

A narrative approach was used, which has been described as being based on the respondent's viewpoint in the telling of their life or 'story'. Miller (2000) argues that narratives also may be distinguished from stories because they are accounts of specific events embedded in the overall narrative. While stories may be a product of the interview process, they may also be well rehearsed and shared with other people who are personally close to respondents (Coffey & Atkinson, 1996). A narrative approach highlights the importance of personal experience and the ways that people are active in constructing their interpretations of the world. It further allows the accounts of respondents to be situated relationally to other people; the central concern of this study. An interpretive approach is used. I selected the questions asked and categorised and organised the data according to these questions.

Accounts of the past given by people will always be seen in the light of the present and subject to re-interpretation (Barnes, 1992), and there is no guarantee that a story will be 'objectively' true in the sense that it can be directly measured or verified (Mason, 1996). However the advantage is that it can offer an insight into the meanings for the narrator. There is a recognition that reality is constructed in a double sense; by the researcher as well as the respondent (Whyte & Ingstad, 1995), and my background is summarised below.

The Researcher and the Research

As a non-disabled, (with an intermittent impairment) white and middle class researcher, doing research with disabled people, families and personal assistants presented certain questions. In a variety of ways, the identity of the researcher can support or hinder both the process of research, and create dilemmas which may be difficult to reconcile (Stone, 1996). I consider myself to be non-disabled because I do not experience systematic disadvantage and oppression. I have a neck impairment following a car accident and this may cause pain for periods of time. During these times I am aware that I receive pity and exasperation from others, but I have much longer times when this is not the case.

My working background has been in supporting people with learning difficulties and disabled people in securing jobs at the full rate of pay with community (i.e. non-segregated) employers, at a local level for many years in southern and northwest England. Concurrently I have been involved in training and development work with the aim of equipping service workers with the skills to do the same. This work was national in scope and allowed me to build up contacts in many areas. Assistance to gain employment is almost universally welcomed by disabled people and I was able to build on previously established goodwill.

In another context I was also involved with supporting the development of a leadership training organisation of family members of young disabled children, and disabled adults. This was not work that I was employed to do but which I supported through practical assistance and moral support. Again I feel this helped in terms of having secured the trust of disabled people and their families in the localities concerned.

Through these involvements I also knew several people who worked as personal assistants: two assistants through their employers and another through having employed her a few years previously. While personal assistants had less contact with one another (although two did know each other) than was the case for disabled people and family members, and personal assistants were recruited through employers rather than independently, I consider my prior contacts here

also helped with the progress of the study in terms of personal assistants feeling comfortable with participating.

This presents certain problems however. Doing research is not the same as assisting with employment. Non-disabled researchers have been roundly criticised in the past for misrepresenting and ignoring the views of disabled people and for producing work that adds to their oppression (Abberley, 1992; C. Barnes, 1997; Hunt, 1981; Oliver, 1992). Debates have also accompanied research on White and Black women (Carby, 1982; Collins, 1989; Hammersley, 2000; Hammersley & Gomm, 1997; Hartsock, 1998; hooks, 1984) and Black disabled women (Vernon, 1997). A further source of division concern a more general focus on status differentials between researchers and research participants (Ribbens & Edwards, 1998). Disability Studies scholars have called for research to be participatory and emancipatory (Oliver, 1992; Stone & Priestley, 1996; Woodill, 1992; Zarb, 1992).

With regard to participation in the research, this was very difficult to do on a formal level. In fact several of the respondents in the study provided continuing advice but this was very informal, and could not be recognised within the structure of the university supervision arrangements. It is a fundamental stipulation of PhD training that the work presented should be the author's own and tensions between 'objectivity', accountability and control are difficult to resolve. It is with this in mind that I have termed people 'respondents' rather than 'participants.' I feel the former term more accurately describes the degree of control I was able to offer those participating in the study.

While the support of respondents and academics alleviated my concerns about my identity, a more important issue concerns the nature of the research itself and the degree to which it supports the agendas and interests of those participating. Oliver (2002) calls for research to do three things: to capture and reflect the experience of disabled people from their own perspective, to provide information helpful to the policy making process and improve life conditions, and to engage with the political struggles of disabled people. Morris (1992) further argues that personal concerns should be represented as political issues.

It was judged essential to produce an account that resonated with the interests and concerns of the people participating in the study. As Vasey, herself an employer of personal assistants has pointed out:

‘How do you deal with PAs in the social context? This is the question that everyone wants to talk about. A hot date with three people at the table presents an immediate challenge to the social norms. How do we cope with that challenge and how do we develop the skills to minimise the intrusion of the PA presence?’ (Vasey, 2000: 69)

I had similar concerns about the situations of family members / friends and personal assistants. In some academic studies the interests of the three parties has been presented as conflictual. I did not start with this premise, while recognising that in some instances this might be so. Similarly, it was possible that as with disabled employers, many might occupy positions of relatively low status and poverty.

Engagement with political struggles was difficult to do as part of the fieldwork because of the need to remain on good terms with all involved. My involvement here has tended to be outside the context of the research. Involvement in various campaigns (e.g. concerning inclusive education for a local child) and other attempts to secure needed resources (direct payments) was largely separate from the research process. I consider this remains a challenge for research practitioners.

The Selection of Geographical Areas

Selection of geographical areas was not initially deemed to be particularly important in this study. As the research questions concern how people related to one another in social groups, local authority arrangements were not seen as being particularly relevant. This view was modified in the course of analysis. It became apparent that social relationships were indeed affected by the support available or not available from third parties, especially through local authority arrangements. Therefore these considerations have been accorded a higher status than was originally envisaged and the following chapter is included in order to examine this issue. This having been said, the focus of the study is on the arrangements made by

employers, family members / friends and personal assistants and therefore sampling decisions prioritised these.

Administrative areas were also important during the interviewing process because there was an inevitable requirement to make arrangements through a point of contact or gatekeepers. Nine areas in the north of England and Midlands were selected. The rationale for this was largely practical. I have good contacts in some of these areas and they are within reasonable travelling distance from where I live. An unanticipated outcome was that family members I interviewed often lived some distance away. While it should be noted that the changing structures of family relationships has been well documented (Silva & Smart, 1999) my initial, and wrong, assumption was that family members and friends would be living locally.

A further rationale for the selection of these areas was that I was aware of another piece of research being carried out concurrently in an adjoining area by the Health and Social Care Advisory Service, and the researcher and I agreed not to target the same areas. I maintained contact with her during the course of the fieldwork and exchanged views with her on a mutually supportive basis.

The Sample of Participants

Thirty disabled employers, nine personal assistants and ten family members / friends were interviewed, and also one family member who worked as a personal assistant for her mother –in-law and who therefore fitted into both the latter two categories. The employers, family members / friends and personal assistants interviewed were connected to one another in the terms of having a three-way relationship. Each of these instances (each sample of three people) is described as a case study. More employers than assistants and family members / friends were interviewed because of the main focus of the research. Nevertheless, because social relationships are considered here as being the property of more than one person, it was judged to be important to include all perspectives within the constraints of feasibility.

The categories described above were not really sustainable if people were to be described individually. For example, as mentioned, one participant (Kate) was both a daughter-in-law to her employer and working as her personal assistant. Another participant (Carol), nominated for interview as a friend of Chloe's, was herself a visually impaired parent of three children. Marilyn, working as a personal assistant for Kathryn, provided assistance to her mother, a disabled woman, with whom she was living. This having been said, the categories largely held up in the context of this study in that the majority of respondents identified themselves as falling into one or another of the categories of employer, personal assistant and friend / family of employers in terms of the relationships that they had with each other. (See Appendix 1)

People with a range of physical and sensory impairments were recruited. Notably absent are people with learning difficulties. This was because at the time of the study very few people with learning difficulties were being offered this option by local authorities, with the legislative clause of 'willing and able' used as a rationale for exclusion (Community Care (Direct Payments) Act, 1996; Holman & Bewdley, 1999). While this situation appears to be changing, many of the subsequent arrangements involve organisation through third parties such as families or trusts and these were excluded from this study (see below for the rationale for this). Likewise few people with mental health issues were receiving direct payments, although some appear in the sample of respondents by virtue of the fact that they had physical impairments. At the time of the fieldwork there were some efforts being made to extend provision.

Ages of employer respondents ranged between 24 years and 77 years. 19 women and 11 men who employed personal assistants were interviewed. Four employers identified themselves as being from an ethnic minority. The original intention was to interview 8 ethnic minority recipients as part of this sample but in practice it proved difficult to do so. In part this was a question of access to services: It was difficult for disabled people from ethnic minorities to get access to services, either because of lack of information in an accessible form, or because of the ways that local authorities preferred to deliver services. For instance, the fact that knowledge about direct payments mostly spread through word of mouth from people receiving

them (mainly white, English speaking) to potential recipients meant that where language differences existed, many ethnic minority disabled people would not hear about opportunities.

The preference of many South Asian households for family involvement in the arrangement of assistance militated against eligibility at the time of interviewing. This study therefore supports other research that highlights similar concerns (Chamba et al., 1999; Hussain et al., 2002). It should be noted that more recent legislative changes have made services more accessible to ethnic minority applicants, particularly those that permit employment of family members as personal assistants.

An issue became apparent early on in the study regarding the description of and the practice of employing personal assistants. While some disability studies literature urges characterisation of personal assistants as employees (Marfisi, 2002), respondents described them both in this way and as friends. Again this reflects previous findings (Ungerson, 1999; Yamaki & Yamazaki, 2004) and examining that issue is an important part of this thesis. This was true of both disabled employers and personal assistants. Therefore theoretical sampling was carried out and respondents sought that reflected both perspectives in terms of an 'ideal type', as well as looking at how characterisations were made. The sample size was judged to be large enough to have covered this issue, with people positioned at both ends of the dichotomy as well as in between.

Making Contact with Respondents: Employers

A snowball strategy was used in combination with more formal approaches to gatekeepers. Recipients of direct payments were not easily identifiable and had to be sought out. Where possible, I arranged to attend meetings of direct payments recipients so that I could explain the study, answer questions, recruit interested people and get advice. This was the most satisfactory arrangement as it served both to support the groups as important points for contact and gave employers the opportunity to ask questions and decide for themselves if they wanted to participate. It also allowed me to explain that I was seeking to recruit people who

employed personal assistants directly. Meetings were attended in three geographical areas (Areas 1, 2 and 3).

In Area 1 I was invited to a meeting by a recipient of direct payments who I knew as an acquaintance prior to the study and this led to my being able to set up several interviews with people present. The meeting was chaired by members of the local social services department and they agreed to send out a letter informing disabled employers of the study. (See Appendix 2 for a copy of the letter) In turn this led to a few more contacts.

In Area 2 I was able to arrange to attend a meeting of direct payment users at the invitation of a former work colleague who worked as a personal assistant, was employed by the social services department and as a Deaf woman was also active in the disabled people's movement. This was a well-attended meeting and I was able to recruit several respondents in this way.

In Area 3 I also recruited several respondents. The meetings here were structured rather differently in that members of the social services direct payments team controlled the agenda, chaired the meeting and in that personal assistants were present. Agreement was reached that the letter describing the study would be sent out to all employers, and copies were given to the manager of the direct payments scheme. In the event the social services team distributed the letters three months later. While this delayed the process I felt that the hold up served to generate sympathy for my study among disabled employers and I received a very good response to my written request.

At the time of the interviews there were no service user groups in Area 4 or Area 5, although some moves had begun to start these up. In both these localities administrative arrangements had been devolved by the social services departments to an organisation of disabled people who were not themselves recipients of direct payments and who did this work in several geographical areas. Two meetings with managers of the service resulted in contacts with employers in both areas. A prior meeting with a social service manager responsible for contracting with the managing organisation resulted in one contact for interview.

In Area 6, one employer was interviewed. Contact with the manager of the direct payments scheme, who was employed by the social services department, was made rather late in the course of the study. Several potential respondents expressed interest, but time and sampling permitted just one interview. In Areas 7, 8 and 9 just one person in each place was interviewed and these contacts were made through snowballing. There was no contact with the social services department or other organisations. In Area 8 the direct payments scheme was administered through the social services department and a large number of employers were in receipt of payments. A concerted effort was made to arrange interviews through these channels but this effort was not successful. This area was one that I had worked in when generating data for my MA thesis, but key contacts had left the organisation and furthermore the department had experienced some internal difficulties in the not so distant past, making the intrusion of outsiders less welcome.

Making Contact with Respondents: Personal Assistants

Personal assistants were recruited through asking employers whether I might request an interview from a P.A. nominated by them. For this study the aim was to gain a three – way perspective on circumstances and therefore to interview family members and personal assistants who were connected with the same employer for each case study. Not all employers were happy with the prospect of other people being approached so there was an element of self-selection here. Personal assistants were offered the opportunity to participate and most agreed when approached about this by employers. A few preferred not to do so. One personal assistant agreed to participate initially but later pulled out of the agreement – it was unclear whether the reluctance was on his part or that of the employer.

Interviewing personal assistants overlapped with the interviews with employers and started approximately half way through the employer interviews (see Appendix 1 for details of respondents).

While some employers agreed that I might approach their personal assistants, not all were asked. Potential ‘case studies’ were chosen on the basis that they reflected

different aspects of experience. The criteria used included variations in the length of time that arrangements had been in place, the characterisation of relationships along an employer – friendship continuum, household arrangements (i.e. employers who lived alone or with other people), the complexity and simplicity of the arrangements (e.g. where few or many P.A.s were employed), problematic and good relationships and areas of ambiguity such as relationships that overlapped categories. A balance in terms of age, ethnicity, gender and impairment was sought.

Because employers nominated personal assistants, this group is not balanced in terms of some personal characteristics. For example just one P.A. who was interviewed was male. Another male personal assistant initially agreed to be interviewed but subsequently changed his mind. While in the overall sample of all potentially participating personal assistants the vast majority were female, reflecting the gendered nature of this employment sector, a significant minority of the overall number of personal assistants in this sample was male. None of the ethnic minority employers agreed for their personal assistants to be interviewed. In part this was seen as being a practical issue because the geographical distances here were relatively large but also it was considered to be undesirable by employers.

Making Contact with Respondents: Family Members and Friends

Family members and friends were likewise recruited through employers at the same time as for personal assistants. Employers were asked to nominate people who they felt could offer a perspective on their situation and who might be interested in participating. As with personal assistants, family members were free to decline.

Ten people were interviewed (see Appendix 1) and of these three were mothers, two were male partners / spouses living with the employer, one an adult son who had left home, another a (child) daughter living with the employer, one a daughter-in-law who also worked as a P.A. for the employer concerned, and two were female friends. Three respondents were male and seven female. One of the

personal assistants in the sample described above lived with her parents and brother at the time of interview and was providing assistance to her mother who had multiple sclerosis. Her perspectives on this have also been included, although her mother was not interviewed as part of the sample of employers. One of the employers, Najmah, elected to be interviewed with his wife (Shaziah) present. She also contributed to the interview but was not asked questions directly. Her views have also been included here.

All the family members and friends were white and identified themselves as English, British or Welsh, except for Najmah's wife who identified herself as Pakistani British. Two minority ethnic employers (Judith and Priti) maintained that the travelling distances involved were rather too large to justify the inclusion of their family members in the sample and although substantial travel would have been involved, I was willing to do this. Nevertheless they expressed a more general reluctance on the issue, and in line with other instances where employers were unwilling, I did not pursue the issue. The fourth minority ethnic employer, Aurang, was not on good terms with his family and preferred that I did not contact them.

Interviews with People not Included in the Study

At the beginning of the fieldwork period I carried out several interviews with respondents who were not subsequently included in the study. Direct payments were becoming available to family members with disabled young children and in Area 2 the social service department contacted two people in these circumstances on my behalf. Neither of the young people used speech as a primary form for communication and I interviewed their parents. It became apparent that there were qualitative differences in the accounts of social relationships given by others in comparison with situations where people gave their own accounts of relationships. For example, there was tendency for the parents to talk about their own important relationships rather than their sons'. It was therefore decided to focus more exclusively on the situations where people were the direct employer of personal assistants and who were adult. It should be noted that since this time payments have been made available to young people between the ages of 16 and 18, but this was not the case at the time of the study.

Two other male respondents were also interviewed and their accounts have not been included here. During the course of the conversations it became apparent that while they received direct payments, they employed all their assistants through a private agency rather than directly. Their accounts were different in that they described situations where they had rather less control over the actions of assistants: for example one man pointed out that he preferred it when assistants did not turn up wearing a uniform, suggesting that he had little choice in the matter. Again it was decided that the focus would be on situations where direct rather than third party arrangements were made, although it should be noted that some respondents employed assistants both directly and through an agency and their accounts have been included here.

These additional interviews were helpful in that they served to clarify some of the issues involved and to set parameters around the scope of the study during the early stages. On the other hand several of the people involved in such arrangements were from ethnic minority groups, reflecting the possibility of different preferences in arranging support that have been discussed above. This decision did also have the drawback of excluding some people with learning difficulties, as in each of the localities at the time funding was channelled to these recipients through trusts.

Consultation with Local Authority Representatives, Managing Organisations and Others

I met representatives of local authorities in four geographical areas. These meetings were held at the managers' places of work and had a dual purpose; to request contacts with potential respondents and to find out more about how administrative arrangements worked. Broad questions to ask were drawn up in advance of meetings: in practice some managers followed their own agendas. While some were willing to provide information, others were less so.

Three geographical areas were covered by one local authority organisation in that two of the areas had 'bought into' another of the schemes for administrative

purposes. Arranging access was complex here, because of the need to negotiate with both the organisation administering the scheme and local authority representatives. Access was secured in two of the areas but not the third covered by the direct payments scheme. The reason for success in two of the areas was certainly due in part to personal connections with disabled people locally who presented my involvement more or less as a fait accompli.

As mentioned above, in two other geographical areas a large support organisation of disabled people had been contracted by local authorities to provide assistance and support for employers using direct payments. A meeting with the regional manager of this organisation was arranged by one of the employers participating in the study and took place at the employer's house. A meeting with local managers of the organisation was held in a café, and further communication continued by e-mail and telephone.

There were difficulties in explaining the scope of the study to some gatekeepers as they tended to assume that the study was about the payments rather than the social situations of people involved and this contributed to a few misunderstandings during the early stages of the fieldwork. The gatekeepers involved inevitably selected people they thought would be interested in participating and who might show their scheme in a good light. This being said it was possible in one instance to arrange to interview a respondent who was less content with the scheme. In three areas gatekeepers distributed letters inviting people to participate as well as nominating people they asked personally.

Finally, I also consulted several other people in the course of the study – notably disabled people with long standing experience, family leaders with an interest in service accountability, three researchers working in the same area of study, two people involved in service development across the region and members of four organisations of ethnic minority disabled people.

The Interviews

All interviews were carried out by the author and took place between October 2003 and March 2004. The time and place for interviews were usually arranged over the telephone or by e-mail and agreed to suit both parties. All employers opted to be interviewed at their homes except Aurang who chose to meet in a café in the town centre and Najmah who elected to meet in a council building. Employers asked permission from family members / friends and personal assistants before giving me their contact details.

Efforts were made to interview respondents on their own but this did not always happen in practice. In three instances personal assistants were present for part of the interviews with employers. Most family members / friends opted to be interviewed at home, but Eva, Joe and Shirley were interviewed at the employer's house and with them present, at Eva and Shirley's request. The extent to which this arrangement had been made by the employers concerned was unclear. One mother (Jessica) had arranged for three other family members and friends to visit so they could add their perspectives. All except one personal assistant opted to be interviewed in their homes. (Marilyn was interviewed at my house). At times thoughtful negotiation was needed to secure agreement that personal assistants and family members / friends could be interviewed without others present, and from the above it is clear that it was not always possible.

With the agreement of respondents, the interviews were taped and the transcriptions written up afterwards. Three employers, Sylvia, Najmah and Graham, preferred their voices not to be taped and notes were therefore taken by hand. The questions asked of respondents (detailed in Appendix 2) were written on cards held together by treasury tags and this permitted jumping to different sections according to the respondent's train of thought. While questions did follow the schedule, supplementary probes were used to clarify points and to gain more information at various points in the interviews. The shortest interview lasted for half an hour and the longest four hours; the latter conducted on two different occasions. The average time was around two hours. A conversational style was used for interviews and typically respondents had much to say on the subject.

The Mapping Exercise

The questions asked of family members / friends and personal assistants broadly corresponded but interviews with employers took rather longer. This was because these also included a large section that asked people about other people who they were close to and asked them to map these relationships in terms of emotional closeness. A chart with six concentric circles was used in this process and respondents were asked to place post-it notes, on which names were written, on the map (see Appendix 2). People felt to be closest were positioned nearest the centre of the map and people more distant in the outer circles. Four respondents had visual impairments and here numbers ranging from 1 to 6 were used instead. The mapping approach has been widely used in studies on social relationships and networks (Flowerdew, 1999; Pahl, 2002b) and proved effective. The advantage of using post-it notes was that it enabled respondents to change their minds about where people were positioned relative to one another and several did this during the course of the interview. The numbering system also appeared effective for visually impaired respondents.

The aim of this exercise was to help thinking in a concrete rather than abstract way about relationships and how they had developed, and facilitate discussion of this. It was judged to be important not to assume in advance that personal assistance had made any impact on social relationships. Using a map to facilitate discussion about key people and how relationships developed over time allowed the perspectives of respondents to emerge in their own words and on their own terms. The presence or absence of personal assistants on the map could be explored, as could the reasons for placing them in particular positions. Using post- its allowed respondents to change their minds about the positioning of people during the course of interviews and this proved insightful (see for example Angela's decision, documented in Chapter 8). It is important to state that the data generated from each map has not been reproduced here because the data is not comparable. Some employers expressed reluctance to express degrees of liking while others distinguished sharply between people. Although this tool has been used extensively in research

into social relationships, it has not previously been employed in disability studies research.

Reciprocal Information

All respondents were invited to ask me for any information they wanted, either personal questions or for information about the study, and many did so. Information was also offered during the interviews where it was judged appropriate. Respondents were asked to make suggestions about how interviews could be improved and while some did, particularly during the early stages when they were aware that the schedules were being piloted, there were not many additional suggestions. All agreed that their names be changed and three people chose names that they liked.

Transcription and Analysis

Each recording or written record of an interview was typed up afterwards. Respondents were offered the option of looking at the transcripts afterwards and eleven employers, three family members and four personal assistants requested this. In one instance a personal assistant made revisions but otherwise the transcripts remained as written. Three respondents who had speech impairments made minor corrections to transcripts via e-mail, where I had misunderstood some words.

Notes about each interview were made at the time it took place and kept with interview transcripts. These contained details of the context of the interviews and observations made at the time. They served as reminders for important additional information. A field diary with dates of meetings was kept to show when meetings were held, the progress of the fieldwork and developing analytical thoughts. Analysis was carried out in the spirit of grounded theory (Glaser & Strauss, 1967). A 'bottom up' approach was used as an attempt to safeguard against data being fitted into a predetermined theory. The procedures advocated by Strauss and Corbin (1994; 1998) have not been used here, such as the use of precise coding procedures for handling data. Instead a more fluid, interpretive process was

selected to give a richer perspective on the intersection of data, concepts and theory (Mason, 1996).

Research questions formed the basis for initial categorisation. Transcripts were studied many times and themes identified from the account of each respondent. These were then cross-referenced. Through comparison the broader themes of employment and 'paid friendship' (discussed in Chapter 6) emerged as key categories. Context also became apparent as a central concept (used here as a overriding theme to the thesis). Transcripts from interviews forming case studies were considered together and analysed. Data was therefore analysed cross-sectionally and non-cross sectionally.

Nvivo was used as a programme for storing and retrieving data. It was used in much the same way as a filing cabinet. The programme was not used for theory building because it fosters a 'top down' approach. For example, there is no straightforward way of creating parent as opposed to sibling or child nodes, which building theory from data would suggest is necessary. Therefore much data analysis was done in my head and on paper.

In presenting the data, the perspectives of employers, personal assistants and family and friends are handled separately, but a problem associated with this is that it can result in repetition or omission, inhibit the presentation of analytical links and a more conceptual flavour to the data. I have tried to get around this problem by including a section (the latter part of Chapter 8) where the structure of maintaining separation between the three groups has been abandoned. I deemed this necessary in order to adequately show the reasons why respondents took certain courses of action.

Review of the existing literature was carried out as part of the initial process of formulating research questions, particularly with regard to recent research on direct payments and personal assistance. A more extensive search took place after data generation, to coincide with themes arising from the data and to make sure that more recent policy directives were included.

Ethical Considerations

A guarantee was made that individuals would not be identified personally and all names have been changed. Geographical areas have been anonymised so that respondents cannot be linked to these, to protect the identities of people further. This is for two reasons. Firstly the areas had small total sample sizes so many people knew each other, especially where service users were recruited through local support groups. Also because snowballing was used, this formed another personal connection, often across geographical areas. Some respondents could be identified just through mention of the geographical areas – several employers interviewed had taken leadership positions or give accounts of situations that might allow others to guess their identity.

Secondly, I have wanted to include respondents' accounts of the policy context and how payments were implemented in local authority areas. Payments remain contested in terms of what they may be used for, and the status of disabled people using them is still uncertain in terms of the continuity of funding. Several respondents enquired about my connections with the social services department and received reassurance that the local authority did not employ me, nor would I divulge what they said to officials. Therefore details of localities have been omitted to try to honour this commitment.

Interviews concerned personal relationships and therefore some people did talk about others that I had interviewed. In a few instances respondents divulged information that another person had obviously preferred not to discuss, although it was highly pertinent to the subject. Where this happened I have included the information with reference to the person who discussed it but have not identified the person they referred to. This is to respect the limits of what each respondent felt comfortable divulging.

Conclusion

This chapter has outlined the main phases of the fieldwork undertaken over a period of a year and a half. While I have categorised the information into various

headings, the process was not as well structured as has been presented here. In practice, the fieldwork involved a considerable amount of negotiation, arranging and waiting. In doing the analysis, insights emerged in pieces rather than in a neat and tidy fashion. Problems with presenting the data in a coherent form posed many issues concerning structure. However from a personal perspective the study presented an opportunity to gain a unique insight into the ways that respondents made sense of living arrangements by juggling a whole series of dilemmas that were not easy to reconcile. The following chapters are based on their accounts.

Chapter 5

Local Implementation

Introduction

This chapter will consider the development of direct payments policy and legislation at a local level in the areas covered by the study. It is concerned with the relationships between disabled people and local authorities. Disabled recipients of direct payments are described here as employers and the rationale for this is explained in Appendix 3.

Disabled people universally disliked previous support arrangements, primarily help provided via private agencies, and direct payments offered more choice and control over aspects of daily living. Preferences for employing personal assistants were invariably made in comparison with the experiences described in the first part of this chapter.

This section is followed by a discussion about the securing of direct payments, often a contested and conflictual process. The grafting of direct payments legislation on to community care arrangements provided a source of friction between ‘care’ managers and disabled people. Each party worked hard to limit the information available to the other. There were differences between the public accounts of ways that direct payment provisions were made to recipients (the language of individual needs) and their practice (the allocation of scarce resources according to fixed criteria). Following the securing of direct payments, employers sought to minimise the influence of local authorities and retain as much flexibility over arrangements as was possible in their circumstances. The issue of employer status is discussed as a way of examining how these conflicts were played out in practice.

Because disabled respondents employed personal assistants themselves, their families and friends had little contact with local authorities. Some family members and friends did have points to make however, as did personal assistants, and these are included as brief sections.

Agency Workers

At the time of this study direct payments were relatively undeveloped in the north west of England in comparison with southern counties (Pearson, 2000). In the main, implementation followed rather than preceded the 1996 Act, after which time progress was slow, except in one area where development had been driven by the efforts of a particularly enthusiastic councillor. Elsewhere, employers described a rather chaotic struggle for access.

While 10 disabled people had received assistance only from family members beforehand, most employers (20) had been in receipt of some form of service prior to taking up direct payments. For this group, the driving force in applying for direct payments was the experience of poor or abusive services. The majority had received assistance from agency workers; that is, staff employed by private agencies that were contracted by social services to provide help. Contracts were drawn up directly between social service departments and agencies, following an assessment of disabled applicants by social services care managers. Three disabled people had used home help services (workers who were direct employees of the council rather than employees of a contracted out organisation) as well as agency workers, and three had received help from Community Service Volunteers or other voluntary organisations. In the following discussion I will refer to agency workers as this was the majority experience.

It is not surprising that respondents reported a preference for direct payments given the fact that this sample had elected to receive them. The accounts of respondents were consistent in describing the reasons for their dissatisfaction with previous arrangements and objections were voiced strongly. There were three main criticisms: that rotas were not based around individual recipients and their families (concerns about timing, duties, schedules and staff rotation), that workers were incompetent and undermining (attitudes, identity and appearance) and that the systems under which agency workers were employed were exploitative (the profit motive).

Staff Convenience

The times that agency workers provided assistance were based around the convenience of the agency rather than the needs of people receiving help. For example, Christine, who had multiple sclerosis, described how she only had the energy to do things such as taking a bath between 1pm and 4pm each day and yet workers turned up outside these hours, according to a schedule which was set by agency managers. Typically agency workers had a large number of people to visit each day and were in a hurry. Frequent experiences were of workers showing up to assist people to go to bed at 9pm or 10pm in the evening, not showing up at all or changing the times of their visits without prior notification. Even when they did show up at the pre-arranged time, the agency workers' timetables had a profound effect on respondents' lives:

'In the end my life was ruled by times when they could be there. The agency alleviated some of the stress, but what they alleviated, they put back. Because I couldn't say 'I'm going out tonight, I'll be back about half past 10'. 'No, if you're not there at half past 9, we won't be there to put you to bed.' There was no give and take, so my social life got totally dominated by them.' (Kathryn, employer)

'One day, before one of the carers came at night time, (my daughter) happened to be here. She said 'shall I get tea?' I said 'no, because the carer's coming and she's expecting to do it. But you have something before you go.' And (my daughter) said, 'well I might as well get it for both of us if I'm going to prepare something'. So I said 'OK,' and we had something to eat. Now one of the problems was that the care agencies wouldn't give me the carers' phone numbers to contact them directly, so I wasn't able to let them know beforehand. Well, when the carer arrived and found out I'd had my tea, she was furious. 'This isn't good enough' she said, 'what about my wages? It's my job to make tea.' Well, I said, 'my daughter's here and she's done it, but would you bring in the washing off the line instead, to save me having to ask my daughter to do it?' 'No' she said 'I'm not touching your washing' and stormed off.' (Sylvia, employer)

Employers complained that agency staff were limited in the range of jobs they would do and refused to say what those limits were. Usually disabled people only discovered the boundaries of the remit when they asked workers to do things that they had not been authorised by the agency to do. This was experienced as an issue of power and control; workers wanting to assert their superior status.

Furthermore, respondents reported that there was a narrowing in the range of tasks over time. Jobs which had been done on previous occasions would suddenly be off the permitted list for no apparent reason and with no explanation.

A further issue was that agencies sent different people each visit and there was no way of knowing who was going to turn up. Having to constantly repeat explanations such as where household tools were kept was very tiresome for many people and also wasted time in terms of what agency workers could accomplish during visits. This issue was particularly problematic for mothers with young children:

‘It would be separate people every week. I found that quite upsetting, especially as I was just widowed, and I found it hard to have anybody in the house. And having a complete stranger.... wasn’t very nice at all..... It really started distressing my son. By the end of it he was really not liking them coming in at all. We found it really quite uncomfortable and quite degrading to be honest with you. It was the last resort, really. It felt like I wasn’t coping.’
(Margaret, employer)

Agency workers were not interviewed as part of this study. However one personal assistant had previously spent several months working for an agency when she was between jobs. She commented on her relationship with the people she assisted and the policy of the organisation she worked for:

‘The majority of people you go in to, when you’re an agency carer, they see you as an intruder.....And it *is* an intrusion because it’s a common thing with agencies that you’re not allowed to get attached. If they see you forming any kind of emotional attachment to anybody then that person’s taken off your list and put on somebody else’s. So I might have been going into somebody’s house for some weeks and then get taken off and they send a new person in.’
(Marilyn, personal assistant to Kathryn)

Employers spoke of personnel not doing any work, or trying to spend as little time in the house as possible and rushing on to the next visit.

Incompetence

The second main complaint concerned the competence and attitudes of agency workers. There were two issues here. What agency workers did come in for

criticism and there was distaste for other behaviour and habits. Incompetence, in terms of not carrying out jobs properly and jeopardising safety was mentioned by many employers. For example, one worker left an iron switched on and children's toys lying on the carpet at the bottom of the stairs when leaving the home of a visually impaired woman; another left toast cooking under the grill when walking out of the home of a woman with limited mobility following an argument. Several workers annoyed neighbours by going into their houses or by making a lot of noise on the street when coming or going early in the morning or late at night.

Unpleasant attitudes were mentioned by all respondents; workers were described as patronising and rude, and 7 employers described instances of bullying.

'I was pretty fragile in those days and I noticed she (agency worker) started to bully. We went out one morning and she met a friend of hers. I was in the passenger seat, she was in the driving seat, and she spoke to this girl through the car window. The girl leant forward to say something to me and I went 'hi' to her, and she (agency worker) put her finger up to her mouth and said 'you speak when I tell you. You speak when I tell you.' And I was dumbfounded..... I sat in the passenger seat and thought 'if I say something, what's going to happen?' (Lynne, employer)

Others exploited people whose houses they visited. Janice was keen to have help in the form of driving so that she could maintain contact with friends who were important to her:

'I used to have to buy her food, because she never had any. Cost me a fortune.She'd go in people's houses, and I found out later she was thieving from them. Well, I mean, she stole from me but indirectly. It was wheedling things out of me. She'd learned to drive but she hadn't passed her test. So I said to her 'go on, I'll get you a few lessons, then you can drive my car, and I'll insure you' ... Well it was 16 pound- odd a week for lessons, and it went on for about 3 months. Nothing was happening - she was just taking the money.' (Janice, employer)

Many respondents also described unhygienic practices:

'I've had people from the agency, coming in in a drunk state....drugs... they've been trying to scrounge money off me....People that are not clean.....I mean we shouldn't judge people by the clothes they wear or stuff like that, but there's certain circumstances when you should at least present

yourself clean. Your hair washed and not six months dirt under your fingernails, to go be preparing someone's meal or to be preparing the vegetables. I can't cope with that. And I think that's my prerogative. But agencies don't seem to think it is. They've got dirty habits as well. They've been to the toilet - and then they go in your kitchen. I'll say 'I didn't hear you washing your hands. Wash your hands please.' Well, you shouldn't have to be telling people.' (Frances, employer)

Some employers had felt worried about being able to defend themselves from attack. Where people had pain killing medication in the house, or valuables, there was uncertainty as to whether the agency worker or their friends might come back to steal from them on another occasion, especially in instances where the workers were addicted to drugs. The continually changing rotas described above exacerbated this fear. Some workers turned up without identification and here there were difficult judgements to be made as to whether the person arriving was a bona fide worker or a stranger who might be intent on stealing from them or harming them. Elder respondents expressed particular concerns here.

Exploitation

The third theme from the interviews concerned the exploitation of agency workers. While blame was attached to workers, many respondents considered the issue to be the way that private agencies were organised:

'To me, an agency, it's a business. It's about making money, it's not about the caring. And it's not about what's best for me....the profit margin is the important thing. That's their first concern.' (Wendy, employer)

Low rates of pay, work pressures and lack of training were considered endemic to the way that agencies organised their personnel and many laid the blame for the poor service with agency managers keen to make as much money as possible. Marilyn, who had worked for an agency before becoming a personal assistant, took home £90, after deduction of expenses such as her petrol costs, for working a 70-hour week.

Obviously all of the employers taking part in this study had switched from using agency staff to employing personal assistants directly. A few continued to employ

workers via agencies where they found it difficult to recruit for particular hours or times of the week. While for many people the switch involved a straightforward change in arrangements, Frances had negotiated an alternative arrangement via social services:

‘I was very, very unhappy with the agency that provided my care. I just could not believe that somebody could treat me like the way the manager of this agency was treating me. She thought she could do what she wanted, send care in when she wanted to send it, send who she wanted to send into my home, including people who were thieves, drug addicts....coming in drunk... and I just wasn’t having it. When I tried to discuss it with her, her attitude was, ‘you’ll have what I give you.’ Until one day I lost my rag. I told her where the contract would end up, in a very unladylike way. And she said ‘ooh, you think you can get away....I’ve got a contract with social services’. She said, ‘there’s nothing you can do about it’. I said ‘watch me.’ Well, I went to the social worker and I said ‘I’m not putting up with this. I’m not having someone speaking to me like this. She’s being paid a lot of money to provide care, and a lot of other people across this city. I’m able to speak up for meself. What about all the poor people that are not?’ I said, ‘can I interview some agencies?’ and she said ‘It’s not been done before, but I don’t see why not.’ So they let me do that. I chose one that I thought would provide a reasonable standard of care and four of the girls that were working for the agency that I was not happy with asked me was there any work going with the agency I was going to take on. So I said ‘well, I don’t know, but I’ll ask for you. And I’ll give you a reference.’ They were good girls - it was the boss’ attitude to it all.’ (Frances, employer)

Given the accounts above it is clear that for employers participating in the study, there were few, if any, redeeming features to the system of providing help through agencies.

Implications of These Accounts

These accounts contradict Ungerson’s (1999) assertions with regard to the ability of employers to exercise control over personal assistants / agency workers.

Ungerson interviewed 7 ‘personal assistants’ (she uses a different definition to the one used here) who worked in a variety of settings. Her work is welcome in that it brings attention to the circumstances of personal assistants and employers who are brought into contact through direct payments and she offers a thoughtful analysis of the changing relationships involved. Discussion hinges on what she terms the ability of employers to exercise a ‘power to command’ (Ungerson, 1999: 591) in

relation to various administrative arrangements but she does not distinguish between assistants sent by agencies and those recruited directly by employers. Although Ungerson does not interview any employers in the 1999 study, she offers speculative comments on the likely relationship between sentiment and this power to command. When comparing the recruitment of assistants through word of mouth with the recruitment of P.A.s through a Centre for Independent Living and private ‘care’ agencies, she states:

‘The recruitment of P.A.s through such agencies or small businesses almost certainly trades off affect and employer choice against reliability, the management of risk and the power to command’ (Ungerson, 1999: 591)

There is no evidence from the data presented in this thesis that employers exercised the power to command agency workers, or for that matter, experienced reliability and the management of risk. From the data presented here it is evident that the opposite was the case. Employers experienced abusive treatment and a very basic level of assistance that was not under their control at all – a far cry from the power to command.

In fairness to Ungerson, she states that she is writing here about personal assistants in instances where funding was routed through employers, but her account is also ambiguous in that she talks of employers having ‘less choice about who assisted them’ (1999: 591) and of personal assistance entailing ‘intimate care by strangers’ (1999: 597), suggesting that agency workers were in fact included in her account. Part of the problem of her account is that no definitions are offered. While Ungerson wishes to question the boundaries between work and ‘care’ the result is a lack of clarity, problematic especially because one of her central concerns is in fact administrative arrangements (the mode of recruitment). In drawing up the parameters of the present study, it became clear that employers who recruited personal assistants via agencies experienced *less* power to command than those who recruited directly. Furthermore, mention has already been made in Chapter 4 of an employer who disliked the fact that assistants from agencies would sometimes appear in uniform and the problem that he could do little about this. Additionally, here the wages were actually routed through the employer. Further concerns about Ungerson’s conclusions will be taken up in Chapter 8.

Much of the assistance provided took place in people's homes. It is a social norm that adults can make decisions about who may have entry to the home and under what circumstances. The idea of a home as a place that is 'ours', a private place where control can be exercised and outsiders kept at bay, remains very significant in British culture (Allan, 1989; Higgins, 1989). Some authors have argued that distinctions between the domains is becoming less clear, at least for some affluent sectors of the population (Montgomery et al., 2005), but this study refers to a very different set of circumstances – mainly to the increasing numbers of people who work from home using information technology. In these circumstances, the degree to which, and how work impinges on home life remains ultimately under the control of the householder. It refers to a blurring of boundaries between home and work in the life of each individual or household. Control over who comes into the home and the basis on which they do so is a marker of adult status and the security of the home provides people with choices such as over what and when to eat, when to sleep and how they are spoken to by others. It is also usually a place where people form important voluntary relationships (Higgins, 1989).

It could be argued that an invitation to agency workers was offered in the sense that workers' needed the assistance provided. On the other hand, the fact that workers turned up unreliably, if at all, diminished disabled people's status as homeowners. Agency managers often possessed and passed out keys to disabled people's homes to different workers, clearly transgressing norms about access to homes on several levels.

Historically, maintaining a strict division between the privacy of the home and work and / or the outside world was an important mark of respectability and this still remains important today (Allan, 1989). Agencies and local authorities were able to define disabled people's homes as a place of work, i.e. a public space, and in the absence of alternatives, disabled people had little option but to comply. The fact that agency workers were able impose a definition of people's houses as their workplace rather than the homes of people they visited, provided a source of potential disrepute in the neighbourhood by virtue of the muddling of boundaries. This was compounded by the disrespectful behaviour of some of the workers. The

presence of agency workers who were addicted to substances or were untrustworthy was particularly resented both for security reasons and because it brought further disrepute. Finally, the fact that disabled people had to build their daily schedules around workers' visits compounded social isolation and the potential for a poor reputation in the neighbourhood.

The boundaries between public and private spheres are frequently constructed differently for disabled people than for non-disabled people (Beckett & Wrighton, 2000). From the above discussion it can be seen that for respondents who were in these circumstances the private sphere was much more circumscribed. One employer, Jean, described the experience as being 'institutionalised in your own home.' How employers and personal assistants dealt with the dilemmas that receiving assistance and sorting out boundaries engendered will be followed up in the following chapters.

Getting Direct Payments

If respondents were critical of the agencies that had provided them with a service previously, there was also discontent with the local authorities that had contracted with agencies to provide the service. Early attempts to claim direct payments were frequently confrontational. The first few respondents who secured payments usually had privileged information and the support of influential people.

Robert had been receiving payments since 1989, through a trust fund he set up himself, until the 1996 Act permitted him to receive the funding directly. Of getting the payments he said:

'I threatened to take the Council to court. They didn't want to do it- they couldn't get their head round it. There was a councillor who threatened them with the sack if they didn't do it. I set up a trust and it took a year to set it up and I was working full-time and doing 2 courses! (both laugh) I was given some time in working time but it was a lot of pressure. My boss offered to pay the legal costs as a gift of support and I could make phone calls from work. My boss was quite high up; he worked with the council and he'd got a lot of contacts: he used them to get the information. I also got a trustee who was with the local paper. Because we got good press we could go very quickly. She was the deputy editor and she fought for me. She also had copies of

documentation we could access, so we could find out what was legal.’
(Robert, employer)

Alan similarly had good contacts. His employer worked in the social policy field and he had ready access to current information and support. He secured direct payments in 1996 but only after a protracted fight:

‘I insisted on it. Arguing and fighting, arguing and fighting. But for many a year I seemed to be the only one who was arguing and fighting for it. It felt like a lone fight. It often felt like it was me there with a shovel trying to clear all this snow and the social services department was just piling more snow that I was trying to clear away. And in the background there was about 10, 20 people just stood there waiting for it to happen. And it was only because of my determination to get that, or face the consequences, that I fought hard to make sure I got what I needed. But it was a long fight.’ (Alan, employer)

Therefore both these men were working and had contacts outside local authorities that they were able to use in their dealings with social service personnel who were frequently ignorant of direct payments loopholes and later on provisions, and hostile to implementing them.

The majority of respondents in the study found out at a later stage about direct payments. Of the 30 people interviewed, 14 had heard about it through word of mouth, often from relatives and friends or from other people receiving payments. Two of this number had read information in magazines and newspapers. The perception was that information about direct payments was not well publicised and that what information existed was sporadic, disjointed and difficult to find. A further four respondents had been told about direct payments following a crisis in the service they were receiving from social service or private agency staff. They had called up social workers and expressed their refusal to continue with abusive or threatening behaviour from agency workers. Three people had been informed about the possibility of receiving direct payments following a sudden change in their health circumstances – these were people who had joined the scheme within the past two years and who had not received any service previously. Just one person found out about direct payments through her social worker volunteering the information. One other respondent arranged direct payments through university in the first instance, subsequently continuing to employ personal assistants. Finally

two people joined the scheme through being selected as 'pilot projects' for direct payments. One of these respondents was told at the time that there was no other possibility for arranging his support, despite his having requested direct payments twice previously and being refused on each occasion. The change in outlook by local authority staff here was due to their need to show results following pressure from central government, by having what they termed a 'high dependency client' on their books.

Class and gender imbalances were apparent. Earlier recipients (although not all) tended to be white, male, and well – connected. The mean duration for receiving direct payments of the respondents was 6 years and 7 months for men and 2 years, 9 months for women. This lends support to Rae's point that securing assistance is easier for disabled men than disabled women (1993). Men were more likely to be selected by local authorities as 'pilot projects' (two of the sample had been selected by local authorities and no women had). With regard to class (see the discussion on p.18), 18 were middle class and 11 were working class. The mean time that the middle class employers had received payments was 4 years exactly, and it was 1 year and 1 month for working class respondents. Ethnic minority applicants were underrepresented due to both lack of information and the formal eligibility criteria in force at the time of the interviews. The numbers involved here are rather too small to make comparisons meaningful.

In summary, there was a difference in the early and later experiences of recipients. While getting payments earlier on involved a protracted struggle that could last years, payments were much easier to get for more recent recipients. This was due to a combination of legislative compulsion, the spread by word of mouth of stories of successful experiences by local disabled people, a gradual convincing of / application of pressure to reluctant social services staff and the development of support organisations for employers in some areas. Employers who had connections, were white, middle class and male were more advantaged with regards to access.

Assessments

The assessment procedure forms the basis for all social service assistance arranged through local authorities, whether agency workers are employed or direct payments are offered, as both arrangements rest on the provisions of the 1990 NHS and Community Care Act. It is the basis for determining eligibility for services and usually carried out by a 'care' manager. In the context of this discussion the process as used in the local areas will provide an opportunity to consider how public and private boundaries were formed in relation to disabled people and the local authorities. These boundaries were not pre-given, as will be shown in the instances below. Rather they were formed in the context of particular circumstances as disabled applicants and care managers each sought to gain as much control as they could over the process and outcomes.

Employers in the study all reported that payments were available only for physical assistance and aspects of daily living involving physical well-being, rather than the wider outcomes advocated by Harris et. al. (2005). Several employers used creativity in order to get some flexibility into the system. This might involve construing activities such as going out to particular places as 'care', or making do with less assistance one week in order to have some extra help the following week for something they valued more highly.

Studies have noted the limitations on access to assessment routinely exercised by social workers in order to limit claims on budgets (Davis et al., 1997; Rummery & Glendinning, 1999). Obviously all respondents in this study had already negotiated the assessment procedures, but it remained an issue because of the continuing requirement for review at periodic intervals. Different standards often applied according to when people entered the assessment process; later applicants were likely to be allocated less assistance than earlier applicants. Disabled people felt that 'care' managers considered it to be more difficult to take things away than to give less in the first place.

The pressure on 'care' managers to keep provision within their budgets was apparent, and during the course of the study allowances were in the process of

being cut back in several areas. With reference to the stipulations on 'Fair Access to Care' set out in Chapter 3, there is considerable scope for determining how serious a situation is in relation to an individual's particular circumstances. However, in the local authority areas covered by the study there was very little evidence of this. On the contrary, specific services were either offered or not offered quite independently of people's individual circumstances. In most of the areas administrators had made decisions about which services they were prepared to fund as part of a direct payments package and which they would not. A blanket ban on providing cleaning to people under 65 had been implemented in one area, although this service was available elsewhere. In another area no assistance was available for helping children with homework, although this was permitted in another. Permission was given for personal assistants to reheat instant microwave meals in one locality but not for the preparation of fresh food: a service available in others. In some areas recipients could claim for personal assistants' expenses, while in others they could not. There was therefore considerable variation in what was allowed in the different areas.

Public Privacy

Administrative arrangements were commonly linked to impairment. For example there was a perception that people with learning difficulties would automatically receive payments through a trust rather than directly. The assumption was that they would not be able to administer the finances themselves, even with assistance permitted under legislation. Furthermore, local authority assessors linked the levels of need described earlier (critical, substantial, moderate and low) with council services quite independently of the circumstances of individual applicants. The following excerpt from a letter sent to existing direct payment recipients in one area illustrates this point:

'The Council has now considered all responses to the consultation and has decided that Social Services can only continue to support people who are assessed as having **critical** or **substantial** needs that can only be met by receiving support from social services. Critical and substantial needs are the basic needs that must be met to allow a person to sustain everyday living, for example help with getting up and going to bed, washing, dressing and help with toileting.....during your reassessment your care manager will discuss

with you, what help might be provided by your relatives and carers or by community services in your neighbourhood. The council expects that most demands for basic shopping and cleaning services will be met in this way.’ (Director of Social Services, 2005) (Emphasis in the original)

The requirement placed on local authorities to consult in partnership with disabled people was rarely experienced as anything more than lip service. Recipients of the letter quoted above were not aware of having been consulted with regard to the reduction in their allocations. Consultations often took the form of invitations to meetings at which future plans were outlined. As one employer put it;

‘They don’t consult. They just tell you what they are going to do’ (Alan, employer)

The focus on individual needs discussed earlier, while sounding worthy, also allowed local authorities to sidestep accountability for decisions made and for providing information on a broader level. Arbitrary decisions were justified on the basis of individual need. The excerpt from the letter (above) may be thought of as essentially a private communication. It was not posted in public but sent to individuals, and it contradicts the public rhetoric of decisions made according to individuals’ needs. It would be perfectly possible for the withdrawal of a particular aspect of support to represent a critical risk for one person but to represent a low risk to another person, as indeed the process of making decisions was described in public. However privately, decisions had been made in advance and without reference to individual circumstances. The outward presentation of individual needs as the basis for decision making allowed the avoidance of scrutiny from the outside, while in practice individual needs were largely disregarded.

A further issue concerned the way that decisions were made in the local areas. There was no information available to the public concerning the processes of deciding overall budget allocations and priorities. The personnel involved and how they did this remained a mystery. This finding supports other research (Flynn, 2005; Rummery & Glendinning, 1999) that has called for these process to be open to public scrutiny. Respondents interviewed tended to assume that decisions were made by a few people at departmental management meetings, possibly the director and finance personnel, but essentially this was a guess in the dark.

Employers and their families also experienced other ways that information was unavailable or withheld. Where an assessment had been carried out and a large amount of support had been recommended, applications were invariably sent to a panel for consideration prior to approval. ‘Care’ managers and potential recipients were not permitted to attend in person – details of applications were sent in the form of a report. Again, the composition of the panels and the basis on which decisions were reached were unknown, even to disabled people who had been very much involved in committee meetings as service user representatives.

Therefore there were many ways in which nominally public organisations operated according to very private principles. Details of local authority circulars issued by the Department of Health and other bodies were reproduced in the form of public information leaflets and on web sites but the actual processes by which decisions were reached remained unknown to people most concerned with them.

Private Intrusion

People on the receiving end experienced assessment as a very intrusive process. Assessors routinely examined personal details that people would have preferred to have kept private. While the accounting systems of local authorities remained hidden, the ostensibly private bank accounts of direct payments applicants were subjected to scrutiny. Several respondents had received compensation payments following an accident, and felt strongly that these amounts had been intended to compensate them for future loss of earnings and should be used to pay for living expenses over and above the costs of their personal ‘care’.

‘You’ve got to let them know all your financial details. And I don’t want to do that. I feel there are parts of your life that you want to keep private. Because there’s a hell of a lot you can’t when you’re disabled; you haven’t got the privacy of a normal person....They want to know (about) any savings that you have.... And I think that’s wrong because they’re not aware of disabilities because probably they haven’t been disabled themselves and haven’t needed money to go along with the disability. You see, when I got disabled, and obviously with it being a car crash, insurance was involved. So that money was meant to keep me going for the rest of me life. But the way they’d look at it is as money as a whole.... I know that’s how they’d look at it, I don’t care

what they say....Now I always like to keep them in the dark about whatever I have. So then there can't be someone in a suit sat in an office somewhere looking at a figure and nothing else and debating and thinking about it as he thinks best...(They) look at it from an economic point of view, from a council's point of view. (David, employer)

Means testing and charging have been and remain a point of dispute between service users and local authorities (BCODP Independent Living Committee, 1999; Mason, 1999). Details of this debate will not be covered here but finance presented difficulties for disabled employers in two ways. On the one hand there was a concern that councils would take their money to pay for services, as for David, and on the other, employers who were working worried that they might have to leave their jobs due to an inability to meet the costs of assistance from their wages.

There were also issues related to financial accounting for the direct payments themselves. For some people the idea of bookkeeping and maintaining records was daunting. There was assistance available in each of the local areas for people unwilling to do the paperwork and the costs of this were met by the direct payments. Audits were carried out at regular intervals by social services officers, and many employers resented the detail with which this was done;

'If the financial rules that are applied to me were applied to the rest of the department, they'd probably say 'bloody hell' because I have to account for every penny. If every care manager had to account for every penny that they spent it would expose all the cock ups and everything. How much money is wasted, and resources. They're very, very prescriptive. And there needs to be a transparent audit to every penny spent, full stop.' (John, employer)

The assessment process itself was not welcomed by employers. Early applicants in particular had experienced unpleasant testing procedures and at least one applicant had been required to undergo a functional assessment to demonstrate a lack of physical capacity. While there was acknowledgement that the situation was not as bad as it had been in the past, current processes were still felt to be demeaning. Kathryn described the experience of meeting an assessor;

'What was most intrusive was the financial assessment. They asked me 'how many times do you have to change the bed?' And I had to quantify this..... They asked 'what happens if you don't get to the loo on time?' It was

degrading. You can't say 'it only happened once' because then you don't get the help you need. For the DLA you have to say how many times you go to the loo in the night. And Marilyn (P.A.) was answering all this because I couldn't. It was so embarrassing. And they ask 'how long does it take you to get undressed?' One person was nice; she said 'It depends who's waiting!' I called up the financial department and had a go at them. I said 'why do I have to quantify all these things? How would *you* like it if people asked *you* these questions?' And I'm a woman of 45 and it's a young kid who's asking me. OK they have to do it but they're not sensitive about it. I know one woman. They were asking her all these sorts of questions and she didn't give the answers she should have because she was embarrassed. They don't even apologise for asking the questions.' (Kathryn, employer)

Frequently getting the desired support still remained a struggle. Some of the more assertive applicants used complaints procedures and several people invited advocates to assessment meetings to give personal support and to help them argue their points of view.

Disabled Parents

So far I have considered the situations of people who were living on their own. However assessments posed particular problems for disabled parents. As authors have noted, local authorities are not typically structured around families; rather there are separate divisions for children, disabled people, elder people and so on. (Priestley, 1999). Frequently these departments are competing with one another for resources. This posed particular problems for people living in family groups with young children. Angela lived with her husband and two young children and was the only member of the household who was disabled;

'At first it was like 'oh, no, we're not getting involved, it's the children's budget. We're' the adult's budget'.....I did find that quite intimidating and difficult, when they first came out to do the assessment.... They weren't very au fait with the personal assistance scheme. And it was almost like, 'well that's not coming out of our budget, that's out of your budget'. I did feel quite isolated. I need to be able to look after my children; I need the assistance. I believe it's changed now because the child care department isn't involved. But I felt that neither one was prepared for it to come out of their budget. And at the end of the day it's all about money and things.' (Angela, employer)

The situation for Chloe was even more complex in that her three young children were also disabled and she was a widow, her husband having died a few years earlier as a result of an accident.

‘As a parent I go and say ‘I need this’, but then who do you assess it for?...We’ve just applied for a shower. Now I need a shower for us all in the sense that Jack and Dave can’t physically get in the bath. I have to lift them. Well I can’t be doing that becauseone, I’m only small and I get a lot of pain myself, and two, Robert needs a shower because as well as learning difficulties he has other difficulties. So he needs to make sure he has a bath every day, and at 15 I still have to bath him. He can’t bath himself. So who then, do you ask for the shower for? Because they’ve got to write some applicant. And yet if they base it on the twins, that they can’t physically get in the bath, that’s basing it on the twins and not us all as a whole family. You don’t get many points and you have to wait 3 years for a shower. Whereas I feel if you base it on the whole family, we’d be getting 10 points and we’d be getting a shower in the next few months.’ (Chloe, employer)

Again, the assessments were based on individuals and took little account of family relationships and requirements, because different council departments were seen as responsible for different members of the family. This being said, the assumption was that once a personal assistant had been employed, based on the assessment of one individual, that this would meet the whole family’s needs.

‘These professionals are saying to me ‘well you’ve got a P.A. now’ . Well I’ve got a P.A. to meet my needs, but my P.A. is not meeting my needs, because she’s helping me to meet the children’s needs. And this is why I want the care package to change. (Chloe, employer)

The statement that assessors took little account of the needs of whole families must be qualified in an important respect. Family members were seen as being either ‘carers’ for disabled people or potential ‘carers.’

Ambiguities about Employer Status

Disability studies literature places emphasis on the status of disabled people who take on personal assistants as employers (Marfisi, 2002; Vasey, 2000). Several disabled respondents considered themselves to be primarily employers vis-à-vis personal assistants and this is discussed further in the following chapter. While

local authorities also characterised disabled recipients of direct payments as employers, there were also ways in which they cast doubt on this status or failed to support it. Concerns about training for personal assistants will be used as a way of illustrating this point.

‘Care’ managers in the local areas emphasised that responsibilities lay with the direct payments user and considerable emphasis was placed on recipients retaining responsibilities as employers. As one manager pointed out:

‘Empowerment needs to be built into the mind set. People need to have grievance, disciplinary procedures and arrangements for a good salary. These arrangements can give people a cushion to fall back on, and one that confirms that what they’re doing is above the law. We also have to get across to people that they are liable as employers and that they will be held accountable, and taken to tribunal if they don’t fulfil their part of the arrangement.’ (Manager, direct payments support organisation)

Where people received assistance with administrative arrangements however, disputes over status could occur. Sylvia reported that it had been clearly emphasised to her that she held the legal responsibility for her personal assistant as an employer. She used a voluntary organisation to assist with the payroll for her personal assistant and got into a disagreement about arrangements:

‘Now Yvonne (P.A.) is over 60 so she doesn’t pay national insurance. She needs a certificate about the insurance because she already earns money from another job, and Yvonne gave me the certificate because on the back it says that it should be held by the employer. (The voluntary organisation) said they needed the certificate in order to pay her wages and I refused to send it to them. Well, they kept going on about it and I kept refusing to send it. I said they could come down here and look at it, and take a copy of it, but I was keeping it. I am the employer, not them, and I keep the card. And I’m still doing as much work as them. In the end the finance officer came down here to check it. I can be awkward. I believe in right and wrong.’ (Sylvia, employer)

Therefore, although people were described as and thought of themselves as employers, there were times when uncertainties or challenges arose. In some instances it could undermine people’s ideas of themselves as having the full range of responsibilities for staff that they might expect:

Sarah: ‘Do you see yourself as an employer or as something else?’

Judith: 'No I don't see myself as an employer!' (laughs)

Sarah: 'What do you see yourself as?'

Judith: 'I don't know. I've never really thought about it. Yes, I am an employer but it doesn't feel like I'm an employer. I think probably because you're not really 100% in charge of what you actually do with the money. There's always somebody looking over your shoulder and that's probably why it doesn't feel like I'm an employer.'

People using personal assistance and organisations of disabled people have consistently opposed training for personal assistants by a third party. The emphasis has been on training on the job based around the needs of each individual employer. There are two main reasons for this. Firstly, professional training has usually been based on a medical understanding of disability, has focussed on impairment as a problem, and developed oppressive attitudes and practices in social work students. Within traditionally organised services, maintaining separation from and the dependence of disabled people has enabled the continuation of jobs for service personnel (Barnes, 2000; Finkelstein, 1981a, 1990; French, 1995; Morris, 1993; Oliver, 1990). There is therefore a fundamental lack of trust concerning the content and process of professional training. For example a gap has opened between 'disability equality training' – typically carried out by disabled people and with a focus on disabling barriers to participation, and 'disability awareness training', often conducted by non-disabled people and frequently employing simulation exercises (Finkelstein, 1991; French, 1994).

Secondly, much of the assistance needed by physically disabled people, as noted above, may be personally intimate, and referring back to Kathryn's description of her assessment experiences, employers did not welcome discussion of their personal circumstances in public. There was therefore a wish to remain in control of the employment process, including the training of P.A.s as part of a broader process. Furthermore, training P.A.s outside of the context of the working relationship runs the risk of ignoring the personal assistance requirements of different employers. People with the same medical diagnosis may not need the same kinds of help (Adler, 1993).

Instead, the Independent Living Movement has emphasised supporting employers to train personal assistant themselves. As Flanagan notes:

‘None of us doubts the value of training for personal assistance users. The problem is convincing those who allocate funds. We all know that you only need to train one personal assistance user but many personal assistants for that user. Unfortunately it is easier to get money to train personal assistants..... We need to repeat the message ‘invest in disabled people’ in order that the truth sinks in’ (Flanagan, 1998 p.55)

Debates were also apparent in the local areas – training for personal assistants had been raised at meetings of direct payments users and some employers had taken steps themselves to ensure access to formal as well as on-the-job training for assistants. Some people were also involved in the wider debates on a regional level. The issue of training brings into perspective the issue of who the employer is. In particular, few people would assume that it was their right to train an employers’ workforce without the permission of that employer.

These issues have been discussed as a way of illustrating the contestation surrounding employer status for people who employ personal assistants. They are intended as a backdrop to the discussion in the following chapter concerning relationships between employers and personal assistants, family members and friends. There are fundamental differences between professional interests and those of disabled employers and that in an unequal power relationship, disabled people’s status as employers remains more assailable than employers with more resources.

The Perspectives of Personal Assistants

While the views of personal assistants with regard to their employment status will be considered more fully in the following chapter, and their roles with regard to disabled employers when meeting officials more fully in Chapter 6, a few did have some contact with and expressed views about local authority staff. One P.A. considered the local authority to be her primary employer, and the person she worked with on a daily basis to be a sub-contractor. All the others identified the disabled person as their employer. Not all P.A.s had contact with local authority personnel. Of the few who did, they generally did not find contact with local authority staff supportive:

'Professionals tend to look down on you a little bit I find. Like high up in social services, the council, the first few times they meet you they might not even acknowledge you being there. A lot of the time if we went to conferences, people would look straight through me because I'd just be the person pushing the wheelchair.' (Marilyn, personal assistant to Kathryn)

In one area, while there were meetings of people using direct payments, these were effectively being used by local authority staff as a conduit for passing on information rather than a forum for solving problems. Personal assistants were invited to the meetings, although this was not the norm in the other areas covered in the study. The following extract is from a conversation that formed part of an interview with Sheila, who worked as Janice's personal assistant, and the interview had taken place not long after attending one of the meetings:

Sheila: 'I don't think much of social workers these days.'

Sarah: '*Why is that?*'

Sheila: 'I think a lot of them sit on their backsides and have no idea of the way people live their lives and whatever. How do you think the meeting went, the one that we went to?'

Sarah: '*I was interested to go, and I knew that there hadn't been that many meetings, so people were sorting it out what they wanted to do with them.*'

Sheila: 'Janice (employer) says they were treating us as if we're a load of kids. Talking to us like that.'

Sarah: '*Did you think that as well?*'

Sheila: 'Yes, and Janice didn't like it at all. It was like being back at school. What are they doing with it? I took Janice because she wanted to go.'

Sarah: '*It was a bit like the team laying down the line to people, wasn't it?*'

Sheila: 'She won't go to any again.'

None of the personal assistants interviewed had initiated any contact with local authority staff independently of their employer. However Neil described how one of the P.A.s working for him had appealed to the direct payment support organisation subcontracted by the local authority, following a dispute with him concerning hours worked. The organisation had backed up Neil's right under employment law not to acquiesce to the personal assistant's demand, effectively supporting him as the employer. It should be noted that at the time of writing direct payments are being made available to many more people in the areas concerned and that approaches made to local authorities by personal assistants have increased. No systematic follow-up of this has been possible in the time available, but there appeared to be some variation in the responses given to personal assistants.

Employers were more likely to receive backing from the independent organisation of disabled people who were providing assistance in two of the areas. In other areas, where the direct payments service was part of the social service department, or had previously been part, staff were more likely to try to solve the problem as a mediator.

Therefore, while direct contact between personal assistants and local authority staff was minimal, personal assistants were likely to take on the point of view of the employer where working arrangements remained mutually agreeable. In instances of dispute, some personal assistants did make appeals to what they saw as a higher authority, and the degree to which this was effective depended on the outlook and organisational position of those they appealed to.

A further issue also links to the discussion of assessment process above. Where employers underwent re-assessment, the hours they were allocated might, but not always, be reduced. As mentioned previously, this was in the process of taking place in one area at the time of writing. Employers were concerned that cuts in their allocation of hours meant that they might have no choice but to reduce personal assistants' hours, and / or make them redundant. This is likely to lead to increased job insecurity for personal assistants and to have negative effects on employers' ability to recruit in the future, weakening their position in the labour market.

The Perspectives of Family and Friends

Family members and friends interviewed also mainly had contact with local authority staff through employers. A few people had provided substantial assistance to employers prior to their receipt of direct payments, and two people had been involved in negotiations to secure them. Jessica, Alan's mother, felt particularly strongly about the lack of assistance that the family had received prior to direct payments:

'There was nothing. Nothing. They had an O.T. that came to my house and said that it wasn't suitable for Alan and what could they do. But they couldn't

do my front.....you sit there, and somebody walks out the house, some official that's come to talk to you, walks out of the house, and you're no further on. Because like you say to them 'well I wanted the help yesterday'. It's only 5 years in front that you get the help. In between all that you're struggling.' (Jessica, Alan's mother)

Mike expressed dissatisfaction with agency workers, echoing the concerns expressed by employers discussed previously;

'I won't trust agency nurses. It's not their fault, the people who are taken on, but in the end it's usually the low-life. I don't mean to sound snobbish....There is people who genuinely want to benefit people, but most people do it because it's the only job they can get. Or they know they can switch to agency to agency from hour to hour because they know they're that desperate to get carers out there. I've no faith in them whatsoever.' (Mike, Wendy's husband)

Family members and friends were unanimous in supporting direct payment arrangements as preferable to previous arrangements. Their main concerns were to do with the stability of arrangements in the long run – that good assistants would stay in the job. Minimal personal contact with officials was welcomed. It should be borne in mind that because all employers made arrangements to employ personal assistants directly there was little need for the involvement of family or friends here, in contrast with direct payment arrangements where family members or friends acted as third party administrators for finances.

Conclusion

This chapter has explored the policy context in which the relationships between employers, personal assistants and family members and friends took place. Differences between the perspectives of local authority personnel and employers were apparent, and these mirror the different priorities that have been discussed in Chapter 3.

Disabled people in this study felt they experienced less privacy than was accorded to non-disabled people. In particular, financial investigations, to make sure that money was being spent appropriately, was experienced by at least some as an unwelcome intrusion, and assessments as personally invasive. Conversely, local

authorities operated in ways that were not open to public scrutiny, and employers and their families felt that they had little opportunity to challenge decisions made other than on an individual basis concerning decisions made about their particular circumstances. There was uncertainty about changes that might be made in the long term.

Employing personal assistants, while offering greater peace of mind on a day-to-day basis, also was a source of friction between authorities and disabled people. Local authorities sought to place as much responsibility as possible with employers. There were also challenges to the autonomy of employers with regard to issues such as training of personal assistants and revised decisions about tasks for which payments could be claimed. Employers were often actively involved in disputing decisions where they were adversely affected. These considerations therefore form a context to the situations and relationships of employers, personal assistants, family members and friends discussed in the next chapter.

Chapter 6

Personal Assistance: Employment or Paid Friendship?

Introduction

This chapter will explore what personal assistance involves and how it is experienced. One of the defining features is that much personal assistance takes place in the employer's home, and as discussed in Chapters 2 and 5, this raises some issues about the meaning of homes as well as expectations concerning what happens there from the point of view of people living there. It brings into question how people manage what is considered to be a public, employment relationship in homes that are considered to be private spaces. It will be shown here that employers showed a preference for either an employer – employee stance or a 'paid friendship' stance as a way of handling this dichotomy. The features of these stances are explored here, using an ideal type framework and comparisons drawn between the two. Implications for the way we think about friendship and personal assistance relationships are discussed.

What Personal Assistants Do and Who They Are

Nine personal assistants were interviewed (see Appendix 1 for details) The work they carried out often included tasks such as physical assistance with getting in and out of bed, using the shower and toilet, and for some, help with turning over at night and applying or taking medication. Other jobs were tasks carried out on behalf of the employer, invariably involving cleaning, cooking meals and simple maintenance and repair jobs to the house and car. Shopping, driving and dealing with administrative work figured highly and personal assistants also fed pets and walked dogs. Where employers were parents, personal assistants often helped with looking after children, transporting them to school or leisure activities and they occasionally helped with homework. P.A.s might also fill in for jobs usually done by partners if the latter were away or unavailable. A few employers were active in employment and/or voluntary work, and personal assistants helped here with driving and with taking notes in meetings. Others helped employers with going to

the cinema, football matches, taking exercise (usually going swimming or to the gym), getting to hospital appointments, the library and so on.

Personal assistants preferred some kinds of work to others. They enjoyed activities that involved interacting with employers and with children. Going out of the house for such things as exercise, meals, visiting the cinema and so on were popular, as was looking after pets (with one exception). There was more reluctance to talk about disliked aspects of the job, but household chores were not well liked, especially cleaning, although all personal assistants recognised that this was part of their job. Three assistants mentioned their dislike of having their hours of work changed (although others welcomed the flexibility of the work), and individual assistants mentioned an employer's fussiness, reprimanding and fatigue associated with the work as areas of difficulty.

Given that there was broad agreement about what personal assistants did, employers used a variety of terms to refer to assistants, the most common being 'carer', 'support worker' and 'personal assistant' or P.A', the latter two considered as synonymous. Two employers used the three terms to refer to the same people at different points in the interviews, but most used terms reasonably consistently. There was no relationship between the nature of the employer – assistant relationship and terms used. An employer might have very different relationships with assistants in circumstances where they employed several people on the same basis (i.e. directly, rather than through an agency) but they used the same terms to describe all the assistants they employed. For the most part however, the terms used correlated with the ages of respondents. Ten employers used the term 'carer' and their ages ranged from 45 to 77 years, with one exception aged 24. Their mean age was 58 years, including the 24-year-old respondent. Fifteen employers preferred the term 'personal assistant' and their ages ranged from 30 to 50, with a mean age of 38 years. Two other respondents (aged 42 and 58) used the term 'support worker', one (aged 58) used the terms 'support worker' and 'personal assistant' equally, and two others (aged 33 and 45) used 'carer' and 'personal assistant' equally. Therefore elder employers used the term 'carer', while younger respondents were more comfortable referring to workers as 'personal assistants'.

Several reasons were given in favour of the use of the term 'carer'. It was asserted that members of the public did not understand what a personal assistant was as information about direct payments was not widely available. The point was made on several occasions that the term 'P.A.' conjured up images of people who worked in offices and the people they employed did not. However some objected to what they saw as needless political correctness:

'They started off as carers and now they're P.A.s. P.A.s are people who work in offices, who work for managers. You can't say that about the work Rita (P.A.) does. She's a carer, and caring is what the job is about.....It's just the council trying to be posh. The same with rat catchers. I've heard they're now calling them vermin operators but what they do is still catching rats...They upgrade the names but not the wages for them. I'm working class and I believe in keeping my working class ways.' (Sylvia, employer)

As Sylvia noted, there was a tendency for middle class employers to prefer the term 'personal assistant' over the term 'carer', although this trend was not as marked as for age. Of working class respondents, three used the term 'P.A.' and seven 'carer'. Of middle class respondents, thirteen used the term 'P.A.' and seven 'carer'. Three out of four upwardly mobile middle class employers used the term 'carer' and one the term 'personal assistant'. Among all respondents there was a general perception that 'personal assistant' implied a higher social standing than did the term 'carer'. Whether this was deemed to be pretension or reflecting the reality of the work involved, was a matter of judgement. As Jessica pointed out;

'I prefer them to be called personal assistants because they're working for one person.....Carers to me are people that go in, make a cup of tea... It's the same thing, but I think, lads especially would like it to be said personal assistant.... I like P.A. It makes the person feel a bit better, especially lads.' (Jessica, Alan's mother)

Distinctions were more likely where people received support through different arrangements. Family members were more likely to be termed 'carers', reflecting the influence of policy debates. Agency workers were invariably termed carers and where people were employed in this manner together with directly employed staff, differences in duties were more likely to be translated into differences in job title.

Personal assistants also used all three terms to refer to their work. They thought there was fundamentally no difference in the work done for different employers and in different locations even though terms might vary:

‘When I worked for (voluntary organisation) I was a support worker. When I worked for the agency I was a carer. And when I worked for Kathryn I was a personal assistant. I was doing exactly the same thing in all three jobs. I was helping people with their daily lives.... To me, support worker and personal assistant sound more high brow than carer. If you’re a carer it’s expected that you’re low paid, unskilled.....but at the end of the day you’re doing exactly the same thing under each job title. It’s just a title, isn’t it?’ (Marilyn, personal assistant to Kathryn)

There is more stigma attached to receiving assistance at the time of life when people are expected to be autonomous i.e. in young and mid-adult life (Morell, 2003). Arguably, elder employers felt less social stigma to receiving ‘care’ in the sense that all elder people might expect to receive some assistance at this point in their lives. Word usage also reflects the changing meanings attached to words over time; ‘carer’ being an earlier term. For some, ‘carer’ suggested lower status due to the association with work in the unpaid, private sphere of the family and its association with low status tasks.

These reflections on terminology should be borne in mind when reading excerpts from interviews. The words used by respondents were used thoughtfully in the sense that most offered explanations for their use, and related to age, social class, and the degree to which employers made distinctions between sources of assistance. During interviews I used the term ‘personal assistant’ as a default. Where respondents used ‘carer’ or ‘support worker’ I switched to using these descriptions when asking questions.

Employment vs. Paid Friendship

The most common ways that employers and personal assistants described their relationships were as an employer – employee relationship and as a friendship. Some respondents suggested that it was a unique relationship, and certainly employers and assistants struggled at times to make descriptions fit into neat pre-

existing categories. To a lesser extent respondents spoke of kinship, in association with friendship. It should be noted though that most respondents did not speak only of employment or friendship / kinship. More frequently people described their relationships as encompassing two of these elements or all three. This study therefore supports the findings and observations of other authors who have used similar descriptions which span a range of commonly described relationships to describe employer – personal assistant relationships (Glendinning et al., 2000; Lister, 1997; Ungerson, 1999; Vasey, 1996, 2000; Yamaki & Yamazaki, 2004).

There were differences however in the relative importance of these two dimensions. Employers and personal assistants had a tendency to stress one aspect more than the other. They showed a *preference* for a relationship ostensibly based on formal employment, or one ostensibly based on friendship. Preferences were apparent in the verbal accounts and behaviour of respondents. Some authors (Marfisi, 2002; Ungerson, 1997, 1999) have presented these preferences as being to do with the balance of power and control exercised by employers and assistants; the assumption being that a relationship characterised by employment accords more influence to the employer, and a friendship relationship more influence to the employee. As I shall show here, the situation is more complex.

Employment may be thought of as a public role, in the sense that it is a relationship that has the formal component of exchange of work for money. There are expectations that workers will perform specific tasks at particular times with a degree of predictability, and not fulfilling these may constitute grounds for ending the formal relationship. Likewise expectations exist with regard to the role of the employer – that reasonable working conditions will be provided, payments will be made at agreed times and that certain conditions of service will be adhered to. These arrangements may be bounded by legal requirements, which set out the limits of permissible arrangements. Friendship on the other hand, exists outside of formal structures, within the private sphere. It is characterised by choice of association, flexibility of arrangements, based on common interests and grounded in notions of equality between the parties, at least in present day idealised notions (Pahl, 2000).

Therefore the dimensions of employment and friendship may be thought of as existing at opposite ends of a continuum, with varying gradations in between:

Employer – Employee < ----- >	Friend / Family
(Public sphere relationship)	(Private sphere relationship)
Formal	Informal
Impersonal	Personal

These concepts will be used as ideal types for the purpose of this analysis. A stance at either end of the continuum presented employers and personal assistants with dilemmas and there were implications for working and social relationships. Each end of this continuum will be considered in turn.

An Employee Stance

Employers' Perspectives

Two disabled women described their relationships with personal assistants as being only about employment and with no further personal bond involved. While expressing uncertainty over whether she would classify herself as an employer, Sylvia gave numerous instances where she had asserted her control of situations with regard to personal assistants. She had been criticised by the local direct payments team for firing agency staff, who she clearly considered to be employees, but had formed a good relationship with Rita, her current personal assistant. Nevertheless she saw this as a working arrangement and nothing more. Priti, who employed 7 personal assistants, preferred them to be out of the way when not needed. She stated,

‘A lot of people, they don’t get the concept of P.A.s., and they think that they are your friend. They’re there to help you to do what you want to do and not to be your friend.’ (Priti, employer)

At the same time Priti also expressed the view that some of the personal assistants were nice and that she enjoyed finding out about their cultures – many of her

assistants were overseas students who worked for her on a part-time basis. Jean interpreted being an employer as about mutual responsibility to one another, She pointed out;

‘Start as you mean to go on with the P.A. The way I’ve handled it is to be very professional, to have everything written down, a full contract, for three months... They know where they stand; you know where they stand...
You’ve got to take care of their welfare like they take care of yours.
 Making sure that the first aid kit’s fully equipped with plasters, paracetamol...
 If there’s a problem at home, don’t think you can’t come and say ‘can I change me hours, I’ve a hospital appointment - me daughter’s broken her arm.’
 ‘Course you can’, you can work round those things.... they are an employee, first and foremost. But then again you’ve got to be able to get on because you’re working one-to-one. That is so important. That you get on. And that she can understand that: why you do things in a certain way.’ (Jean, employer)

Frequently behaving like an employer was seen as a means to an end rather than an end in itself. Neil, who also described P.A.s as friends – this being termed an advantage of the arrangement from his point of view – pointed out:

‘At the end of the day it is a job. It is employment; I am the boss so I expect to be respected in that way. Not greatly respected, just not forgot that what I say goes. At the end of the day it’s not me being fussy, it’s not me trying to make a hard life for anybody, I’m just trying to achieve ultimate independence, and for me to achieve it there has to be rules.’ (Neil, employer)

Some felt that they had had to get better at fulfilling the role. Over time, disabled people who defined themselves primarily as employers made adjustments and refinements to how they did things. Priti had employed personal assistants since she was 18, at which age she had found the experience very stressful. She had sacked seven community service volunteers while at university but with more experience felt she was now able to manage people better.

The majority of people felt it important that they started out with a rather more formal relationship, and this had changed over time as they got to know assistants better.

‘To start with I was very ‘can you do this?’ It was not regimented but ‘oh would you mind just doing this for me?’ Now, because it’s over time, I trust them. I was the kind of person who would check them out. Because at the end

of the day if there's someone coming in who you don't trust, you're going to cop it.' (Angela, employer)

The beginning of an employment relationship was therefore seen as a difficult time. Having no real knowledge of people beyond police checks and references, most felt the need to be fairly formal and to avoid familiarity, as a way of circumventing the risk of personal assistants taking advantage of the situation. Relationships frequently became more relaxed over time.

There was pressure from two sources to behave like an employer. Firstly, social services assessors urged disabled people to be employers:

'(Our organisation) has found that having clear guidelines around employment legislation lessens the potential for an abusive relationship. Sometimes things start well, but as people get to know one another better they often develop friendships and the line becomes very wishy-washy. Very cloudy.' ('Care Manager)

Respondents mentioned this across different administrative areas, and the ambiguities about this have been discussed in the previous chapter. Secondly there is a received wisdom within disability studies that the relationship *should* be that of employer – employee (Marfisi, 2002; Vasey, 1996). Respondents who emphasised this aspect of their relationship with personal assistants tended to be well-connected socially. They all had other sources of support on which they could rely should problems arise. These sources were not uniform; they might be family members (Angela, Neil, Priti, Jean, Sylvia, Wendy), partners or spouses (Angela, Priti, Wendy) or neighbours (Jean), and some could rely on support from several sources. The support might not be welcomed or given without grudge, but it was there. Employers could therefore afford from a practical point of view to be more distant with assistants. In addition, these social connections gave employers another source of personal friendship and family and neighbourhood connections, which they constructed as more private to the relationships they had with assistants. This having been said, all the employers in this group expressed personal liking for assistants and deemed it important in the job.

Bounded Space, Time and Duties

Employers who emphasised employment used different strategies to retain a sense of home as a personal and private space. They constructed boundaries around the spheres of operation within which assistants worked in order to retain the home as a personal space while ceding areas to personal assistants as work spaces. Two of these strategies were control over space and control over time. Priti, whose perspective was described above, was the employer who stressed the formal nature of the arrangement in the most definite terms. She made various arrangements, even when space was very limited, to circumscribe the movements of personal assistants:

‘In this house I haven’t got a specific P.A. room. I did that before, but then I converted it into a study. And so now they sit in the dining area, which has an easy chair. It’s next to the kitchen, so sometimes it’s a bit strange if someone is sitting there’. (Priti, employer)

Her preference was for P.A.s to make use of specific areas from which they would be called when needed. She also made use of her mobile phone to call assistants and communicate with them when outside of the house. Reasons for this were explained at interview to ensure that potential assistants did not interpret her actions as rejecting: she emphasised how personal assistance can be intrusive and her reasons for seeking to minimise it. Inevitably in a small house it was not always possible to maintain geographical boundaries despite best efforts, and these encounters with other people such as her partner she described as ‘bizarre’.

While the space Priti defined was physical, space could also be interpersonal. John described how there were differences between personal assistants he employed. With one assistant he would discuss personal concerns but with another he was more formal:

‘Paula is quite private and she has her own space. I don’t go too far into that space and that was from day one.....I didn’t overstep the mark.’ (John, employer)

A second strategy used by employers was to impose boundaries in terms of duties. Angela's husband provided her with assistance with things like bathing:

'I think if I had a P.A. who I needed to do personal care, I'd find it difficult.... I think I would have to look for another person to just deal with that..... I think that would be a completely different ball game. I know it's in their contract but hopefully it's something they won't have to do.' (Angela, employer)

Jean, as well as being clear about duties, put in place a definite routine around the time and nature of the work that was to be done, how it was to be done, and where. She established a rota of jobs to be done each day, which was strictly adhered to and which remained constant from week to week i.e. cleaning a particular room each Tuesday; a different one on Thursday, and so on. With employer – employee relationships there was an emphasis on working time as fixed. Contracted hours were adhered to and only varied in exceptional circumstances.

Several people who employed more than one personal assistant had agreed some form of division of labour between different personal assistants. These arrangements appeared to be based on the length of time that a personal assistant had worked for the employer. Assistants who were the most long standing tended to have the more agreeable tasks, such as supporting the employer in social activities, while newer employees might be allocated unpopular duties such as cleaning. Employers often attributed this division of labour to the qualities of the assistants involved, and an increase in trust, but it may also be seen as an attempt by employers to improve working conditions in a context where pay increases were difficult to secure and to retain the assistance of long-standing employees whose services were highly valued. While all personal assistants had some boundaries around their work in that they were contracted to do particular work, with the employer – employee relationships the emphasis was on limiting the sphere of influence of personal assistants rather than expanding it, a different emphasis from the relationships where friendships were the dominant theme, as will be discussed below.

Where employers emphasised the formal nature of the relationship, and employed more than one P.A., they preferred to retain control of the organisation of work.

Angela, Jean, Neil, Priti and Wendy, who employed more than one person, all expressly channelled communications through themselves rather than permitting personal assistants to communicate directly at times when there was a need to do so, such as when working rotas were altered.

There was therefore a variety of ways in which employers sought to both take charge of the situation and to retain a sense of work as separate from home, even where the context of the work was their home. Limits were placed on space, time and duties.

One further point may be made here. Several respondents did talk of other situations where they felt assistants had been poorly treated, primarily because they were not valued or given leeway to learn. One respondent, Sylvia, had received criticism for harsh treatment of assistants, and she described a previous incident:

‘One day her (P.A.’s) boyfriend called her up when she was here and jilted her over the phone. Well, she was upstairs crying and she’d left the iron on downstairs. She was sitting on the bed and crying and kept saying, ‘I love him to bits - I’ll never get over him..’ I said to her, ‘get downstairs and get on with the ironing - that’ll take your mind off him!’ I said ‘you’re far too immature - you’ve got to go.’ (Sylvia, employer)

Two respondents mentioned other people they knew who were prone to sacking personal assistants unnecessarily, although this was generally seen to be a rare occurrence. The incident Sylvia described had happened some time ago and she had established a reasonable working relationship with her current assistant, who had been working with her for five months at the time of interview.

Family and Friends’ Perspectives

Family and friends’ views were mixed. Comments related to the degree to which personal assistants *ought* to be more like employees. Mothers had the strongest views here and made the point that personal assistants might pull their weight more. Emphasis was placed on the appearance of the house and cleaning in particular:

'I'm one of these people that want everything done right. I go in his house and I think 'they should have done this, they should have done that,' but at the end of the day I've got to sit back and think, 'well, he's all right and they're there.' I mean I would like to shipshape them into the perfect...(laughs), like what I wanted. But I can't do that. I can't step on Alan's ground.' (Jessica, Alan's mother)

'They're probably doing the best they can...See, everybody's views are different and what I think matters i.e. clean, or what I think might be dirty, they might think's clean.....I just want things to be done right. I do think sometimes they have an easy time of it.' (Eva, Amy's mother)

Views were tempered by the recognition that personal assistants' work was invaluable both for their disabled relative and themselves as a family member. They recognised that personal assistants could do things that they were less able to do, such as assisting sons and daughters with doing things outside of the house.

Personal Assistants' Perspectives

Only one personal assistant described her work as being mainly about employment, in the context of the house. Samantha, working for Wendy, expressed a liking for Wendy but did not view her as a friend. At the time of interview, Samantha was in some dispute with Wendy concerning duties and the organisation of her work. Samantha's preference for status as an employee was expressed by voicing a wish for clearer and more fixed work duties, but she also recognised that friendship had become less a part of their working arrangement in recent years:

'When I first started, I knew I was an employee, and a friend at the same time. But it's only like since she moved to the big house, where I've had to do more.... I have thought 'well, things have changed from the beginning', where I wasn't told to do things or asked to do things. But things have changed in the last two years.' (Samantha, personal assistant to Wendy)

Several ambiguities surrounded Samantha and Wendy's circumstances. Friendship had become less of a feature of the working arrangement and Wendy's expectations had altered without Samantha having agreed to these at the time of interview. These issues are taken up later in this chapter and in Chapter 8.

A Paid Friendship Stance

Employer Perspectives

The majority of disabled people and personal assistants in this study described friendship as an important element of their relationships;

‘You need to have a friendship. It’s intimate in one way because of the nature of the job. You’ve got to get on or else it won’t work.’ (Robert)

Some employers expressed the view that the development of friendship was in fact an integral part of the job, and one that they valued:

‘It does turn into a friendship when you know people for the length of time you do.....if you work in an office you get friendly with the people who work in the office but you’re doing a job aren’t you? Whereas your job here is to be able to personally get on with somebody. So throughout time you get on so well that you become friends and know each other’s lives. That’s the personal side to what I think is good.’ (Neil)

Authors have noted that friendships take many forms and that there are many contexts for friendship with the home assuming increasing importance (Allan & Adams, 1998) and workplace friendship an important source of support (see for example Andrew & Montague, 1998). All participating respondents, even those such as Wendy and Samantha who were in conflict, emphasised the need for liking between the parties. Where this was absent, employment relationships ended. As Robert and Neil point out above, work is also an important source of friendship for many but the friendships involved in personal assistance relationships meant more than this. In the following section I will review the reasons why this was the case in terms of the links drawn by employers and personal assistants before discussing the implications.

Disabled people in this study employed personal assistants for varying amounts of time, from a few hours a week to almost 24 hours every day. For people employing assistants for greater amounts of time, relationships were particularly important because of the intensity of the experience. Alan, for example, had employed one personal assistant but had terminated the contract because of a lack of common

interests. As someone who needed assistance with almost all aspects of living, and had personal assistants present for 23 hours a day, he pointed out:

‘I had this guy who worked with me and I extended his probationary period because it didn’t feel comfortable with him....He was brilliant – he came on, he could manage me but the relationship and the interest wasn’t there. I didn’t want to go out anywhere with him because he bored me. If I’ve got to spend twelve hours a day with someone I want to be able to get on with them - to have a laugh and a joke. And for them to get on with me. Otherwise that twelve hours are long; it’s a long time.’ (Alan, employer)

One of the aspects particularly welcomed by employers was that direct payments allowed them to choose their own assistants and they showed a preference for assistants with whom they had interests in common as well as who could handle the practical parts of the job. As discussed above, choice and common interests are also important components of friendship (Pahl, 2000). These interests were not necessarily static. John felt that although there were no good aspects to having personal assistants, in the sense that needing physical assistance was generally not a good position to be in, he welcomed the opportunity to meet people he might otherwise not have done:

‘You do come across some genuine people. Nice people, who genuinely care and who do a fantastic job, who you come to trust. And they remain as friends. And that’s a good aspect. Probably people who in a different mode you would never have bumped into.....you may never have been in a situation where you could have become friends.....It fairly broadens your horizons.’ (John, employer)

Many employers and personal assistants expressed the opinion that the nature of the work meant that it was inevitable that personal bonds formed between people. Most disabled people in this study employed assistants to help with daily tasks such as getting dressed, using the bath or shower and in some instances using the toilet. As Twigg (1997; 2000) has pointed out, receiving this kind of help puts the recipient in a vulnerable position; employers avoided this where it was possible. Often it was not possible to do so and employers felt embarrassed about having to get undressed in front of new staff. As people got to know one another better, so the difficulties associated with embarrassment lessened. The development of a good working relationship was seen as being important for both to feel at ease with

the personal nature of the assistance needed. Friendship can make these circumstances easier or at least more comfortable in the sense that the person providing assistance is not a stranger as was the case for many people who had received help from agency staff.

Inevitably personal assistants were party to a good deal of employers' personal circumstances. They frequently had access to all parts of the house, and the most intimate details of employers' lives. This in contrast to visitors, who commonly may have access only to certain parts of a house when invited in, with certain parts, such as bedrooms, being more private than others (Lohan, 2000). Assistants might be asked to rummage in drawers, enter bathrooms while employers were using them and so on. Many felt that it was not possible to be comfortable having people coming through the door without trusting them. This was a particular issue for people with visual impairments, as they might not know about various actions taken by personal assistants.

'I do see it as like a friendship. You talk about really personal things like you do with a best friend. If you have to go and get things like sanitary products or underwear it can get quite personalso trust is a big thing, especially if you're dealing with money and they have to go to the cash point for you. I think trust is a big major issue.' (Amy, employer)

Because personal assistants had detailed information about, and were party to so many events in disabled people's lives, they were often people that employers confided in and received advice from. As Morris (2005) has argued, where disabled people pay for assistance this creates the basis for developing a more equal relationship rather than one based on having to show gratitude (Galvin, 2004) or being made to feel subservient (Twigg, 2000). The need for confidentiality, in the sense that P.A.s would not disclose personal information to other people, was deemed important and employers often also had information about details of personal assistants lives. Again, trust, and being party to intimate details about each other's lives is a hallmark of friendship, as is the sense of being social equals, even if money rather than the return of favours forms part of the exchange.

However another reason why the presence of friendship was so prevalent was because of the physical context of the relationship. With the base for arrangements being the employer's home, the construction of the relationship as a friendship may be seen as employers establishing their ownership of the home as their place for living, rather than the workplace of the employee.

Being in Charge of Your Home

Employers who characterised P.A.s as friends typically constructed looser boundaries around duties and physical space; here the emphasis was on P.A.s helping with whatever was going on during the day, not on fixed duties and routines. Employers took the position of 'person in charge of their home' rather than 'boss'. Asked about the work that assistants did, these employers tended to give open-ended answers:

'Um, very, very varied.... So really, she's got quite a large haul. We're seeing how it goes and if I see that she's stressed... So when I say she's got lots of jobs, it's like running a family basically.' (William, employer)

'Basically they come on, lots of the time, with no idea of what we're going to do during the day.' (Alan, employer)

Duties, time and space were less bounded in these instances. Ellia, working as a personal assistant to William, quoted above, worked about 60 hours a week, much of this on a voluntary basis, although William was negotiating for payment with the social service department at the time of interview. Behaviour was also much less proscribed. As Alan pointed out:

'Because they're friends or I treat them as friends, sometimes they forget they're working. And they take liberties. They'll go to the fridge and eat a bar of chocolate and think 'oh, you know'. And if I want it then I get pissed off. But they know they can do that. I always say, 'do that but make sure you put it back' There's big problems - they don't realise they're workingAt three o'clock in the morning, if I want to get up and they start moaning, I have to remind them that they're actually working. So there's lots of that. I wouldn't have it any other way, it's about how it works for you, and it works for me that way.' (Alan, employer)

This points to another aspect of these relationships – the ‘person in charge of their home’ had to actively manage this process for it to work, and it was not necessarily a sign of being weak or ineffective. It was a conscious strategy for many, and it did require a more active engagement with working out arrangements on a day-to-day basis. From a position of friend often reference would be made to the fact of work, but the fundamental stance was the decision to treat personal assistants as paid friends rather than ‘friends who were paid’.

While employers consistently described friendship relationships with personal assistants, some also talked in terms of P.A.s being like family as well as friends and authors have argued that there is an increasing convergence between family and friends (Pahl, 2000). Where employers were receiving funding for support from the Independent Living Fund, some people had actually employed members of their families. However, where employers talked about kinship relationships, this was almost always mentioned together with the more common theme of friendship. Jackie talked about Ann, her P.A., as being like a member of her family, a situation made more ambiguous by the fact that Ann had started a personal relationship with one of her sons. She was keen to present a picture of a strong family that had come through hard times and in which friends are welcomed as part of the kinship network.

‘She’s not just me carer, she’s me friend. She’s like part of t’family now. Everybody that comes, they’re like part of t’family.we embrace everybody. Friends are like part of the family.....so it’s like an extended family. Not just friends.’ (Jackie, employer)

There were some ways that Ann was seen as not being ‘like family’ however, and this was expressed differently at different points in the interview.

‘Naturally she’s not me own. Naturally I’m not as involved wi’ Ann’s life as I am with me own children ...if Ann wants to talk to me (about the relationship with her son) she can, but I won’t ask her anything. Which I would with me own because I’m nosey. But with Ann it’s different. She’s not mine (laughs).’ (Jackie, employer)

‘I like to keep me family life separate. It would be different if Ewan and Ann got married. Then she’d become part of the family but at the moment she’s not

really. And I like it like that.She's not really part of the family and yet in a roundabout way she is. But yet she's my carer. If Ann's here and any of my family are here, she's welcome.... a bit of banter between them but at the end of the day Ann's my carer.' (Jackie, employer)

Alan also described Matt, his most long-standing assistant, as being like a son to him, although it should be noted that while Matt recognised that Alan saw him in this light, he did not wholly identify himself in the same way.

In all of these instances however, the main relationship identified was that of friend and kinship attributes were woven in with this dominant theme. From the point of view of this discussion, while the distinction and blurring of boundaries between family and friends is of interest, it may be noted that both these relationships fit into the private sphere as commonly conceived. Personal assistants were seen as, and saw themselves as being more part of the household than part of a fixed employment relationship in these paid friendship arrangements. This way of managing personal assistance has several ramifications and these are discussed further after the perspectives of personal assistants have been outlined.

Personal Assistants' Perspectives: Employers as Friends

Eight of the nine personal assistants interviewed described friendship as the main component of the arrangement or at least as important as the aspect of employment. Sheila assisted Janice with driving from home to see friends and with shopping. She commented:

'We're very, very similar in ways of thinking and she likes everything that I like.So I wouldn't say we were dead, dead close, but we get on really, really well. She's funny – she makes you laugh sometimes the things she says.' (Sheila, personal assistant to Janice)

Anna's remarks were typical of many of the personal assistants. While the difficulties that she and her employer experienced are discussed in both the following chapters, the theme of friendship remained strong.

Sarah: 'How do you get on?'

Anna: 'Very good. I'd say like best friends really. Very good.'

Sarah: 'In what way would you say that you were friends?'

Anna: 'We'd say to each other things that are confidential. I think Amy feels very, very at ease and I wouldn't say she looks on me like a carer, more of a friend, a companion.' (personal assistant to Amy)

In the context of the home, these personal assistants felt that the relationship of employee and friend were not really distinguishable. They did place more emphasis on the employment aspect of their work but also valued the personal relationships they developed with employers. Although some authors have suggested that people may move in and out of different roles, in the context of the home this was not really borne out:

Sarah: You mentioned William's both a friend and you're an employee. Do you think that you're both of those things at the same time, or do you think you're sometimes more of an employee and sometimes more of a friend?'

Ellia: 'Probably both at the same time. Maybe sometimes I could be more of an employee.....or I feel like it. Usually more as a friend. It's relaxed as well. Like there's no time on it....I'll know that I'm working. I do feel like an employee. But usually it is at the same time as a friend. I think.' (laughs).
(Ellia, personal assistant to William)

Several personal assistants did not see what they did as being work. Marilyn would often forget about her wages and saw it more as a way of life – just what she did during the day. Emma, working as a P.A. to Jean who emphasised the importance of a professional working relationship, saw herself as more of a friend because it involved working with just one person:

'I know it's work, but it doesn't feel like I'm going to work. I suppose you're more friends. I know she's still me boss and you have to think like that, because sometimes she is your boss and not just a friend. But she's more of a friend than a boss I think. Whereas I suppose when you're working for a big firm a boss is more a boss..... She's more of a person. A friend, whereas normal bosses, there's more of a line.' (Emma, personal assistant to Jean)

Emma had previously worked in a residential home for elders. She described other staff as her friends there and residents of the institution as providing her with more 'variety of work'. The distinction she makes above is that she sees Jean, as well as being a friend, as more of a person – more human. While many authors have pointed to the dehumanising effects of institutions and the training of 'care' workers in oppressive practices (e.g. Finkelstein, 1980, 1981a, 1981b, 1991;

Goffman, 1975; Hunt, 1981), Emma did not recognise the link between the two situations explicitly. The jump made was to one of 'friend' rather than 'boss.' In common with all other personal assistants except one, she saw no real difference between the kinds of work done in an institution, or under the management of an agency, despite the fact that disabled people experienced these situations very differently.

The other reason given for friendship was that the kinds of things done equated with personal assistants' experiences of private sphere activities that they did themselves. Anna, for example, pointed out that it didn't feel like work because they were 'always going shopping.' She would note items seen on these shopping trips that would suit members of her family and either come back for them later or agree to take time out from work to buy them. Employment was something seen as happening within more formal, less fluid structures and this concurs with friendship – oriented employers' emphasis on flexibility and lack of formal job definitions. Ellia, who was paid to work for William for 42 hours per week, actually worked 60, providing the difference on a voluntary basis. Therefore her public employment and private home spheres were not well distinguished, with work encroaching significantly on her home life.

Other P.A.s talked about the flexibility of the work. They valued options to re-arrange work times and hours to fit in with other commitments, although it should be noted that the desire for flexibility was something that could cause problems as both employers and assistants sought to maximise this on their own behalf.

In summary therefore, personal assistants appreciated good relationships with employers and saw this as a valuable part of the job. Several mentioned that it didn't feel like working, while recognising that it was in fact a job. Conversely, personal assistants who had done assistance work either for private agencies or social service departments in the past did not distinguish between this kind of employment and working as a personal assistant – they saw it as essentially the same.

Reciprocity

Friendships, as commonly conceived, do not involve formal arrangements such as contracts, job descriptions and payment. Nevertheless, for the employers and personal assistants in this study work and money represented the exchange. While unsatisfactory pay and conditions of employment for personal assistants have been highlighted in other studies (see for example Morris, 2004; Ungerson, 2003), these issues were not commented on or expressed as particularly problematic by personal assistants. In part this may be due to the fact that they were not asked about this, and there may also be regional employment variations involved, where higher costs of living in the south of England may affect relative prosperity. Also, at the time of interview most personal assistants were not living in households where they were the main or only earner. More frequently they combined part-time working as a P.A. with other work such as looking after young children where women were employed, or with other forms of paid employment. Pay and conditions for personal assistants had improved for personal assistants in recent year vis-à-vis the terms and conditions of other ways of doing this work, or rather, other means of earning a living from this work had become less attractive. While in the early years of direct payments an employee could earn more doing comparable work when employed directly by a social service department, and was eligible for pension and holiday entitlements, this was no longer the case. Direct service work of this kind had largely been replaced by the work for private agencies discussed in the previous chapter. Terms and conditions and rates of pay working for agencies compared unfavourably with those offered via direct payments. Securing pay increases was not straightforward or automatic. Several employers had made representations to local authorities on assistants' behalf and in one area the direct payments group was trying to link wages into social services annual pay increases as there were no clear mechanisms for reviewing pay.

Given that disabled people may not be in a position to repay favours in the conventional form in the private sphere (Rae, 1993), money was a way of redressing the balance. This position may have been overstated however, as employers did help out personal assistants in ways that extended outside the formal confines of the job on a reciprocal basis. For some employers the rationale for

exchanging favours was that they needed to call on help at unexpected times but were not always in a position to be able to pay money for it. Insecurity in the form of potential cuts in allocation by local authorities remained a reality, and for many the allocation of hours was simply not enough. Therefore systems of informal exchange of favours grew up to cover the gaps. For some it was around these extra favours that relationships developed.

‘Take Miranda (P.A.) for example. If she’s had a bad day at home....she’ll come and say, ‘what do you think he’s bloody done?’She has two boys and they come to me for help with their homework. I give them extra tuition. And in return Miranda will do extra things for me that she doesn’t get paid for.Like ‘can you go somewhere?’ or ‘take me to the hospital?’, which is outside the funding, so that’s where the relationship develops.’ (Tom, employer)

As mentioned earlier, Marilyn had worked as a personal assistant for Kathryn for many years before changing her role to support her at work. Due to an administrative anomaly, her new role did not occupy her sufficiently so she found herself doing a wide range of other jobs more in line with her previous duties as a personal assistant before her employer had herself become employed. She did many things that were outside her formal job description as it stood at the time:

‘Doing things round the house that you’re not employed for. Decorating, gardening.....Just gradually taking on jobs that weren’t in the job description, or expanding things that were in the job description and taking them further. Staying around because Kathryn’s having a down day, till John’s come down in the evening so she’s not on her own – maybe appointments or something happening over a weekend when really other weekend girls should have done it, but Kathryn didn’t feel comfortable with the weekenders supporting her so I’ve done it. Even now I still look after her personal accounts, bills and other things that come in, organising appointments that really are personal or social and so should be kept separate from work.’ (Marilyn, personal assistant to Kathryn)

Kathryn had returned these informal favours, as Marilyn pointed out:

‘When Ken (Marilyn’s partner) was made redundant, he was out of work for three and a half months. Things were tight for money so she lent us money. She’s come to the doctor’s with me when I needed a bit of support at the doctor’s and it couldn’t be my mum. She’s been there for advice and generally a friendly shoulder, which you wouldn’t necessarily have with work

colleagues in an office. ...When....my mum was ill I'd be in to help her get up in the morning and then she'd be letting me go home because my mum was ill.' (Marilyn, personal assistant to Kathryn)

Marilyn and her parents had also moved in with Kathryn on a rent-free basis for three months while their house was being substantially adapted to enable her mother to continue living at home.

While Marilyn and Kathryn gave each other a great deal of practical reciprocal assistance, more commonly the exchange was in the form of moral support for one another. There were differences in the degree to which employers and personal assistants felt comfortable with this. Where informal arrangements were made, or where personal assistants were seen to be going out of their way to do more than they might have been expected to do, employers were at pains to return favours wherever possible. It should be pointed out that some people had no informal reciprocal arrangements and this was more likely to be the case where personal assistants were employed for shorter periods of time during the week, had been employed for less time, or were employed for specific rather than broad purposes.

Discipline

All employers who had done this disliked disciplining personal assistants. Often an issue was left to build up for some time before something would be said and sometimes issues were avoided altogether. Although for most employers it was simply that disciplining personal assistants was just a disliked aspect of the work, some were concerned about how the assistant would react and whether this might put them at risk (Beck, 1992). This risk might be that the assistant would leave, leading to the problems associated with finding a replacement, that they might leave the employer in a vulnerable situation, or that the P.A. might react adversely. One employer, Robert, described an incident in the past where he had been attacked by a personal assistant and had had to go to court to get an injunction to prevent further assaults. Concerns about this could influence how employers felt about tackling areas of difficulty:

‘Because I’m so dependent with the care that I get, I’ve got to think twice before I let something come out of my mouth, which isn’t ideal because all it does is create stress and frustration.’ (John, employer)

Employers adopting an employee stance vis-à-vis personal assistants tended to have in place agreed duties, times of work and agreement as to uses of space, as has been discussed above. Due to this, disagreements and misunderstandings were less likely to arise. For employers adopting the paid friendship stance, with more fluid agreements, arrangements were less certain and the potential for disagreement on a day-to-day basis more possible. Employers who preferred informality did bear in mind problems of physical safety and took precautions:

‘One minute you’ve got to discipline someone and the next minute you’re saying ‘actually can you help me go to the toilet.’ It’s extremely difficult. ... I’ll wait and I’ll wait. I tend to tell them but when I feel safe.... So with Dave, I’ve let things build up and I’ve waited until just before he’s finishing the shift I’ll say, ‘well actually Dave, I’m really pissed off because of this and this.’And he’ll say, ‘well why didn’t you tell me when I did it at the time?’ I can’t, because if something’s pissed me off, in the middle of London, I would never dream of telling anyone that. I’d wait till they got me home, sat me in this wheelchair, we’re in the house and with ideally a table between me and them. (all laugh)’ (Alan, employer)

The resolution of conflict between employers and paid friends presented issues, because of an emphasis on equality:

‘It’s really hard because you’ve got the title of ‘I am the employer’ - the big cheeseand I don’t like that side of it, because I don’t want my life to be controlled and that’s why I like direct payments. So therefore, I wouldn’t like to control somebody else’s life.’ (Kathryn, employer)

Conflict resolution between paid friends could be volatile at times. Kathryn, who had felt very nervous about disciplining Marilyn in the early days of her employment, described episodes when they shouted and yelled at one another when disagreements arose. They had come to accept lively arguments as the way that they resolved issues and explained this to other personal assistants who were perturbed to witness explosive outbursts. They both described the process:

‘We can talk about anything and everything under the sun - we can switch from politics to what’s the latest colour top to be seen in at the moment....

Have a giggle with each other about if Ken's pissing me off or John's doing her head in or ... We can bang heads about something going on at work and sit down and watch Neighbours half an hour later. We can have a good argument about something where we have differences of opinion - shout and bawl and arguing the toss about it, and then say 'OK, let's agree to disagree, want a brew?' (Marilyn, personal assistant to Kathryn)

'It was funny when you look back - to hear these two women screaming at each other like banshees. And next minute talking about god knows - anything. 'Are you going to do that? Are you coming out for a drink?' or whatever.' (Kathryn, employer)

There were obviously other instances where conflicts were not resolved and in many instances employment ended. However conflicts also often led to changes in working arrangements and the instances described above point to some of the ways that disagreements were handled. With or without accompanying conflict, relationships did not remain static; typically there was change over time and context. Before considering these issues, I will clarify the distinctions between employer – employee relationships and paid friendships and provide a summary of the main points of the discussion.

Comparisons

So far this chapter has explored the ways that disabled people and personal assistants characterised their working relationships / friendships. It has sought to consider how people manage what is considered to be a public, employment relationship in the home, a private space. An ideal type framework has been used to make a distinction between employers who showed a preference for an employer – employee stance and those adopting a paid friendship stance. Differences involved are summarised in *Table 1*, on the following page.

Why Paid Friendship?

There are several reasons why friendships developed between employers and personal assistants. Close physical proximity and assistance with personal tasks meant that relationships were likely to be more comfortable when some degree of personal liking was present: all respondents judged this to be essential. Personal assistants were also needed to carry out tasks for which a high degree of trust was

required, such as getting money out of a bank account for a visually impaired employer. They were often chosen on the basis that they were of a similar age and had interests in common with their employer. These elements overlap closely with ideals of friendship today (Pahl, 2000) – that it is something that is freely chosen by people, involves trust, liking, and a perception of equality between the partners. As has been discussed, the home is an important place for friendships, and this sense of recognition by both parties provided a powerful impetus in the direction of friendship.

The negative side of this was that it could be devastating for employers when a particularly liked assistant left employment for one reason or another. There were instances where people kept in contact after working arrangements ended but relationships inevitably altered. This is why there were some differences between this form of friendship and other kinds as commonly conceived. It was bounded by certain circumstances and conditions. However according to the literature, friendship is an unpaid relationship. Different forms of friendship have been noted but payment is not a feature of any of these. I am therefore proposing a new category of ‘paid friendship’ that arises in these specific circumstances, although there may be others. The features are that it starts after employment rather than before (see the section on disabled parents in chapter 8 for further distinctions between social and paid friendship), that it shares the substantial areas of overlap with social friendship discussed above, that it has the capacity to develop in a more formal or informal direction over time and is a consciously chosen relationship. It shares more characteristics with friendship than employment and this is recognised by both parties in the relationship. Friendship relationships are bounded by the presence of payment.

Two further distinctions may be made. These are to do firstly with the difference between social and paid friendship, a point that will be clarified in Chapter 8. The second point concerns context and activity (Allan & Adams, 1998), and this will be clarified in Chapter 9.

Table 1: Summary of Distinctions between Ideal Types of Employer – Personal Assistant Relationship

	Employer - Employee	Paid Friendship
Relationship in the home	Emphasis on work.	Emphasis on home.
Job description	Emphasis is on getting a set range of jobs done.	Emphasis is on maximum flexibility in range of duties carried out.
Space	Domain of personal assistance is limited.	Domain of personal assistance is expanded.
Time	Set hours of work.	Hours of work are blurred. Significant number of working hours may be involved.
Management style	<p>Explanations offered for arrangements. Overt recognition of P.A. as an employee.</p> <p>Hierarchical relationships</p> <p>Communication between P.A.s channelled through employer.</p>	<p>No overt explanations offered. Emphasis is on personal friendship and informality.</p> <p>More equal relationships</p> <p>Interaction between P.A.s tolerated or encouraged.</p>
Conflict resolution	Formal procedures, supervision.	Informal discussion – may be volatile at times.
Relationship to friends / family *	Separate sphere – distinction made between P.A.s as employees and friends / family.	<p>Separate sphere – distinction between P.A.s and social friends framed in terms of being different kinds of friends.</p> <p>Occasionally P.A.s constitute close social friendships when additional commonalities exist.</p>
Work boundary	Set boundaries – few additional favours outside work.	Permeable boundaries – several to many additional favours outside work.

* Discussed in Chapter 8

The lack of this concept, I would argue, has presented difficulties for authors seeking to theorise employer – personal assistance relationships. Marfisi (2002) for example, concludes that the reason why employers form friendships with personal assistants is because they are socially isolated. This is not borne out in the data from this study. While some employers were socially isolated, there was no correlation between social isolation and the adoption of a paid friendship stance. On the contrary, the employers who selected a paid friendship stance were among those who had the most supportive kinship and friendship networks and access to a wide range of social contexts such as work, leisure etc. Three of the four employers who were in paid professional work were positioned on the continuum described above at the extreme end of the paid friendship continuum. They were in fact employers who exercised some of the highest levels of autonomy in the sample. The lack of the concept of paid friendship results in a negative attribution by Marfisi where none is warranted. The difficulty is that Marfisi conflates social friendship and paid friendship, and respondents in this study made clear distinctions between the two different kinds of relationships, as will be seen.

Findings with regard to ‘false kinship’ (Cox & Narula, 2003; Gregson & Lowe, 1994) characteristic of households employing domestic servants and *au pairs* have been discussed in Chapter 2. As was noted, assertions of kinship by employers in these instances were used as a way of imposing hierarchical relationships whereby workers were positioned as children or as part of the family, at the same time as status demarcations were maintained. Bonds of affect were used to extract more effort from domestic workers. The question arises as to whether there is an equivalent concept of ‘false friendship’. With reference to the earlier discussion in Chapter 2, several relevant points may be made. Firstly, relationships were characterised as friendships and not kin relations. Furthermore favours outside of working hours were often reciprocal rather than one-way. Equality was stressed in the paid friendship relationships rather than hierarchy: for example several employers and personal assistants pointed out that while the employer might worry about the P.A. leaving, the P.A. might worry about getting the sack, especially with regard to the sometimes volatile arguments about arrangements. Paid friendship and false kinship are therefore not the same thing.

The Concept of Companionship

Yamaki and Yamazaki (2004) suggest companionship as one of four constituents of employer – personal assistance relationships. Although no formal definitions are offered, their description of ‘close relationships’ that are ‘mutually supportive’ (2004: 38), infer affinity. In this section I will consider the UK literature, and as will be shown, the concept of companionship is used to denote a very broad spectrum of relationships. For some authors (e.g. Gleitman, 2000; Mival et al., 2004) companionship may denote trust, a characteristic of present day friendship (Pahl, 2000), while for others (e.g. Tadmor, 2001; Warde et al., 2006) a less close connection is suggested. Thirdly, companionship as a formal position of employment, and its relation to the concept of ‘paid friendship’ is discussed.

Utility

Mival et. al. (2004) note that companionship is rarely defined, even though it is an idea that is familiar to all, as a relationship entailing mutual caring and trust. The authors suggest that companions may be divided into two categories that lie on a continuum of usefulness: for example, they contrast a cat (no usefulness) with a care assistant (useful) in respect to elder people. While what counts as utility may vary across different groups, they argue that it is an essential basis for the development of relationships. Mival et. al are concerned with the development of artificial companions (robots), but seek to offer a broader contribution to theorising companionship.

The theme of utility is also apparent in Titchen’s (2001) concept of ‘critical companionship’, where a more senior nurse offers guidance and mentorship to a junior colleague who is learning her trade. Here the notion of companionship is used to denote the fostering of a sense of equality between the parties, although the companion mentor is considered to be the senior party. Companionship has also been seen as a key therapeutic tool for assisting the recovery of a variety of service users within medical settings (Kelsey, 2004; Ormerod, 2005; Tse & Howie, 2005). Particular interest has been shown in animal companions as having the potential to assist the recovery or cure of marginalized people.

Companionship as a Social Relationship

If utility is stressed within the medical literature on companionship, then the literature on social relationships tends to use the term companionship to refer to relationships that are placed somewhere between friendship and acquaintanceship (Rook, 1987; Rook & Ituarte, 1999). Companions in this sense are people who take part in social activities that are shared because they are enjoyable rather than useful. The emphasis is on taking part in routine social activities in the public sphere, although relationships may cross over into the private if relationships become closer (Warde et al., 2006). Used in this sense, the term companionship bears similarities to the ‘mateship’ described in Chapter 2 (Allan, 1996).

With regard to this study, ‘paid friendship’ may be distinguished from companionship as the term is used above, on the basis that it operates the other way round: its main location is the home rather than the public sphere although further activities may emanate from home.

Companionship as a Formal Role

As a formal role, the term companionship often invokes notions of young women employed in an intermediary position between friend and servant in the 17th to 20th centuries. Remarkably little has been written on this form of companionship in the historical and sociological literature. The role has a higher prominence in works of fiction. So for example, the unnamed future Mrs de Winter is described in du Maurier’s (1992) novel *Rebecca* as occupying the role of companion to Mrs Van Hopper. The companion relationship, about which both the heroine and her future husband are uncertain, is described in the following extract:

‘Your friend’ he began, ‘she is very much older than you. Is she a relation? Have you known her long?’ I saw he was much puzzled by us.
 ‘She’s not really a friend’ I told him, ‘she’s an employer. She’s training me to be a thing called a companion, and she pays me ninety pounds a year.’
 ‘I did not know one could buy companionship’ he said; ‘it sounds like a primitive idea. Rather like the Eastern slave market.’
 ‘I looked up the word “companion” once in the dictionary,’ I admitted, ‘and it said “a companion is a friend of the bosom”.’

‘You haven’t much in common with her’ he said.
 He laughed, looking quite different, younger somehow and less detached.
 ‘What do you do it for?’ he asked me.
 ‘Ninety pounds is a lot of money to me.’ I said.
 ‘Haven’t you any family?’
 ‘No, they’re dead.’ (du Maurier, 1992: 27)

Du Maurier here points to the dichotomy in the formal relationship of companion. It is the same as has been described above as for personal assistance. The relationship involves payment and possibly friendship (although in the above extract an employer – employee stance is described). A difference is that friendship is not necessarily expected or put forward as a central principle of the present day personal assistance relationship from the start. It is made explicit in the terms of reference of the companion, and affinity is assumed at the start, whether it may or may not be present. Later in *Rebecca*, Du Maurier draws a connection with women’s position in marriage through the narrator’s husband:

‘So that’s settled, isn’t it?’ he said, going on with his toast and marmalade; instead of being companion to Mrs van Hopper you will become mine, and your duties will be almost exactly the same. I also like new library books, and flowers in the drawing room, and bezique after dinner. And someone to pour out my tea. The only difference is that I don’t take Taxol, I prefer Eno’s, and you must never let me run out of my particular brand of toothpaste.’ (du Maurier, 1992: 58)

Companionship in this instance is therefore is not a relationship of equality: it is portrayed as an unequal position of favoured servant, corresponding to the position of wife within a patriarchal relationship. A ‘companion’ as described in the novel is however different from a servant: the plot of *Rebecca* hinges on the relationship of the new Mrs de Winter and the housekeeper, Mrs Danvers, who serves the dead, previous Mrs de Winter.

However the formal role of ‘companion’ does not tell us anything about the nature of the relationship between the employer and companion. Du Maurier does map out the dilemma of employment and friendship and portrays this particular relationship as one between employer and employee, but the possibility of friendship is present in the account of the dictionary definition. Therefore in this sense, a formal companion corresponds to the position of personal assistant: they are synonymous.

Companionship as a Relationship in 17th and 18th Century Literature and History

Other literary accounts use the term companionship to denote a very wide spectrum of relationships. It is generally used to describe relationships between people, animals and things. Jane Austen (1988), for example, makes multiple use of the term in many of her novels. Companionship is used to describe relationships with family members, people who are not related and animals. Here the meaning of companionship simply means being with, and agreeable or disagreeable companions are described.

It is however important to note that novels do not necessarily illustrate social relationships of the time accurately (Blackford, 2005). As Tadmor (2001) has pointed out, at this time the meanings associated with terms such as friends and family were not the same as they are in the present day. She notes several notions of the family that were current at this time, including the household-family and linear family. Although the latter is broadly similar to the understanding of family today, the household-family might include people who were not related by blood. She quotes the Registrar General's instruction for the census in 1863:

‘The family in its complete form consists of a householder with his wife and his children; and in the higher classes with his servants. Other relatives and visitors sometimes form part of the family; and so do lodgers at a common table who pay for their subsistence and lodging’ (Tadmor, 2001: 41)

Tadmor points out that family members were very commonly referred to as friends. In her analysis of Thomas Turner's diaries she notes that companionship did not mean the same thing as friendship but companions might become friends. Noting an instance where a long-standing companion was, after a number of years, designated a friend, she points out that:

‘It seems in this case long-term personal companionship, linked with many exchanges and services, had matured over the years, and was cemented by trust. Thus, this long-standing tie of neighbourhood companionship was eventually designated as ‘friendship’ (Tadmor, 2001: 209)

Silver (1990) makes a similar point when he notes that social relationships need to be understood in historical context: the paradigm of friendship in earlier centuries is different from that of the present day.

Companionship and Paid Friendship

From the above discussion it may be seen that companionship as a concept has shifting meanings. It may be used to refer to a formal relationship of employee, where payment is made for someone to live in or accompany an employer, and this corresponds to the position of personal assistants. However this relationship needs to be viewed as part of the prevailing pattern and definition of social relationships in society more broadly at particular historical points in time. Paid companionship was, as Du Maurier (1992) points out clearly, rather similar to the position of wife. While not the same as a servant, it was not an equal relationship in relation to the employer. In contrast, personal assistants and employers in the present study did characterise their relationships as equal. The difference here was the social position of employers. As Ungerson (1999) has pointed out, unlike the landed gentry of the eighteenth and nineteenth centuries, disabled people are not accorded high social standing in society.

The association of companionship and therapy in the medical literature about disabled people makes the term an uneasy one. Defining companionship as a public sphere relationship that may be broadened to include visiting at home also does not correlate succinctly with employer – personal assistance relationships. The presence of trust in the paid friendship relationships was deemed to be essential to a successful partnership, and with home the base and intimate assistance with bodily activities part of the routines, a new definition for companionship would be need to be asserted. Paid friendship has been preferred as a term because it was the description used by respondents in the study. No employers used the term in regard to personal assistants, although one employer (Lynne) used the term when talking about her husband.

Personal Assistants and Companionship

Three personal assistants (Sheila, Emma and Anna) used the term companion in relation to employers. Emma was asked for more details about this:

Sarah: 'How do you describe the work you do to other people?'

Emma: 'I just tell them the same, that I'm a support worker, a companion, go out with her, whatever she needs really.'

Sarah: 'When you say companion, ...what do you think a companion is?'

Emma: 'A friend really. Can't really say it any other way.'

Sarah: 'I'm just interested because the word companion's come up a few times and I'm just thinking about it myself.'

Emma: 'I suppose it's more friendship really. Company for her as well. Yes, I suppose - I can't think of any other way of putting it.'

Sarah: 'I agree. It really is like a friend isn't it?'

Emma: 'Yes.'

Sarah: 'Are there any differences do you think? Between a companion and friend?'

Emma: 'I suppose when I think like of me best friend, there is a little bit. I suppose you still have that little bit of a line. I don't mean a line, that's the wrong word. Because I do talk to her like a friend - well I do talk to her like a friend. But I perhaps talk a bit differently to me best friend. I probably tell me best friend a little bit more than what I tell Jean! (laughs) Probably! But she does know most things anyhow.'

Sarah: 'And obviously we have different kinds of friends, don't we?'

Emma: 'I mean I have to remind meself sometimes that it is work and she is me boss! You don't feel like that. You don't feel like she's your boss at all. It's weird really. It is, it's strange.'

Personal assistants used the term companion in the formal sense, to describe a contractual relationship. When pressed, they described companionship as friendship, a finding also reported by other researchers (e.g. Warde et al., 2006). Paid friendship is therefore used in this study as a way of describing the meaning attributed to many employer – personal assistant relationships.

Movement between Ideal Types

Mention has already been made of the fact that many employers started out on a rather more formal footing with personal assistants, later developing a relationship characteristic of paid friendship as trust developed. This could not be taken for granted. While Alan expressed a clear preference for paid friendship, he also stated in relation to a new personal assistant:

‘Whether Darren might get that way, I don’t know. Dave’s getting that way now and I think the longer people get to know you the more they become, you know, reliable. I mean I always say personal assistants do become reliable once they realise your needs.’ (Alan, employer)

Paid friendship was a more complex relationship than an employer – employee relationship. An evident advantage for employers was the degree of flexibility involved. Some employers started out with a preference for paid friendship but abandoned it as it became difficult. For example, Margaret had initially welcomed direct payments as offering her the possibility of having work done when she wanted it. Having employed a friend and neighbour, she ran into difficulties agreeing the hours that work would get done.

‘I really wanted it to be flexible initially, and that’s where we first had teething problems. She wasn’t even coming round to ask ‘when shall we do it this week?’ I was constantly going round to her house to say ‘can we discuss when we can do this?’ I ended up getting really worked up about it, because I felt that she’d started getting very laid back about it, and doing things when she felt convenient. She was just coming round and saying ‘right, I’ll do the cleaning for you now’ . And I’m like ‘hello? Its not appropriate for me at the moment’ eventually, after talking to me support worker, and another friend who’s on direct payments, we did sit down, and I said ‘look, issues have come up, and what we need to be doing is possibly meeting on a Monday, and making it slightly more structured.’ (Margaret, employer)

The solution here involved moving from a less to a more structured working relationship, i.e. towards an employer – employee arrangement rather than a looser friendship and this was typical of most situations where an informal friendship pattern had not worked for employers. Formal arrangements lessened the potential for future conflict but reduced the possibility of flexibility. This instance also points to the fact that Margaret, as with many employers, had had little experience of this kind of management previously and made adjustments to the arrangements based on advice from others.

Developing Success as an Employer

There were no characteristics that defined the employers who opted for employer – employee relationships or employer- friendship patterns in terms of class, age,

ethnicity or impairment, although it should be noted that the sample of ethnic minority employers was rather too small to draw any clear conclusions here. Gender was a significant factor however, and this is discussed in Chapter 8. Employers who defined their relationship as primarily a friendship relationship felt their arrangements to be as successful as those who defined it as primarily an employment relationship.

Longevity of experience was deemed significant. Employers considered that they had learned the best way of managing situations over time. This finding is rather at odds with the policy notion that disabled people should be willing and able to manage direct payments (Department of Health, 2000b), which implies a static notion of capability. It concurs however with the findings of Saxton et. al. (2001) who also point to the significance of experience. Employers developed proficiency over time.

Personal assistants prioritised good working relationships and a sense of satisfaction gained from helping others. Furthermore, success is problematic as a concept. An employer – P.A. relationship that was judged by both parties to be ‘working well’ might end some time down the line in acrimony and disappointment, and a situation that might at one point in time be judged problematic could be resolved as the parties dealt with difficult issues.

This having been said, problems did arise where there was no clear stance agreed. To illustrate this I will present a case study. Considering the circumstances surrounding the employer – personal assistant relationship here also allows the discussion so far about employment and paid friendship to be connected to the concepts of public and private domains, offers an explanation for both why employers preferred a particular stance and how this related to the meaning of home.

Case Study: Wendy and Samantha

Wendy and Mike were married and living in a smaller house when Samantha started working for Wendy. The couple had married soon after Wendy was

involved in a car accident and initially Mike had provided Wendy with all her assistance, giving up his work as a financial advisor to do so. With Wendy having secured direct payments, Samantha was employed to help with housework and to assist Wendy with going out to do various activities during the day. Following financial compensation for her injuries, which had involved protracted legal proceedings, Wendy and Mike moved to a larger house. Samantha's job became more about cleaning and less about assisting Wendy to do things outside of the house, a development that Samantha did not welcome. She felt resentful about the changes this had involved:

Samantha: 'Since she's moved to a different place, I do more grin and bear it.... I'm told to do more things than I would ever have to do in the other house. I've learned over the past couple of years to be more tolerable.....I think 'well there's no point in moaning'. I just get on with it really.'

Sarah: 'If you did moan, what do you think would happen?'

Samantha: 'I think she would.....moan back. Come the heavy employer bit – 'Well I do employ you and you're supposed to do this and that and the other'can't be sure because it's never happened, but I do think she would.... I might be wrong. But I do think that's what she would say.'

Wendy described how she felt about the struggle between them:

'I have a real power struggle with.....you're home's your castle. With employment, if you have a business, it's outside your home.... I'd say one of the things that I struggle with sometimes is that because **this is the workplace** and..... there's one (Samantha) that will come in in the morning and then go off and just do what she thinks wants doing. And I find that quite a hard power struggle, in controlling that. Now I've learned that I've got to get in there first if I want something doing.....Sometimes you've got all these people coming in to you; sometimes **you feel like it's just not your home**. But because the need that you've got because of the disability, you've got to have it..... And really it's more about me trying to adjust to having that amount of time with people in **my house**. And I think that's one of the hardest things in getting over.'

(Wendy, employer) (Emphasis added)

Wendy highlighted here one of the dilemmas involved in asserting her role as an employer. In so doing, she also defined her home as a place of work. In the process, the sense of ownership of the place is lost and the home becomes a house. Defining oneself as an employer also involved defining the home as the territory of the personal assistant, as her workplace. Wendy sought to contain Samantha's

autonomy by placing boundaries over her duties, often changing her instructions when Samantha was in the middle of another job. As Samantha pointed out;

‘I just like to get on with it everyday, what I’ve got to do cleaning wise, so the house looks straight and tidy.....And then it works well. But it don’t work well in my mind if I’m half way through mopping the kitchen floor and it’s ‘Samantha, can you just change the water in this plant’ or ‘can you polish the living room’, and I’ve got to stop what I’m doing half way through to go and do that, instead of her saying ‘well when you’ve finished doing that will you do this.’ That’s when it don’t work well. Well it does, because I keep me mouth shut. I just grit me teeth and get on with it. And then go back to my half finished job.’ (Samantha, personal assistant)

Samantha’s job had become not much more than cleaning, although she did also stay overnight on an occasional basis to help when Wendy’s husband was away. Other assistants had the more interesting jobs such as accompanying Wendy shopping. As a cleaner she might typically expect rather more autonomy than she was given (Gregson & Lowe, 1994; Mears, 2005) and felt that there were certain jobs, such as scrubbing out the oven and washing the dogs’ paws that she should not have been expected to do.

Equally significantly, Wendy did not herself express a clear preference for an employer stance with regard to personal assistants, but saw value in treating P.A.s as friends:

Sarah: And do you think of yourself as an employer, or as something else?
Wendy: I think a bit of both. I do see myself as an employer, and I think I am mates with them as well. And flexibility-wise. If you can be flexible then you’ll get that reward back. And it has happened in the past, where one of them might not have been down to work or I’ve been in position where there’s been nobody and something’s happened and I’ve had to ring up and say, ‘can you come in this afternoon?’ And they’ve said ‘yes, not a problem.’

Wendy and Samantha’s situation was muddled therefore in terms of the two ways of managing situations outlined above, and was unsatisfactory to both. While many accounts have attributed responsibility for this kind of confusion to the individuals concerned or to their social group membership (e.g. Ungerson, 1999), it is argued here that a firmer understanding of context can make situations more intelligible.

Conclusion

When considered in terms of space, the definition of the house as a place of work, while superficially giving precedence to the employer, also concedes definition of the space to the personal assistant. Employers who used this strategy sought to limit it, primarily through putting in place boundaries of time, space and work done, thereby retaining space for the house as a home.

Other employers sought to subsume the working relationship within the private realm, as a friendship. Some employers who used this strategy needed more assistance in terms of time. People receiving assistance for many hours would have very little time and space for a private sphere of life were this not the case. The solution was to incorporate assistants into the private sphere of home. Others did not need this amount of help, but found that relationships developed through an instrumental need for favours or because of the length of time spent together and the intimate nature of the working relationship.

As discussed in Chapter 5, Ungerson (1999) counterpoises sentiment and attachment with the power to command in a similar way to paid friendship and employment as discussed here. There are important differences however. The assumption she makes is that greater emotional sentiment between the parties reduces the ability of the employer to command or to get things done. This is again not borne out by the data presented by respondents interviewed for this thesis; rather employers who adopted a paid friendship stance were able to impose – or retain – the definition of the space as home, and were possibly also able to get more done than those who used more rigid structures to guide the relationships with personal assistants. In particular the existence of reciprocal help outside of the formal boundaries of the contracted work would suggest that some assistants took on more work than in situations where hours and duties were more tightly adhered to, thus bringing into question the notion that the power to command is separate from affect. It was clear from this study that not all employers chose to issue commands. Within paid friendship there was often negotiation and sometimes quarrelling with personal assistants but they didn't issue orders. There was one

employer in the sample (employer – employee stance) who had done so in the past but she had abandoned this strategy some time ago.

This chapter has outlined the ideal types of employment and paid friendship and proposed the latter as a new concept for a particular form of friendship. Implications of each preference for the meaning of home have been discussed and some preliminary reasons given for why employers elected for a particular stance. The reasons are preliminary because they do not take into account employers' and personal assistants' structural positions as part of their own social networks: the subject of Chapter 8. Before turning to this, I will consider the question of the relationships between employers and family members before picking up and extending the themes introduced here.

Chapter 7

Personal Assistance and Social Relationships

Introduction

This chapter will answer one of the questions posed at the start of Chapter 2, namely: how do the social relationships of disabled people and family / friends change or remain the same as a result of receiving direct payments? In answering the interview questions associated with this issue, respondents gave particular priority to kin relationships and emphasis was placed on qualitative changes to these. Authors have documented how family members feel about becoming a 'carer' and the experience of giving assistance on a long-term basis (Katbamna et al., 1997; Kittay, 1999; Parker, 1990, 1993). However they do not consider the reverse, i.e. what is involved in giving up being a 'carer' or a person who is 'cared for' and how this impacts on social relationships. This chapter addresses these questions.

Here again the emphasis is on how people managed their daily lives and dealt with their circumstances. In particular this chapter is concerned with the ways in which personal assistance *per se* changed the relationships between employers and family members and friends over time.

Social Connections

For the most part employers identified a wide range of people with whom they were in regular contact, people who were centrally important and others who were typically met in 'public' circumstances such as work colleagues and shopkeepers often outside of the home. The latter are the subject of Chapter 9; here the emphasis is on people identified as personally important; those with whom employers had strong ties. The boundary between the two sets of people was obviously not fixed; social networks changed, particularly in the case of friends, as has been shown to be usual among the general population, with ties becoming

stronger or weaker (Allan, 1996; Pahl, 2000; Wellman et al., 1997). Relationships with family members tended to remain more constant over time.

All respondents in the study had social relationships that were important to them, although two employers were very socially isolated. Christine lived in a rural area that was geographically quite difficult to reach and had few personally valued contacts with others beyond her personal assistant, neighbours and a former assistant who was a friend. Graham lived with his wife, also in an isolated rural area and the couple had no friends or contact with family members. Others described several to many important people. There were variations in terms of network density, strength of connections and closeness and distance. Employers were more likely to be single than were personal assistants and family members / friends (see Appendix 1). This being said there was a wide variety of household arrangements, reflecting societal trends with regard to diversity of living arrangements among the general population as well as disabling experiences following the sudden onset of impairment for some. Family relationships ranged from close and supportive to openly hostile and there were also differences in relationships with particular family members. Because friends were more freely chosen, relationships tended to be more uniformly agreeable, but for some there were difficulties as well as supportive connections.

Prior to receipt of direct payments many family members and some friends of employers had been involved in providing assistance to disabled relatives / friends on a regular basis and respondents did discuss relationships in these terms. It should be noted from the outset however that this was by no means the only dimension to interpersonal relationships; there is a risk of overemphasising the issue of assistance, a trend that is clear in much of the sociological literature (see Chapter 2). In reality, the mapping exercise carried out during the interviews with employers (see Appendix 2) gave rise to many stories about people and events that had very little to do with impairment, disability or assistance and much more to do with daily social life in general (see also Watson, 2002).

There is a public dimension to these issues because questions about 'care' and what families should do have been hotly debated (Lloyd, 2000; Morris, 1997a,

2004; Ungerson, 1997) and policy interventions have sought to influence family and household arrangements (Department of Health, 1996). Respondents were aware of these wider debates and some took points of view in relation to them.

Previous Assistance Arrangements

Several family members had provided significant support to disabled people prior to direct payments. By 'significant support' what is meant here is help with practical, physical aspects of daily living that was given regularly to disabled people and which may be distinguished from the reciprocal exchange of smaller favours either on a one-off or longer-term basis. The most frequent source of this help was from family members and it varied according to individual circumstances, in terms of who was available, and the position in the life course. Younger people were more likely to receive help from mothers; those without good relationships with parents or who were older were more likely to receive assistance from minor or adult children. Siblings also provided assistance although relationships here were less certain, with supportive siblings being contrasted with those who were deemed to be unhelpful. Sources of support shifted over time. Four disabled men had received significant help from their spouses or partners at one time, or continued to receive it, and one disabled woman continued to receive significant help from her husband. Two female employers had relied on neighbours and four had previously received no other help except from formal services or volunteers. Living in the same household was the most likely indicator of practical assistance.

It was not easy to separate out support from social relationships more generally, although some respondents tried to do so. Disabled parents stressed that their relationships with children had 'always been good' and were more likely to portray their relationships as essentially unchanging with regard to this. Several employers had parents who themselves needed more assistance with advancing years and here earlier patterns and the balance of assistance often altered. Other respondents discussed changes in the quality of their relationships, which they attributed to direct payments. Nevertheless, for employers there was a balance to be had

between being able to live and get on with things and their reluctance to rely on receiving help from others that they might not be able to reciprocate.

Losing Social Relationships and Gaining 'Care'

The sudden onset of impairment resulted in changes in the social networks of employers. People with acquired impairments often experienced a decline in the number of friends as well as close personal relationships. As Tom pointed out:

'The initial response was for everybody to gather round and support. And say 'I'll be here for you' and 'things will work out'. But very quickly that support withdrew when they realised it was a permanent issue.... And you end up with less and less contact. Until you get to the point where you're dependent on your tied contacts, i.e. friends and family. But even then, if your marriage isn't strong enough.....Marriages break up..... And then there is the demand for dependency - on the institutional side of it. The people who are then tied to them through professionalism, i.e. the doctors, the support workers, anybody else. Then, you come out into the community and you're left with a situation where you haven't got any tied support and your social circle has disappeared. You have nobody to call on except professional groups. And that's where institutionalisation begins to creep in.' (Tom, employer)

Decrease in support in the private sphere through the disappearance of family and friends was accompanied by the increase in interest from the public sphere - for 'dependent' people potentially of value to service workers as a source of income (Barnes, 2000). Options could become limited as disabled people were left with fewer allies.

For other respondents, loss of friends following acquired impairment was accompanied by increased reliance on close family members. Such new arrangements often presented problems in that they encroached on the lives of both parties to an extent that they did not welcome. Following his car accident, David's brother and sister-in-law were presented with a threat concerning his well being in order to coerce them into providing him with a home:

David: 'When I first came out of hospital my brother and his wife looked after me, and it lasted 6 years..... but it put his wife really in a spot, which I don't think was right... they said 'well, if you can't look after him, we'll have to put him in a home somewhere.' So they really tied my brother's wife's hands.

And not being a blood relative as well, she found it a bit hard to cope with. But it was a good thing really, because it made me go down a track that I'm on now.'

Sarah: What happened after that?

David: 'We had a bit of a falling out... I think it was just getting on top of both of us....I did put her in a situation where it was a bit unfair really...It forced her.... In the end though, we didn't fall out over it, which is a good thing..... It weren't just because she hated me, or anything like that, she'd just had enough really. And I can certainly see why.'

Employers who had experienced impairment from birth did not face such sudden social network changes but were more likely to have had geographically dislocated childhoods; Judith, aged 49, had spent six years in hospital from the ages of 6 to 12:

'Then I came home and I had all these brothers and sisters that I hardly knew. They did come for the odd visit, but it was a time when children..... weren't really allowed, but they did come. And my parents didn't come very often because they had all these kids at home and visiting was like three times a week and that was it. And no parents at Christmas.' (Judith, employer)

Other employers had been sent to residential schools away from their home areas when young, also disrupting family relationships. Younger respondents such as Neil, although still living at home, had had to attend special schools away from the immediate locality, which meant that they did not get to know other children in the neighbourhood. These accounts concur with the findings of other studies (e.g. Barton, 1995; Lyons et al., 1995; Morris, 1997b).

The Perspectives of Family Members

The family members interviewed universally welcomed personal assistance. (Some employers did discuss instances where family members had been opposed to outside assistance in the past and where their relationships were personally valued there were no instances where people had gone against these wishes. It was therefore not totally surprising that the relatives interviewed were in support of the current arrangements.) Family members who lived in the same household as their disabled relatives generally provided substantially more help than those who lived elsewhere.

Jonathan had provided substantial assistance to his mother Kathryn over a number of years. Living at home as a teenager he had had to assist with some things that he would have preferred not to do, such as helping with bathing;

‘It’s a bit difficult... having to like undress your mum and put her into bed and there was some ikky stuff that you really just shouldn’t have to deal with when you’re a teenager. And I felt I couldn’t go out and do the stupid, rebellious teenage stuff, but at the same time I didn’t really want to. I think I always came up with a mindset of ‘if I don’t do it, who’s going to?’ (Jonathan, Kathryn’s son)

Similarly, Naomi had assisted her mother Jean before she left home. She found the experience difficult, in part because she was on her own, her brother Paul having left home a few years earlier:

‘I couldn’t stop crying. Because you don’t see an end to it. It’s like you’re there 24/7. When you’re at work you come home and what do you do? You feel you can’t go out.... you’ve got to stay in because there’s nobody else to do for your mum. I loved her so I did for her. But I couldn’t cope.’ (Naomi, Jean’s daughter)

Although both were adult children who assisted their mothers, Jonathan and Naomi had different experiences due to the amount of help that they themselves received from other family members. Two half-sisters lived in close proximity to Jonathan and Kathryn during the time he lived with his mother, and they reliably helped on a regular basis. One of these sisters received a ‘carers’ allowance in recognition of her help. Naomi helped her mother on her own; although her brother lived in the locality he assisted more sporadically after moving out. Two other women also mentioned the lack of help they received from others:

‘Things were terrible....I’d worry meself all night long and all the rest of it. And I don’t think men accept it the same as women. When you’ve got five teenagers, that you wanted to be on the right road....I’ve got good children. It was a shock - I had a nervous breakdown, and my husband was quick tempered and was shouting. He was always out working....but I don’t think they understand what you go through, watching your son suffer. I mean, he must have watched him and suffered in his way but threw it to one side. I coped with it.’ (Jessica, Alan’s mother)

‘You’d been at work all day and me dad wouldn’t be home from work yet and I used to get really annoyed that my brother had been sat on his backside all day and hadn’t thought even to peel some potatoes, and having to think ‘oh god, what can we have for tea? What have we got that’s quick that doesn’t require three hours in the oven?’ (Marilyn, assisting her mother and working as a P.A. to Kathryn)

The Impact of Assistance on Social Relationships

The need to help disabled relatives impacted negatively on the quality of relationships. Jessica, Naomi and Jonathan retained strong and supportive relationships with their relatives throughout, but this was not inevitable. Lynne, while interviewed as an employer, had also provided assistance to her husband for many years prior to his death some years earlier. She spoke of her husband’s reluctance to have assistance from anyone apart from her, of arguments when he wanted her to do things and how their relationship had changed:

‘I would defy anybody to turn round and say at the end of it all they felt exactly the same towards their partner as they did when they walked down the aisle. Because you can’t..... During that period of nursing, something died in the relationship. I loved him and I cared for him and I wouldn’t have seen anything happen to him. I’d have shot anybody that hurt him but at the same time there was that little something where I wasn’t a wife any more, I wasn’t his girl any more - to me, my home was like a little nursing home and I was having to protect him from himself and protect him from the outside things that could harm him.’ (Lynne, employer)

A further issue was the precarious financial position that resulted for some family members. Mike also provided substantial assistance to his wife, Wendy. As a young couple, they married shortly after her injury in a car crash. He initially worked part-time and then stopped working due to the financial complications of continuing to do so. Although now in receipt of direct payments, he wanted to provide assistance and felt that ‘care workers’ were generally uninformed and incompetent. As a previously financially successful young man working in the financial services industry, he pointed out the precarious nature of his situation and of the lack of respect he was accorded:

‘The Government take advantage of it because they know that in the end you will do it for nothing because it’s part of your family.....I don’t think we’re going to get divorced and I hope we don’t, but if we did I’m potless. I’ve no

career left, I've no pension for me in the future. I've given up a hell of a lot and yet the Government say I'm worth £43.15 a week. And it does bite and it hurts. But while I'm here, yeah, great. But if things did go wrong, I'm out in the cold in a one bedroom bedsit somewhere with no job, no career, and no pension for later years.' (Mike, Wendy's husband)

The Benefits of Assisting

While these accounts highlight the difficulties experienced by family members, it should also be noted that two people, Jonathan and Jessica, pointed out the ways that they had personally gained from their experiences:

He's given me the confidence I never used to have. The confidence to go into places and look if it's suitable for him..... And he's learnt me a lot...you know, 'get going'. Like, I never drove when I found out. 'I've got to drive.....he needs me'. It gives you all that incentive to get on with life. You sit back and think, 'well, if he's done it, you can. Get on with it and do it'. So he's been very good in bringing me to the person I am.' (Jessica, Alan's mother)

'One, it helped me to become a lot more independent. It gave me a lot of living skills. I can cook, can do my own laundry, I can if I choose to (laughs) tidy up, and it also gave me a push into the career that I'm doing now..... It's also helped with other family relationships. It's brought me a lot closer to my grandma and granddad than what we used to be.... it has been of great benefit to me.' (Jonathan, Kathryn's son)

These accounts therefore provide a balance to the more negative experiences described above.

Feeling Guilty

There were several themes apparent in the interviews with family members. One of these concerned the way that people felt about assisting and the pervasive sense of guilt that they were wrong for feeling resentful:

'Sometimes I just think I feel like I was selfish. You know, me mum can't help what she's got.' (Naomi, Jean's daughter)

'You get to feel guilty at feeling annoyed. There's a huge guilt side of it for me. I used to think 'I should be happy to do these things for me mum.' But I

wasn't. The more I had to do, the more annoyed I got. The more frustrated I got. And then the more guilty I felt.' (Marilyn, providing assistance to her mother and working as a P.A. for Kathryn)

'And it was pretty much I had to do it. Because mum was daft enough that if I didn't do it she'd do it and the chances were she'd mess herself up even more and I just couldn't have that guilt.' (Jonathan, Kathryn's son)

These feelings were also associated with the sense that disabled relatives had often expected that they would do things for them, especially if they were living in the same house. They considered that it was assumed they would help and weren't asked:

'My mum.....I've seen her change from expecting me or me dad to provide support if Diane's (P.A.) not there, to asking us if we'll do something if Diane's not there. So she's gone from assuming to asking us if we will. And Kathryn's the same. She's gone from expecting Jonathan just to do something just because he's home, to asking him if he will do something.' (Marilyn, providing assistance to her mother and working as a P.A. for Kathryn)

New Family Relationships

Personal assistance was considered to have greatly improved relationships. Other benefits included being freed up from hard work and stress:

'It's a lot of stress off me. A lot of stress..... I mean there's been times when he's fell out of his wheelchair,.... just a big weight lifted off me.' (Jessica, Alan's mother)

However the strongest viewpoint was that family members could now relate to each other as such. The sense of not being under an obligation was linked closely to the notion of being a proper family member with regard to disabled relatives. In the three accounts below family members expressly counterpoise giving substantial assistance (rather than reciprocal favours) with *being* a family member:

'It (personal assistance) made it better. Because I'll go down now and if there's anything she wants doing, I'll help her out. Before it was she'd ring me up at work and say 'can you call in because I need this doing?' or 'I need that doing'. Now it's that **I'll call in because I want to go see me mum. I'm not going down because I know I have to do something for her.** I'm going

down because - like anybody would go and visit their mum, for a chat...it's made it like a hundred times better.' (Naomi, Jean's daughter) (Emphasis added)

'I mean obviously he (P.A.) doesn't do anything specifically for me but when he comes down and he's looking after Mark, it's nice that he's there to be able to take over then. **I can just be in the house with Mark as being a mother** and seeing to him, with George seeing to his needs then.' (Shirley, Mark's mother) (Emphasis added)

'I'm not a high-strung now, I'm not as snappy.....When I'm spending time with my mum, **I'm spending time with me mum**. If we've got a few hours free together I can sit and have some lunch with her and not be worrying (about doing jobs)... One of the things I used to hate was that every single day I would get a phone call. 'Can you pick up such and such a thing on the way home from work? We've run out of sugar can you get some?' And now Diane (P.A.) does all that, so I'm not dreading it when the phone rings and it comes up 'mum'. (Marilyn, providing assistance to her mother and working as a P.A. for Kathryn) (Bold emphasis added, italic emphasis in the original)

Choice and Change

Family members were in touch with disabled relatives because they wanted to be rather than because they felt they had to be. Many still did provide help and for some this was substantial. The key difference was that it was help that they considered they had chosen to do rather than help they felt they had to do. Mike for example spoke of himself as part of a couple – in terms of his family rather than assistance relationship to Wendy:

'Even though I do get a number of hours and a number of evenings, it still is a minority of the time rather than a majority, and the rest of the time I'm here. So we spend more time together than virtually any couple I know.' (Mike, Wendy's husband)

Eva emphasised that the work she did was of her own free will:

'It's all on a rota system between me and the support workers. When they're not here, I come. I wanted to do that.' (Eva, Amy's mother)

'I chose to apply for the job to support Kathryn because that's what I wanted to do for work.....I chose to take on the stresses and strains of it, whereas I didn't choose to become my mum's main carer.' (Marilyn, providing assistance to her mother and working as a P.A. for Kathryn)

As a direct result of employers' securing personal assistance, several family members had made life-altering changes in their own lives. Jonathan left the area to go to university, subsequently starting work for a social service department in a large city outside of the north west of England. He had a palpable sense of pride in Kathryn's achievements. Of direct payments he remarked:

'It's worked so well for mum, and other people that I've met who've been on it. Basically their lives have just improved beyond measure. What mum's done since she started with it has just staggered me basically. She accomplished quite a lot before she started.....but this just blows it all away. I'm just ever so proud.' (Jonathan, Kathryn's son)

Marilyn had also moved out of her mother's house and was planning to get married to her partner, while continuing to work for Kathryn. Jessica had divorced her husband, moved to a new area and was now in a relationship with a supportive partner. Naomi continued to work and was living with her partner. All remained in close contact with their relatives.

Uncertainty About the Future

A final concern however remained with regards to the stability of arrangements. Family members understood that personal assistants could not be expected to stay in the long run, but also expressed worries about insecurities:

'Nobody knows if these people are going to be with him all the time. I wish I could say 'yes, they're guaranteed a job for life' ...It worries me when he thinks there's something wrong around his help. Because there's not many people suitable for that job. He's been very lucky to get them lads.' (Jessica, Alan's mother)

'I honestly don't think I could cope now if for whatever reason, Diane left suddenly..... even the thought of having to step in and do that support in the short term, strikes terror (laughs).....because it does take over so much of your life.' (Marilyn, providing assistance to her mother and working as a P.A. for Kathryn)

These accounts point to both the concerns of family members with regard to retaining their sense of cohesion as a family and to the way that they considered the provision of long –term assistance as undermining and fundamentally opposed to their sense of doing what family members should for one another and their relationships with one another. Providing assistance to family members, as Marilyn pointed out, took away independence. What was different following direct payments was that family members no longer felt obligated. They still helped but they considered they did so through choice.

The Perspectives of Employers

If family members had struggled at times in the past, the effects on employers were no less pernicious. Disabled people have likewise pointed out how requiring help from family members beyond what the parties consider reasonable can erode the quality of social relationships (Davis, 1995). Most employers placed more emphasis on the sense of independence and freedom they experienced as a result of personal assistance rather than past difficulties. Although the experiences were similar, they discussed different aspects. Wendy was an exception and she was clear that her relationship with her husband had improved significantly since employing personal assistants in that it allowed them each time to follow their own interests and concerns. She discussed her expectations and experiences of receiving help from her husband. In the same way as for family members she considered ‘being’ a husband and wife incompatible with the assistance she received, and highlighted the sense of guilt that permeated the situation:

‘The relationship went from being a husband and a wife, to a patient - carer. And the relationship that I have with Mike, I don’t want my husband as my carer. I want a husband, not somebody that’s there just to look after me.....but now that tension, that stress part of it’s gone. And also you’ve got the guilt thing with it as well, that this guy that you’ve married is absolutely dead on his feet because you’ve had a bad night. The next day he’s got to get up and do everything all over again - cook, clean, wash...(and).. ‘it’s all my fault. I’ve had this accident and I can lie in bed and have another hour’s sleep and he’s got to get up and he’s got to take the dogs for a walk, cook the dinner, come back, go shopping’. And you’re just sat there being waited on hand and foot.’ (Wendy, employer)

Employers linked receiving assistance with the quality of interpersonal relationships but most did so less directly, by noting the continuity of relationships as well as changes. Kathryn explained her relationship with her step-daughters and one, Sandy, in particular:

Sarah: 'And what was your relationship like before getting direct payments?'
 Kathryn: 'It's different, becauseneither of them feel obligedthey don't feel as if they have to do things. Sandy.... tends to do things for me because she wants to, rather than because she has to. I think it's different, because we can be mum and daughter.because she used to be like a carer to me anyway. She used to get like a carers allowance, where she got paid. And now, we can be more like friends, which is nice. It's not really changed that much, but I'm very aware of me restrictions and we take it in our stride.'

Alan recognised the assistance his mother had given him in retrospect. He described the process of adjustment his mother went through after he started receiving direct payments:

'It was difficult for her when I got my first personal assistant because I suddenly had this personal assistant who now took over her role. It took about twelve months. She'd spent all these years supporting me, and then she didn't have anything to do because they took over. When I realised, I started making sure if we went anywhere, my mum came with us. She did basically give up work to make sure that when I needed support she was there for me. It's important to recognise that because I didn't recognise it at first. She struggled for me. She always likes to be invited anyway, but nowadays she'll say 'no, I'm busy doing something else.' Which is nice.' (Alan, employer)

Not Feeling Obligated

Employers did not appreciate feeling dependent on others and sought to limit the assistance they received from others, hence the emphasis on independence. Receiving unpaid assistance created a sense of obligation, and indebtedness, which was not welcome. The effect of this had been isolating for some employers in the past as they went without the help they needed in order not to feel obligated to others.

Some employers expressed a different view concerning other people's wish or choice to assist discussed in the previous section. Judith described how she

preferred now to rely less on family members as a result of direct payments even though they wanted to do more:

Judith: 'I am very independent really. There's times when I feel that they'd like me to need them more, but I'm not that type of person.'

Sarah: 'When you say that they'd like you to need them more, what do you mean?'

Judith: 'I think they feel that they'd like to be more helpful. And I've said 'no, that's far enough. That's enough.' I'm entitled to my own life.'

Kathryn's partner John had been keen for her to move into his house, an offer she had declined. He was ambivalent, not so much about direct payments, but about the increasing independence she had gained through working, something that personal assistance had enabled her to do:

'Yes, he's supportive. But I do feel that because I've got so much independence now, he doesn't like it as much. Because I don't rely on him. I think he'd like me to rely on him more than I do. Really he could be from that circle to that circle (referring to map). He *should* be a very important part of my life but when it comes to support, and work, then he's not as supportive as I would like him to be.' (Kathryn, employer)

Independence From the Family

Not all relationships with family members were harmonious. Aurang, a student living in the Midlands although in receipt of direct payments from a local authority in the north west, pointed out that he had fundamental differences of opinion with his parents and other relatives and this had strained their relationships:

Sarah: 'So do you see much of your family?'

Aurang: 'I don't think the same way, and I don't have much to do with them.'

Sarah: 'In what ways do you not think the same?'

Aurang: 'They think they're following Islam and I know I'm following Islam. I like lots of different people, no matter who they are. It's like reverse discrimination, and I'm not like that. They're saying things.... and it's double standards. And it's principles. I wouldn't fob them off but I wouldn't hang around with them.'

Aurang wanted to establish his own adult identity away from parents and other family members. Neil, also a student, living in his own flat near to his parents,

described shouting and arguments before he was able to move out. Being forced to live with parents was problematic for disabled young adults and their parents as it tended to push people back into earlier patterns of behaviour or to inhibit the development of adult life patterns for young adults. Although many young adults face these difficulties, the process was more difficult for disabled people because of the need for assistance. Amy had left home and worked for several years, later moving back to her parents' house after the onset of visual impairment. She resented her parents' attempts to control her eating disorder as well as impose their routines:

'They're my family, parents, and I love them and I felt safe and looked after but there was a lot of uncomfortable issues as well. I had no privacy, I'm not in my own house, I had to mind this, or the only thing I'd got in my name - it's not like I could just sit on me own and just play my music loud. I had to obey by their rules such as go to bed at this time, I couldn't eat what I wanted to eat - I couldn't just pick something. I'd have me meals made for me and I'd have to eat it. Probably nagging. I think that was the main difficulty.' (Amy, employer)

John described his family as dysfunctional. Prior to his accident family relationships had been difficult and finances strained. The award of his financial compensation resulted in a dispute and he maintained his family stole some of his money. He had given his sister and her partner £1,000 for a deposit on a house on the basis that she was providing him with assistance but they disappeared within a month of receiving the cheque. There was also little help from his mother, who as a lone parent was short of money:

'My mother thought that when I received my compensation award that she would look after the purse strings and she would just give me a bit of money. I tried to explain to her that if the money's given me it's for what I might have earned in the rest of my working life, it needs to be something that I decided what happened to, and if I was living at home then fine, it would be to everybody's benefit, and everybody would be considered, but she wouldn't be the one making the choices. And she wouldn't accept the choices.' (John, employer)

John resolved the situation by remaining in hospital until home and transport arrangements were sorted out, independently of his family. He described his lawyer at the time as a friend.

Other employers felt uncomfortable with receiving help from particular family members for particular reasons. Lisa's father had helped her for several years but buying personal items such as underwear and clothes presented problems, as she had to rely on his judgement about suitability and appearance. His alcoholism also meant that support was sporadic and not always welcome. On other occasions she received help from her sister, who lived 300 miles away:

'And when it came to actually shopping for me, I'd go down to hers on the train, and the few days that I was there, we'd have to go shopping. Really essential shopping. Not things like nice holiday shopping. And fill the suitcase up with shoes and stuff, you know. Do it that way. Even though you were going away for a break, it wasn't a break, because you were still working. And the same when she came up here. That would be the same thing. 'I need you to do this, do that' so doing things - social things just went completely. And now, because I've got the P.A.s with me, now we can do things like other people.'
(Lisa, employer)

Being a 'Proper' Family Member

Shakespeare et. al. (1996) point out that self-esteem assists with relationship formation. Direct payment arrangements allowed employers to take roles in relation to family members that they deemed to be appropriate and enjoyable, and also indicative of their proper place as a family member:

'I haven't done it very often but I could say, 'I want to spend an hour, just an hour, with Marie (grandchild), on my own, without (the rest of the family), just with me and Emma (P.A.). And I want to watch Sleeping Beauty with her. You can all go.' I can do that can't I? Well, I couldn't have possibly done that before. 'Cos I couldn't be on me own with a child, because it's dangerous for the child isn't it? If she runs off, somewhere where I can't reach her, or.... I'm not particularly strong. So you need somebody here - and it's like I've got her to meself if you like. (laughs) Well, it sounds like a proper granny doesn't it!!
(laughs) (Jean, employer)

Relief from worry was a major theme – the sense of not causing concern to others and being concerned about relatives' welfare. Ruth found her sons had felt obliged to visit each weekend, something she found stressful, and which was no longer necessary with alternative assistance in place:

'I have to say that they (my sons) are extremely overjoyed and relaxed.... since I've been choosing my own carers, with it all going through direct payments, they've been really relaxed. Indeed they've met the carers and they're very, very happy about it.' (Ruth, employer)

Disabled people were acutely aware of the strains placed on family members who were either coerced or freely gave their time to provide assistance. They sought to extricate themselves from situations where they were placed under obligation. Personal assistance opened up the possibility for the development or re-establishment of relationships based on their ideas of what a 'proper' family member should do.

While some employers found that friends disappeared after the onset of impairment, others retained strong connections. However similar issues around providing assistance remained. Employers were sometimes unsure as to whether friends were there because they wanted to be or because they felt they had to be. Kathryn pointed out, in relation to her friend:

Kathryn: 'She sees a lot of difference in me, as a person.....she says 'nobody feels obliged to have to do things for you any more because we know you can sort that out for yourself. But now, if she wants to take me shopping, she takes me shopping because she wants to.....She used to take me Christmas shopping every year. And she admitted that sometimes she didn't really want to, but she felt as if it was her duty to.'

Sarah: 'How did you feel about that?'

Kathryn: 'I was hurt really. Because I'd hate to think somebody just wants to do something because you need it. Whereas I prefer for people to do things because they *want* to do them, not because they feel they have to. Well, that hurt me quite a lot.'

Keeping the Family Together

A few employers had relied on neighbours for help before receiving personal assistance. Angela got help to look after her children or to collect them from school from other people living in her street.

'It was awkward because it wasn't necessarily other people coming in to me, it was sometimes by taking the children to their house. So that left me on me own. Someone else with my children. It wasn't what I wanted. I wanted to be mum. I wanted them here....I was grateful for the help, but it would have been

so easy to be disconnected as a family. And to me, it's important to be a family.' (Angela, employer)

Summary

Reliance on unpaid informal assistance was therefore disruptive of relationships between disabled people and family members and friends. This kind of one-way help was particularly problematic at times of transition, such as when growing from childhood to adulthood. It was not only personally difficult in terms of the unequal giving and receiving of assistance and the sense of concern that people voiced about one another's well-being, it was also physically disruptive of living arrangements, whether that was the desire to live on one's own independently or to hold a family together. Where employers had relied on others for help, whether from family members, friends or agency staff, often their lives had to be constructed around the schedules of others. A basic and important aspect was getting jobs done that had to do with the business of daily life, whether this might be washing, shopping, cleaning and so on. Having help to do these things gave space for what was seen as 'quality' time with family members and friends. Getting jobs done at times that fitted in with the ability to see family and friends enabled people to have more of a social life. For some people, personal assistance meant that they had opportunities to see other people that they would otherwise not have the opportunity to.

So far this account has discussed the changes in family and friendship relationships that were attributed to personal assistance. It should also be noted that family and friends continued to provide practical help to employers but this was largely seen as either within acceptable parameters and as something that people chose or preferred to do: this decision being a two-way process. In this sense, the public campaign by disabled people for Independent Living may also be seen as having a private counterpart of the reclamation of social and personal relationships.

However assistance, either 'private' (unpaid) or 'public' (paid) was viewed differently according to some circumstances. Issues of gender and ethnicity will be

briefly considered next, before turning to the question of how the intersection between family members and friends was dealt with and why.

Who Does and Ought to Help? Gender and Ethnicity

Literature on personal support that has focussed on ‘carers’ and the one-way nature of giving help (e.g. Carers UK, 2004; Holzhausen, 2002; Knussen et al., 2004) has tended to gloss over important aspects of interpersonal support. There was evidence of substantial reciprocal help within the sample group of respondents. Employers gave help with a wide range of things – emotional support, babysitting, lending money, driving, mending household appliances, helping friends in trouble, helping a brother to get a job, etc. These forms of help tally with kinds of help that are a typical feature of family relationships.

Gender and Assistance

Expectations about household and assisting relationships remained highly gendered. Female employers were frequently involved in providing a great deal of help to others and indeed disabled mothers often sought assistance to help with ‘caring’ for members of the household. Additionally, female employers also helped parents and older relatives who themselves needed assistance; a few providing substantial help on a regular basis. Chloe, for example although a lone parent with three disabled children, assisted her mother a day a week and also her former mother-in-law on a regular basis. Women were more likely to describe personal assistance as a resource for the family:

‘It was very hard trying to think ahead, when I employed (the P.A.s), about what we might need as a family. About what I might need as an individual to maintain that family.’ (Angela, employer)

Men on the other hand, unless they were parents, tended to seek personal assistance to help them to do things as individuals. There was also less recognition that help provided by women should be reciprocated. Several male employers described their opinions as to women’s roles in this regard:

'I've been talking to auditors off the record, they told me about things like a bloke's been on direct payments and he's been living with his wife and his wife's been caring after him and I can't understand that because that's pathetic - because she's there to look after him anyway - she's his wife. And she thinks why shouldn't she get paid for it? But that's illegal, that's wrong, it's - and there was hardly nothing wrong with him anyway.' (Neil, employer)

Alan regretted the reduced contact with other people that had resulted from receipt of assistance from P.A.s. While pleased that his mother was less involved in his support, the reduced contact with his brothers was not welcome. They visited less than in the past and he felt they should. In their defence his mother argued that with young children at home, his brothers were entitled to do less. The presence of young children was seen as a legitimate excuse (Finch & Mason, 1993). Alan's sister did continue to provide help - she would come round to his house to check things were all right on a daily basis - but he did not really recognise this as help; it was taken for granted.

Jean on the other hand was very aware of expectations other people had of her daughter in respect of providing assistance and made sure that her daughter was not placed in this position. She had essentially thrown her adult children out of her home as a prerequisite for getting statutory assistance. She understood that her daughter was expected to remain living with her in order to provide help and had tried to limit the requests made on her daughter. As well as not wanting her adult children around all the time, a sense of their well-being was important for her own as a parent:

'Everybody expected Naomi, who wasn't married; 'stay at home and look after your mum'. That's not what either me or her wanted that.' People were saying, 'I thought she would have stayed with you'. And I was saying 'no, it's not how I want her to live her life'. Because there would become the problem of me getting up stairs, getting to the bus, getting up the stair lift...., it interferes with boyfriends, and things, doesn't it? It would be; 'your mother's coming up the stairs' now wouldn't it? I wouldn't have wanted that. I like being independent and.... with me being in hospital for months at a time, then your own safety's been important. Being able to have a drink when you want. Being able to shut your eyes if you want to. And you can't do that with your children always, can you? So I like me own space too. It's just worked out very, very well.' (Jean, employer)

Fathers

Fathers were mainly absent in terms of relationships with employers. No fathers were nominated for interview and the majority were spoken of in pejorative terms. Relationships with fathers remained an issue for younger and middle aged employers whose parents were still living. Several of these employers considered their fathers to be personally unsupportive:

‘Everybody’s talking that he’s very proud of me, but he’s never ever told me that. And he criticises me. About everything. I don’t think I’ve ever sat and chatted to my dad on the phone. He’s not the kind of person you chat to... He always refers to us as - having two children and one’s handicapped. And that hurts a lot. But he’s still my dad I still love him.’ (Kathryn, employer)

‘He’s a very practical man but not very emotionally supportive, although he will talk over a drink.’ (Robert, employer)

‘You’ve got my dad who lives in a caravan and expects me to go over to see him and I can’t get in the caravan because there’s three or four steps up there. And expects the lads to put me on their back and carry me in. And if you don’t, it’s me being seen as awkward....I fight for making things accessible - Yet my own family can’t do that, especially my dad. He thinks I’m being an awkward bugger because I won’t go in his caravan.’ (Alan, employer)

In common with others, Lisa talked about loving her father but also problems involved in the relationship. Unusually, her father had helped her with some chores such as shopping on a regular basis for some time, but this had presented difficulties as well:

‘It started off very fine, but he was an alcoholic and after a while he lapsed into thinking that he could drink when he was with me and so it got very awkward at the end. So when he actually died, although it was incredibly difficult for me in practical terms, in one way it was a relief because it took the pressure off. Although I struggled by myself, to be with an alcoholic, who should be looking after you....it’s better not to have that....they’re not going to treat you right, and it’s better not to have them. So, it was very difficult at the end.’ (Lisa, employer)

Two male employers lived with their children or had shared custody, and expressed a determination to be a ‘better father’ to their children than their fathers had been to them.

Mark: 'I've got a lot of negative baggage from my long relationship with my own father and I desperately want to avoid that happening again.' (pause)

Sarah: *'When you say avoid that happening again, what do you mean?'*

Mark: 'That it will be different.'

Sarah: *'What do you hope for your relationship with your son?'*

Mark: 'I hope it will be a lot better - it can't get any worse.'

These views should be balanced by the fact that two employers did talk of their fathers as supportive. Neil, the youngest employer at 24, had appreciated the help that his father had given to him in the past with completing tax forms and other paperwork, and he kept in regular contact with him, going to see him sing at local music venues. Priti also spoke highly of her parents and did not criticise her father.

This having been said, employers talked much more about their mothers and the support they had given them over the years, both practical and emotional. The one exception to this was John, who felt both of his parents were unsupportive, and whose circumstances have been discussed earlier with regard his family stealing his compensation money.

Personal Assistance and Gender

Working as a personal assistant was considered to be women's work. From Jackie's point of view this had to do with competence. Referring to a man who had been sent by an agency:

'And then they sent a man. A man to clean up? Now come on, let's face it, I mean they're not - I think he didn't know his head from his backside. So I thought, 'this is no good.'" (Jackie, employer)

Alan employed male personal assistants and his mother Jessica noted that P.A.s often experienced a lack of respect for the work they did:

'I've found a few of the lads that works for Alan perhaps gets needled at other lads saying 'oh, you big sissy....you're working in care'.... And these lads, they're strong and they're giving a lot of assistance. And personally I think they all need a badge because the work they do is tremendous. They're helping somebody to live a normal life. And I think sometimes people should have a different outlook. Say you've got a lad in the street and he's out of work and is

like 'I'll do anything'. And then you get this lad. They both go in the pub..... And he's saying 'what do you do?' And he says 'I look after a lad - a disability lad'. 'You what?' And they look down on him. But it's the other way round I think. The lad that looks after should be looked up to. And they've got a better job than say ten other lads, because there's more involved. You can all go to work, drop your tools and leave. You can't on this. This is a job where you're giving that person a special life.' (Jessica, Alan's mother)

Ethnicity and Assistance

While the sample of ethnic minority respondents interviewed was rather too small and diverse to draw firm conclusions, a few points may be noted. Family connections spread across the UK and internationally. Priti and Najmah emphasised the importance of family obligations with regard to parents in particular. Priti, as a young professional Indian woman, was working. Najmah and Shazia, his wife, both Pakistani, maintained separate spheres. Najmah used personal assistance to get out and about: although not working he led an active life in his local community. When they were both in the home, Shazia stayed in a more private space to her husband:

Shazia: 'The way we do things is different from the way English families do things because we have purdah. If we have people there I will be in a different room to family and friends and if I serve people things I will try to do it through Najmah.'

Najmah: 'It's OK if the personal assistant is from the family but not if we don't know them. It's OK at the moment; we feel comfortable, but not completely. We say when we need them and they're not there all the time.'

The presence of an assistant in the home was deemed to be acceptable provided that the assistant was part of that private sphere (family), rather than recruited from the wider Pakistani community. As mentioned above, Najmah used personal assistance to assist his participation outside the house rather than in it, for this reason.

On the other hand Aurang (Pathan British) was seeking to keep a distance between himself and members of his family, and Judith spoke about different perspectives on disability between herself and family members in Jamaica, and between the generations:

‘Another thing about Caribbean people and disability is that it’s very sort of taboo - like the sins of the father are visited on the children etc. That’s the old way. I don’t know what newer people are like. I mean I had an auntie that wouldn’t come anywhere near me when she was pregnant. Its just ignorance isn’t it? I think it’s still there with like the older generation people. Like I never felt valued as much as the rest of the children, because I was disabled.’
(Judith, employer)

Given these rather different accounts, no generalisations can be made, except one. Three respondents, Aurang, Priti and Najmah had employed personal assistants from the same culture and deemed their understanding of the way they lived their lives to be very important. Judith employed a white woman who was deaf, remarking that on visiting Jamaica with her, people there believed her to very rich because she was able to employ a white woman. Having been mainly brought up away from her immediate family, her links with them were less strong. Nevertheless she emphasised the importance of culture and respect for this.

The public and private divide had particular salience for ethnic minority respondents because of ambivalent or hostile treatment of cultural expression in the public sphere. Recruiting assistants with the same cultural identity could circumvent these problems. Both Najmah and Aurang expressed concerns about the potential of money to change relationships but considered the alternatives to be worse. In this regard, the position of ethnic minority employers shared common ground with the position of some disabled lone parents, discussed near the end of the following chapter.

Issues of gender and ethnicity therefore intersected with beliefs about who ought to assist and the ways in which help and the amount of it should be offered. There were no particular commonalities with regard to social class. People strove for a balance in help offered to and accepted from family and friends and this was made much more possible through direct payments.

A Discussion of the Concept of ‘Care’

The experiences detailed here prior to direct payments tally with studies about how family members and disabled people feel when they feel obliged to give and

receive substantial non-reciprocal assistance to others (Galvin, 2004; Lyons et al., 1995; Parker, 1993). However the data presented here has shown two additional things. Firstly it points to changes in the quality of social relationships between employers and family members that resulted from direct payments, lending support to other studies that have detailed improvements in social life more generally (e.g. Kestenbaum, 1999) but have not described what this means for people. Secondly, it has made the point that both family members and disabled people counterpoised 'caring' with a sense of self and each other as a family member. Personal assistance changed the shape of family relationships. This was not merely to do with hours of contact: for many people the time that they saw each other decreased. It had more to do with the re-formation of ties on a different basis. Parents and adult children, for example, were able to re-form their relationships on the basis of adulthood. For some, increased independence was literally liberating, allowing an escape from oppressive arrangements.

As has been discussed in Chapter 2, there is not much, if any literature on the changed form of kin relations as a result of direct payments. There are however some implications for the concept of 'care'. The debates about this issue have been far ranging and have been discussed in Chapter 2. It is not my intention here to try to solve the dilemmas involved but to offer a perspective on the implications for the debates arising from the findings presented here. The main issue is that employers and family members considered as contradictory two aspects of 'care' that are often conflated. While 'caring for' may be separated from 'caring about' (Ungerson, 1983) and labour from love (Graham, 1983), they are both usually considered within the feminist literature to be two complimentary aspects of 'care' as a unitary concept. While some authors may point to good and bad 'caring' (see Morris, 2001a) both these fall under one roof. As the physical aspect of providing assistance diminished, so the sense of 'caring about' others increased. Family members looked forward to spending time with disabled relatives rather than felt they were spending time with them because they had to. This raises a question about how the concept of 'care' can accommodate the distinction. McLoughlin & Glendinning's work (1994) on de-familialisation (see Chapter 2) does not appear to have been followed up by others to date and there is further potential for this to be done.

Another issue concerns 'care', social relationships and the intersection with the state and social policy. While Ungerson (2005) argues, albeit tentatively, that there is potential for payment policies to shape the nature of kinship relationships, a different position has been suggested by Sevenhuisjen (2000), Tronto (1993) and others. Here the ethic of 'care' is generalised to a moral imperative concerning the well-being of others. There is a call for the political recognition of 'care' as a citizenship virtue. This is challenged by Silvers (1995) on the basis that 'care' undermines equality and Morris (2001a) on the basis of a need for the recognition of human rights. The extent to which it makes sense to talk of human rights within social relationships may be disputed. Given the discussions so far about how family relationships and friendships actually work, an assertion of rights in relation to family members would not appear to make much sense. However, these are not necessarily incompatible positions on a surface level

Simply 'caring about' people on the basis of a moral imperative does not restore balance between family members in a way that the introduction of a third factor may do. It does not address disability as a social relationship as it appears in family relationships and appealing to goodwill seems unlikely to be effective (Shakespeare, 1994), not least because much attitudinal disability is unconscious (Shakespeare, 1994; Thomas & Wolfensberger, 1999), therefore not necessarily available in a conscious debate of positions. Given the findings of this study it makes sense to assert equality and rights but in relation to social policy concerns rather than between family members. Shifting the responsibility from the private to the public sphere with regard to responsibility for assistance can thereby alter relationships in the private sphere.

Conclusion

This far, the thesis has made comparisons in social relationships between paid helpers (agency workers and personal assistants) and between disabled people and family / friends before and after the receipt of direct payments. As such it has drawn attention to some details of how circumstances altered and the meanings associated with this for the people concerned. The thesis has also pointed out the

dilemmas involved in personal assistance in the context of home, and presented the ideal types of employer – employee and paid friendship relationships as a way that employers dealt with the intersection of public and private relationships. This second theme is picked up again in the following chapter. How and why personal assistance took the shapes it did in relation to daily social life forms the subject of the following chapter.

Chapter 8

Personal Assistance, Privacy and Intimacy

Introduction

This chapter will discuss the ways that all three of the parties – employers, family members / friends and personal assistants – organised their daily lives. Friendship is a larger part of this discussion than in the previous chapter, forming the basis for a consideration of space and the overlap between personal assistants and visitors to the home. This leads on to an analysis of the ways in which structural positions as family members influenced the shape of and changes to employer – personal assistance relationships. The position of disabled parents with young children is considered next, and it is shown how their position as parents influenced the recruitment of personal assistants. Finally, dating and intimate relationships are discussed as a potentially problematic area for assistance.

Privacy

Some employers expressed the importance of having time without personal assistants:

‘While they’re in your house, your prison can become your coffin, because you can’t potter round in the way you would in your own home when you’re not being watched... It’s very, very weird having somebody in a small house like this house.’ (Christine, employer)

‘I like some days to meself.....if she wanted more hours I’d say ‘no’. Because I’m happy with what hours I’ve got. I like a bit of a rest.’ (Linda, employer)

Where employers needed a lot of assistance the constant presence of assistants could be claustrophobic but all managed to have at least some time on their own, even if it was just one hour a day. Alan, for example, while needing assistance for twenty four hours a day, arranged for two workers to be present at the times when he got up in the morning and for an hour on his own in the evening, with one worker on call should an emergency happen. This gave him some personal space in

a context where it was difficult to gain it. Lynne also pointed out that the house had to be in a reasonable state when personal assistants arrived; that it was like having visitors for a large part of the time. These points about privacy should be balanced with the observation that for many employers an issue was getting enough hours to cover the assistance they wanted or needed.

Another concern was the way that assistants might behave in the presence of social friends or the things that they might say to others. Often expressed as confidentiality, employers did not want personal assistants to discuss aspects of their lives or assistance needs with others. The most straightforward way of achieving this was to keep people separate. Judith preferred to keep personal assistants out of the conversation:

‘I wouldn’t want the P.A. saying ‘oh, she’s ever so good’ when she gets on to people..... talking about you. I don’t mind them sitting and having a beer with me but not to get involved in my conversation.’ (Judith, employer)

People with a preference for an employer – employee stance were often explicit about this:

‘It’s not that they’re in the way, but I find it a bit odd when I go to my friend’s house, because they live in London and my P.A.s can’t just go home.They’ve got to stay around, which is OK but when you want to have a gossip it’s not best that somebody’s there. Then it can feel a bit intrusive with a P.A. So I try to manage it so they go away for a bit and come back.....Or another strategy I have is - and I’m not being rude and they know that I need them around but not in my face - is for them to sit at another table. If say we were in a café or something.’ (Priti, employer)

Paid Friends and Social Friends

Paid friends were different from social friends. The following extract from an interview illustrates this point. Angela changed her mind with regard to positioning people on the chart used in the course of the interview and explained her reasons for this. In common with many other employers, she felt that personal assistants were friends to the extent that they were so central in their lives. Many would just not be able to achieve the things they wanted without them, or even be able to live. Because of this, many employers, although not all, placed personal assistants

centrally on the map used during interviews. But in terms of emotional closeness, friends were seen as more important. Social friends were prioritised over personal assistants:

‘I’ve never gone out with a P.A. and friends. Because.... that’s my friendship with my friends.....What I share with my friends, it’s generally not about something I’d choose for my P.A.s to know. Although I do share with my P.A.s, it’s on a very different level. Although they’re friends - and they are important to me, what I would choose to share outside of their hearing is very different. It isn’t anything about them, I don’t believe in breaking confidences, but I wouldn’t necessarily want them to know my feelings about things. Can I move my friends and P.A.s actually? (referring to map) Change them over....My friends are an important part of my life actually. Because they’re my social life. My P.A.s are my....day to day living. Although they enable me, my social life is better.....yes.’ (Angela, employer)

Emphasis was placed on personal assistants and friends as being qualitatively different:

‘Well they’re completely different friends. They know things that Molly (personal assistant) doesn’t know. And we talk about completely different things. There’s certain things that Molly hasn’t a clue about. And she never will. Although I’ve known Molly 17 years ...We’re not that kind ofthere’s things we all talk about - last Christmas they all got together and bought me a three quarter coat and things like that. We’re *those* sort of friends you see and there’s a different situation altogether.’ (Lynne, employer)

Other employers pointed to restrictions on the inhibiting effects of the presence of personal assistants in some social situations. Neil liked to visit friends on a regular basis and usually stayed over at someone’s house when he did. His friends provided the assistance he needed on these occasions:

‘I wouldn’t feel like I could take somebody and say ‘right, well I’m coming to the pub and we’re going to go there and we’re going to do this and it might be till 5 o’clock in the morning..... you’d feel like you owe that person a bit of respect and you’d have to calm it down and you wouldn’t be able to do the same things as you would if they weren’t there. Out of respect, you would not stay up till 5 o’clock. You’d think ‘well, they’ve got to sleep, you’ve got to calm it down a bit (laughs).’ (Neil, employer)

Keeping People Separate

If employers tended to choose between employer – employee relationships or a stance of ‘paid friend’, then the influence of close family and friends exerted a push towards the employer – employee dimension. This was because employers constructed some areas as more private than others, with family and friends being seen as more personal than assistants. Where it was possible, employers kept personal assistants and members of their family and friends separate (see also Table 1 in Chapter 6). People who received a smaller amount of assistance and people who lived on their own found it fairly straightforward to do this; they simply scheduled friends and personal assistants for different times of the day or in doing different activities. This also applied to Kate, who kept in the background when working as a P.A. for her mother-in-law. The situation was more complex for people living in households with others and for people receiving substantial amounts of help. Many employers who lived on their own described the separation of P.A.s and others as something that ‘just happened’. However employers taking an employer – employee stance were more proactive in this regard.

Employers who stressed the formal side to relationships emphasised social distance from personal assistants and this was presented as being fairly straightforward in terms of expectations of personal assistants. The employers who emphasised paid friendship with personal assistants relied more on informal procedures for maintaining separation. Several people mentioned how personal assistants ‘naturally’ withdrew from social situations where family or friends might be present. Associated with this position was a view that personal assistants were either ‘naturals’ or they were not. In these instances, personal assistants were charged with making decisions themselves. William pointed out the delicate manoeuvres that were involved here:

‘I don’t like her taking a back seat, because I think it’s demeaning...I don’t want people to think that she’s just a hired help in that sense, because she is close. Because you can’t treat her one way, as a friend, and then because you’ve got visitors in, ‘oh, sorry, no, you’re not a friend now, you’re an employee’. It doesn’t work that way because they don’t know where they stand....I don’t like it at all. She’s more conscious. She thinks she’s got to be doing something and not rest if someone’s here. That she has to work, whether there’s work to be done or not. She’ll find some stuff to do, because she

doesn't want to give the impression.....I'll say 'rest. You deserve to rest' and she won't. But that's her own way. She's very self-conscious, she's very house proud as well.' (William, employer)

With employers who stressed the dynamic of paid friendship, the expectation that personal assistants should withdraw in the company of other people was present but it was implicit rather than explicit. Those who could often used body language in preference to overt explanation. References were often made to assistants just deciding to do this themselves.

Therefore employers drew sharp distinctions between the paid friendship involved in direct payment arrangements and the social friendship of other friends. This lends support to the notions of different kinds of friends (Pahl, 2002b) as well as different degrees of public and private relationships (Lohan, 2000). In effect, employers placed tighter boundaries around private relationships - reciprocal relationships that involved a non-economic component, were judged superior, or more personally valued, than relationships that involved the exchange of help for money. Again though, personal assistance was judged highly because it was so central to existence. The reason for designating people as 'different kinds' of friends was that they offered different things. Personal assistance could be relied on in a way that help from social friends, while available, could not be in the long term:

'Before I was getting direct payments I was very reliant on friends. But they could only offer, obviously, a limited amount of help at a time. Because they had other responsibilities....I did struggle, to be quite honest, you know, where the support would come from.' (Angela, employer)

Having reliable help from personal assistants did underpin personal social friendships as well as the family relationships discussed in the last chapter. Frances, for example, pointed out that she offered to help friends with such things as driving to the airport and returned favours, being aware of the importance of reciprocity for the maintenance of friendships:

'P.A.s are P.A.s. And although I appreciate the support I think the quickest way to lose friends is to put on them and for you to always want a friend to do something for you. It's very difficult to get the happy medium whereby you're

not seen as always wanting them to do something for you. It's not that people complain about it. It's how I feel about it. It's me. Because I've always been the sort of person where, if somebody does something for you, you do something for them.....It shouldn't be all take. You should always be doing some of the giving as well, in whatever way you're able to, and contributing, because friendships.... don't just happen, you have to work at them, don't you?' (Frances, employer)

One further point may be added here. Kathryn and Marilyn had both lived in the local area for many years and knew many local people. They found that their social networks overlapped to a substantial degree although they had not known each other beforehand. There were dense network connections between their family members and friends, which they described as a 'huge tangled web'. Over the years they got to know more people who were part of this social network. The perception that they were part of the same social and neighbourhood network and social equals strengthened the bonds between the two women within the context of the home. By mutual consent it did not mean that Marilyn joined Kathryn's friendship circle during Marilyn's work time. As Kathryn pointed out:

'I see my time with that circle (friends) as being *my* time, on my own. They make it possible for me to do that - they help me get ready and they arrange things with me. But on the whole they don't have to be physically there. They are there in the background.' (Kathryn, employer)

For two people however, personal assistants were in fact part of their friendship circle. Alan and Robert both needed substantial assistance and had elected to deal with this by making them part of their personal networks. They socialised with P.A.s outside of their P.A.s working hours. Both employing a team of people, one assistant would be formally working during these times but others invited, usually to take part in pleasurable activities such as socialising in pubs or going to concerts. They employed this strategy to give themselves a sense that they were not working for 24 hours a day. While these situations also needed managing, it was felt a better solution than using a more formal employer – employee strategy. Some of the dilemmas involved with this are discussed following a consideration of the perspectives of personal assistants.

Personal Assistants' Views on Visitors

Personal assistants were more consciously aware than employers of their roles with regard to visitors in the employers' home. Almost all felt the need to stay out of the way when friends or family members arrived in the house. To do otherwise was often seen to be an intrusion and this applied equally in households that were oriented towards employment and those oriented towards friendship, although in the former often the rules were clearer and in the latter more initiative required from the personal assistant. Jean took a formal approach (employer – employee) towards assistants and one of her P.A.s remarked:

‘Usually you can tell. **If they want me to join in** they'll usually say, and I'll go and join in. Apart from that, I usually cotton on and get on with what I'm doing.....because sometimes people don't like saying, do they? That they want to speak on their own? I usually just toddle off and do me own thing.’ (Emma, personal assistant to Jean) (Emphasis added)

While Emma felt clear about when she was not expected to be present, Ellia (working for William, who took a paid friendship stance) was less so, presenting the decision to stay out of the way as her own:

Sarah: 'Would you join in when people pop round or something?'

Ellia: (pause) ‘I suppose so. I usually end up making the brews or something.....I don't always.....they may come late in the evening or weekends.....So I wouldn't say that often really, no.’

Sarah: 'And are there times when you think it's important to stand back? Keep out of the way a bit?'

Ellia: ‘Oh yes. Especially if they have close family or friends coming over, yes. **I wouldn't like to intervene really**.....you don't think you should be there.’ (Emphasis added)

Using Judgement

There were also occasions, although less frequent, where assistants who were paid friends were more actively involved in situations where family or friends were present. Typically this was in situations where employers needed more assistance or where people had busy lives for which support was needed. Although many friends

and family members did offer practical support to employers, this was variable. Some experienced assistants could read social situations and judge the degree of assistance that might be or might not be forthcoming. Marilyn, Kathryn's assistant, had accompanied Kathryn to visit her daughter and to see her son for weekends, staying with the families during these visits and pointed out how she had balanced the provision of support with sensitivity about how her presence might inhibit family conversations:

Marilyn: 'It's being able to read the situation. Like when we.... went into town shopping, and I said to (Kathryn's daughter), 'are you all right pushing the wheelchair for a few minutes while I nip in this shop here?'because maybe her kids wouldn't talk to her about something they wanted to talk about if I was pushing the wheelchair or at the side of her. I'm quite good at judging if people want time alone.

Sarah: Does that depend on the situation, or.....

Marilyn: 'I think that's from spending so much time with Kathryn over the last few years...Knowing which members of the family are more inclined to help out than others.'

The other reason given for keeping out of the way when visitors called was the competence of the employer to represent their own interests in situations where conflict might arise, mentioned by Kate, Jean's assistant and daughter in law, and Matt, Alan's personal assistant. Personal assistants were often aware of issues between employers and family members or friends. Matt, who was party to family discussions, explained how he made decisions. This involved deciding what the issues were about, the degree to which they affected him and other personal assistants, who the people involved in the discussion were and their relationship to him and Alan, his employer. The pivotal point for making a decision was the relationship between Alan and the other person(s) involved:

Matt: 'If Alan said 'I want to go to Benidorm for three weeks', and his dad said 'well I don't think you should, because you won't be able to manage'. Then I would intervene and say 'well actually, you're wrong. Because Alan will be able to manage because he'll have me and Andy to support him. So don't worry about it.' ...'..

Sarah: 'Are there times when you'd stand back?'

Matt: 'If it was personal issues to do with the family and it wasn't going to influence Alan's support, then I wouldn't really get involved. If it was Alan's argument with his mum about his diet, then I wouldn't intervene. Because it's Alan's personal choice about whether he wants to diet or not. My views on

that are that he should diet because it is influencing the support workers, because he's a big weight to carry. But you can't force Alan to have something when he wants to eat. But he must realise that these are the consequences of putting too much weight on. That there may be a point when we won't be able to do what we want to do. But I wouldn't intervene between him and his mum or whoever - it's reading the situation.'

Therefore situations varied. In employer – employee relationships personal assistants often had clear guidelines and were mostly kept separate from friends and family members, although contact did occur in all cases, however infrequently. In paid friendship relationships there was a tendency to leave the initiative to the personal assistant, but often an expectation that privacy would be accorded. Long-standing personal assistants, particularly those who were highly trusted, tended to have the most contact with friends and family and they often had subtle judgements to make about the degree and nature of their participation.

Problems with Social Friends

While personal assistants had more contact with family members than with friends, some also expressed their views on employers' friends and echoing the notion of 'different kinds of friends', relationships were not always harmonious. Status concerns were uppermost here. Marilyn spoke of having been treated rudely by one of Kathryn's friends and expressed relief that it had not caused more problems than it had:

'I was very nervous about bringing it up with her because at the end of the day it was her friend. But the next time she came round she said something, and Kathryn clocked what she'd said to me and took her to one side and told her in no uncertain terms that I deserved more respect than that. So it could have been very awkward but it turned out all right in the end.' (Marilyn, personal assistant to Kathryn)

A further point may be made in respect of circumstances where personal assistants had been friends beforehand. Laura spoke openly of her dislike for some of Chloe's friends and particularly resented being seen as a cleaner by one person:

'One friend.....she's a teacher or a lecturer, and we go in and I don't really say much in her house unless I'm spoken to. When we go in I always feel like

she just thinks I'm a cleaner. Her perspective is 'if you haven't got a degree then you're nobody.' I don't like her for who she is because at the end of the day *she's* a nobody. I mean we live in a council house. It's our own house in a council estate and so does she. But for somebody with a degree who's supposed to be ever so, so cleverI don't like her. I really don't like her. And the fact that she just thinks I'm Chloe's cleaner.....but oh, didn't I come in handy when she didn't have a car and she wanted to get to somewhere!' (Laura, personal assistant to Chloe)

Laura had retaliated by trying to emphasise her happy relationship with her husband and her successes at losing weight in front of this friend, wherever possible. She felt able to do this by virtue of the fact that she had been a friend of Chloe's previously, although she did not articulate her behaviour in this way. The friend Laura mentioned was not nominated for interview, but Carol, another friend was. Her views are included in the next section.

Family / Friends' Views on Personal Assistants

Two themes were evident in the accounts of family members and friends, although the nature of these varied according to the position of the respondent vis-à-vis the employer. Firstly, family / friend respondents welcomed the assistance and all felt that it contributed to their relationship. Family members, as has been discussed above, welcomed the fact of less physical assistance being necessary and felt that the quality of their relationships had been enhanced because of this. For friends, contact might not have been possible without the help from assistants, often through driving. Secondly respondents expressed ambivalence about their relationships with personal assistants. Three mothers (Eva, Jessica, Shirley), two spouse / partners (Joe, Mike), three children (Annette, Jonathan, Naomi) and two friends (Carol, Grace) formed this sample.

Friends

Both of the friends interviewed expressed preferences for personal assistants not to be present and this mirrors some of the negative reactions from friends described by personal assistants. Both women relied on personal assistants in order to meet their friends and acknowledged this. They did not welcome P.A.s' presence

however. Grace, who had been friends with Janice for many years had met when they worked together before they both retired. As Grace said:

‘I knew Janice for 30 years, so sometimes there’s things that we want to discuss that you don’t want to discuss with somebody else. It might be a friend that we know about, and Sheila (personal assistant) wouldn’t be interested so naturally if Sheila is with us, you talk about a certain thing - not that there’s any secrets but naturally, when you’ve known someone that long it’s nice sometimes just to see them on your own, isn’t it?’ (Grace, friend of Janice)

Carol expressed her opinions in rather stronger terms. She pointed to problems where people, such as her friend Chloe, had employed assistants who were friends prior to their employment, and felt this had a negative effect on getting jobs done:

‘On a personal level Laura’s lovely. But I think sometimes the fact is that you can get into bad habits through friendship. Things need to be done and like because you’re comfortable and relaxed things that should get done don’t.’ (Carol, friend of Chloe)

However, friendship between the employer and employee prior to employment also gave rise to the difficulties about personal assistants standing back in the context of other friendships. Laura, Chloe’s friend and personal assistant would drive Chloe to Carol’s house to visit, and when there tended to stay and join in the conversation:

‘It is different when Laura’s there. With the best will in the world it’s not as close and not as intimate, not as casual, not as....free really.... I think it does change the relationship. When I’m having a conversation with Chloe, if Laura’s there as a friend - well even if she’s not, I feel I have to include her. But as far as I’m concerned when she’s a P.A. she should not be chipping into conversation. I’m talking about something with Chloe, and it’s nothing to do with Laura, and she’s her P.A.’ (Carol, friend of Chloe)

Carol expressed ambivalent feelings about this. As a disabled parent who was considering applying for direct payments, she felt strongly about social inclusion:

‘She (Laura) gives off that feeling of wanting to be included. That’s the only way I can describe it. I feel awful about leaving her out. So that isn’t her fault, it’s maybe my perception....Because I’ve been on the edge before, and been pulled in, to actually see people on the edge is really hard. And that’s why I

know I would find it hard not to include everybody, even if they are meant to be there in the background.’ (Carol, friend of Chloe)

Only two friends were nominated for interview and here both employers tended to have friendship patterns in which friends were largely kept separate from one another and seen on an individual basis. It may be noted that one employer, Frances, had a particularly dense friendship network, where there were many overlapping connections among a large network of friends, and she stressed how personal assistants were encouraged to join in activities such as social weekends away. However the personal assistants she employed had not been friends of hers beforehand and no interviews were possible in this instance.

Mothers

Mothers expressed relief that the presence of personal assistants meant that their sons and daughters were ‘OK’. Eva (Amy’s mother) expressed different points of view. She thought it nicer if P.A.s were present for them to be invited to join in rather than be on the sidelines in a social situation:

Sarah: Say you were meeting at a pub- would they come in as well or would they wait outside or.....?

Eva: ‘I think they’d probably come in. Yes, that’s fine with us. I think it’s nicer them joining in really. It feels more....I don’t know if they’d want to do that with the family but it’s nicer. And for everybody to get to know them as well.’

In the house, Eva preferred that their paths did not cross. Eva helped Amy with cleaning on a regular basis, something she had wanted to do, and her work formed part of the scheduled rota. She also recognised that personal assistants were better placed to help with activities that her daughter was involved with outside the house:

‘I feel more at ease when they’re not here, I feel....I’m not a control freak but I feel more in control (laughs).’ (Eva, Amy’s mother)

Jessica’s account was linked to assistance her son Alan received. Because Alan needed physical help that she was not physically strong enough to provide, he had

to have assistants present when they met. She relied on her son's judgement with regard to who he employed and treated assistants as part of the family when they visited her:

'Alan's two people. It's him, and it's who's on Tuesday. That person relaxes, the same as anybody else..... you give them tea, but they're there to carry and lift him... to be around him. They're very good lads and he's got good helpers. The right age....it's not often you find good people around these days, especially with lads their age, and they're very good people. And if they wasn't Alan would get rid of them anyway. And I wouldn't be happy, but - all I worry about is that he doesn't lose them.' (Jessica, Alan's mother)

Shirley, while working alternate weekends as a P.A. for Mark, also had assistants visit when her son came, because he needed them to drive to her house. Both Jessica and Shirley lived some distance away from their sons and could see the need to entertain personal assistants within the home. They treated personal assistants as part of the family while separating the work done from the relationship they had with their sons. Other employers whose family members were not interviewed described similar instances of hospitality to personal assistants from their parents or in-laws.

Children

Two adult children, Naomi and Jonathan were interviewed and they lived in their own homes. One child (Annette) was a minor aged 12 living with her father (William) and her sister. While Jean preferred to adopt a stance of employer – employee, her daughter Naomi offered the perception that it was important for her mother to have someone to talk to as well as have someone to help with the jobs. She was aware that her mother had been very isolated in the past because of access issues in terms of getting out of the house. However her relationship with Emma, the P.A., was essentially through her mother.

Kathryn's son Jonathan, who also lived away from home, had a rather different relationship with personal assistants. He appreciated that the reason for assistants being there was to help his mother, but there was more overlap in terms of social interaction when he visited:

'I get on really well with Marilyn. We fight like cat and dog, constantly..... Brother – sister - squabble. Just constantly trying to out-insult one another. But it's all in fun. And everybody else that I've met has been great.... I've got on really well with.' (Jonathan, Kathryn's son)

The stance taken by employers here was relevant in that parents typically had more control over the nature of the relationships in their homes, and their children, adult or otherwise, tended to fit in with this ambiance. This was particularly so for Annette, who as a child, had many hours of contact with Ellia, her father William's P.A. Her view was similar to her father's in that she saw Ellia as a friend, but also resented her telling her to tidy her room, a situation made more complex by a number of factors: William sometimes did not feel up to directing the children due to mental health issues, the upstairs rooms where the children slept were not physically accessible to William, and Annette's mother, who was divorced from William, resented Ellia's presence in the house and suspected them of having an affair:

Sarah: 'Do you fall out with her?'

Annette: 'Yes.'

Sarah: 'What about?'

Annette: 'If I've done something for me dad, like helped her with anything, she won't agree with it sometimes. She'll say I haven't helped enough. That sort of thing.'

Sarah: What sort of things?'

Annette: 'Like if I haven't tidied my room but I've tidied half of it or I've tidied the carpet but I haven't tidied my bed, or something like that.'

Sarah: 'So it's things like that you disagree about?'

Annette: 'Yes. Depending on if she's in a bad mood.'

Sarah: 'And do you think it's her job to do that?'

Annette: 'I don't know really. I don't know if my dad pays her for that. She's a childminder! It's good of her to do it voluntary though.'

Sarah: 'Does she do quite a bit voluntary then?'

Annette: 'She takes us to school voluntary. She doesn't have to. She does. She had the day off today, but she still picked me up. She did take me to school.'

The situation for the children was complex. There were issues concerning the extent to which they ought to participate in housework such as tidying their rooms, and the degree to which personal assistants should be involved in enforcing this. Literature on disabled parents has emphasised the importance of support for mothers in their parenting role (e.g. Newman, 2002; Prilleltensky, 2004), including

discipline. However gendered expectations with regard to the division of labour within the home also exerted pressure on women rather than men to look after children. In this household, William, the father, had recognised the issue that Ellia had been pushed into the role of mother to the children and planned steps to clarify the situation: sorting out Ellia's pay and clarifying with the children that it was he who told them off, even if it was through Ellia at times.

Partners

Two partners of disabled women (Mike and Joe) were interviewed and their perspectives were similar in that both sought to keep themselves separate but in different ways. Both found the presence of personal assistants intrusive. Joe exerted pressure on his partner (Amy) to reduce the P.A.s' hours and his comments are included in the section on intimacy below. Mike's views shed more light on some other issues and the following extracts may be read with reference to the case study (Wendy and Samantha) at the end of Chapter 6.

Case Study: Wendy, Samantha and Mike (part 2)

Mike kept out of the way when personal assistants were present. Living in a large house, this did not present a problem as he simply went to another part of, or out of the house. Here he clarified how he saw his relationship with assistants:

'I don't have a lot of contact (with P.A.s) myself because **in the end it's to give me respite**. So when they're here, it's a waste of time (being present).....it's hard to let somebody else do something not as well as I can do it.... Because as good as any of the carers are, they're not as good at looking after Wendy as I am. I can pick her up. I can do transfers and everything more quickly, more efficient than they can.' (Mike, Wendy's husband) (Emphasis added)

'I think with Wendy's condition, I don't want to get too friendly with anybody because **I want them to know that they're the worker and we're the employer**. And it's this respect....being too family and too close. It's then that people let you down. Because they can take advantage.' (Mike, Wendy's husband) (Emphasis added)

The reader will recall that Wendy and Samantha were in informal dispute at the time of interview and that Wendy had pointed to the struggle she had to maintain a sense of home in relation to Samantha's view of the house as a place of work. Mike's perspective brings in another dimension. He sees himself and Wendy as joint employers, and argues in favour of an employer – employee stance as opposed to a friendship stance on the basis that this will make people more reliable. However ultimately the reason for the assistance is to give him respite, rather than for Wendy to have the help to do things she needs to do. There is no mention of Wendy as an employer in his interview. It is therefore difficult for Wendy to see herself as an employer in that she is not accorded this position in her relationship with Mike. In her account, direct payments have allowed Mike to take up interests such as football and fishing as well as allowing her to follow her own interests such as shopping.

It should be noted that Wendy and Mike described their relationship as strong and both were evidently committed to their marriage. There were however differences in perspective on how personal assistants should be seen and treated. Mike emphasised an employer – employee stance as more likely to engender reliability but Wendy emphasised friendship as a successful strategy that was more likely to result in flexibility, as discussed in Chapter 6.

I have used this example as a means of showing that considerations about an employer stance or a friendship stance are best seen in context. The different points of view of Wendy, Mike and Samantha go some way towards showing how uncertainties and differences of opinion can arise in working relationships in the home. This example is of a difficult situation at a particular point in time. Respondents also described past issues and how these had been resolved. Further examples are given in the following section in order to provide explanations for why working arrangements developed in the ways that they did.

Personal Assistance in a Social Context

Differences in the relationships between employers and family members / friends have been discussed above and the parties have been considered separately because

for the most part personal assistants and close family and friends were kept separate. (Two exceptions to this were where personal assistants were friends prior to employment and that prior friendship was highly valued by both parties - see the section on disabled parents, below - and where it was not possible to keep the parties separate by virtue of the amount of assistance needed by employers.) The data will be presented differently for the remainder of this chapter. A number of case studies will be used to illustrate how employee and paid friendship stances developed and longer narrative accounts or stories will be used.

As I will show, a consideration of the wider social context of private sphere relationships can offer an explanation for why employers took an employer – employee stance, preferred a paid friendship stance or moved towards the other pole during the course of the employment process. Pivotal here was the impact of wider family rather than friendship connections, Both employers and personal assistants were themselves involved in social relationships where the roles they had vis-à-vis the other party might or might not be supported by each of their family members and family members did not have to be present in order to make this influence felt. This should not be thought of as a one-way process; it was not the case that family members ordered employers or personal assistants to do certain things; rather it could be accepted because of the importance of the relationship to the people involved, or might be disputed or negotiated in the case of less centrally important relationships.

Although influence could be brought to bear from a variety of family members, spouses and partners were the primary source and the issue of gender is most pertinent here. Female employers were often simply not seen as autonomous employers by their partners, as in the case of Wendy and Mike, discussed above. Even where jurisdiction over personal assistants was accorded to the disabled woman, male partners might see this as a sub-contractual relationship within the household. While Mike saw dealing with assistants as being Wendy's domain, he described them as jointly employing personal assistants, who were ultimately there to provide him with 'respite'.

Case Study: Janice and Sheila

Janice, a woman in her 60s, had lived for many years with her husband from whom she was estranged. She remained living with her husband through lack of alternatives:

Janice: 'I haven't slept with him for about 20 years; we've got different bedrooms.... We don't go out. I don't like him! (both laugh)....A couple of weeks ago we had to go to Asda....and he caused a terrible row, so he's never coming again.... Sheila (personal assistant) thinks I should have left years ago. But it's not so easy.....talking's cheap.

Sarah: 'So what's your husband's view on you having a personal assistant?'

Janice: 'You want the truth? The relationship with him I have is that he never does anything that helps.....I find things out and I apply and get them.... I'd have a horrible life if I were left to him.'

Sheila's main job was to drive Janice so she could get out of the house, in particular to visit friends, including an ex-lover for whom she had wanted to leave her husband many years previously and with whom she remained good friends. In the event Janice had stayed with her husband both because her husband refused to co-operate with a divorce and because her son refused to leave with her. She remained on poor terms with her son and very poor terms with her daughter-in-law, who had instructed her son (Janice's grandson) not to speak to Janice if he met her outside the house. Sheila, her personal assistant, had been upset at the way that Janice was treated by her relatives and spoke of the incident:

'When Janice had the little lad (grandson) last weekend, he said 'my mum says that if we see you in Morrisons in the wheelchair, I've got to ignore you'. She was heartbroken. She was nearly crying. She said, 'why would a little lad say that?' (Sheila, personal assistant to Janice)

This then was the family context in which Janice lived. She had arranged direct payments some months prior to the interview of her own accord and employed Sheila as a driver. Shortly before the time of the interview Janice had needed to buy a new car. She took Sheila with her to test drive the one she wanted, and during the test drive Sheila complained to the salesman that the seat was too small. Janice took exception to this because she felt Sheila should have discussed it with

her instead. Later, Janice mentioned the incident to her husband, who decided to intervene, something that Janice regretted:

‘I made a big mistake; I told my husband about it and he said to Sheila, ‘if you don’t want the job....you’re supposed to be a driver’. And I said to him ‘if you do that again...’ I’m never going to tell him again, because he’s spoiled my relationship with her. She went home and her husband phoned here and he played heck. Whereas I would have dealt with it diplomatically. And I hadn’t decided on the car, but if I’d have really wanted that car then I’d have got it. She’d have had to cope. We had her husband round here saying ‘don’t shout at my wife’ and really it wasn’t a thing to do with him.’ (Janice, employer)

With Janice’s husband having argued with Sheila, Sheila’s husband joined in the fray by calling Janice’s husband up for an argument. The interview extract below is taken from a point when Sheila’s husband was briefly present:

Sheila: ‘I mean he (Janice’s husband) was very polite when I first met him, really nice. But he just went bananas. (to her husband) I was just telling this lady about (Janice’s husband) - when he was going mad about me - about Janice’s car.....’

Sheila’s husband: ‘I had to phone him up and tell him. He said ‘what’s it to do with you?’ and I said ‘excuse me! Don’t you dare say that to me! It’s my wife you’re having a go at! And he went ‘oh, right.’ And I said ‘any problems and you’d better talk to her with a bit more respect!’ And he said ‘I’ll give you back to Janice’. Oh, he’s arrogant! I feel sorry for Janice.’

This incident shows how Janice and Sheila, as well as having a relationship with each other as employer and assistant, were also positioned in households where their husbands considered it their right and duty to intervene as a family member in a way that would not be regarded as acceptable in other employment arrangements. In part this was due to the base for employment being in the house; in part it was due to overlapping contact, albeit rarely in this instance, and in part it was due to the view of the husbands that this was not really a ‘proper’ employment relationship, or if so, one that was subordinate to the women’s position as members of their respective households. Janice and Sheila resolved the situation by placing tighter boundaries around their contact – by excluding husbands from their sphere of activity:

‘I do me job, take Janice out and that’s it. I almost gave the job up because of her husband. But I’m not working for him, I’m working for Janice. I’m

looking after Janice and we get on really well.’ (Sheila, personal assistant to Janice)

This was not an isolated occurrence and there were several other instances where family members exerted their influence. In the following scenario it was the personal assistant’s husband who intervened to change the relationship rather than the employer’s.

Lynne

Lynne, an elder employer living on her own, had employed Molly, a friend who she had known for seventeen years and she described Molly’s husband as very traditional:

‘He’s got the idea that women should stay at home...It (working as a personal assistant) works perfectly because he knows where she is, and he knows the environment she’s in and he knows me. But he wouldn’t like her working in an office. She tried to work in an office and he used to pop in the middle of her working day....They used to say ‘your husband’s outside’ and she used to feel very embarrassed and packed it all in. I told her laughingly only a few months ago ‘you’ve got a lot more confidence since you’ve been coming to me’ and she has.’ (Lynne, employer)

Lynne had needed to spend some time in hospital during a period of illness. In her absence, she entrusted Molly, to look after her affairs. Molly had returned her pension book to the post office under the direction of Carl, her husband. When recovered, Lynne was upset that this action had been taken without her permission. Lynne’s solution was to put the relationship with Molly on a different footing:

‘I expect her to respect the fact that I am who I am as regards her employer, and that’s why I was so upset with regards her doing that with the pension book, without asking me.....Carl decided this was going to be done and the two of them went (to the post office)..... She should have respected the fact of who I was to her and she should have come and asked me if it was all right to do it. And then I would have said to her, ‘no, leave the book with me.’ And I would have put it in the hospital vault. But to go ahead with that at a time like that when I was absolutely imprisoned, with tubes down my stomach, with tubes down my neck... I told her when I came home, I wouldn’t expect her to do that sort of thing again.’ (Lynne, employer)

Having known Molly and Carl for a long time before their working arrangement began, Lynne used to go out socially with them to the theatre and the opera on an occasional basis. This social contact ended after the incident with the pension book. She consciously moved their position away from a stance of paid friendship towards that of employer – employee, effectively forfeiting the social aspect of the friendship. While the relationship between the women remained good, she was in the process of laying down the line with regard how she wanted Molly to look after her dog as she faced another operation in hospital in the near future.

Female Employers and Male Friends?

The employer – employee and paid friendship stances were therefore gendered. Women were over-represented among employers who stressed the formal nature of the arrangement and men over-represented among those who adopted the paid friendship stance. This finding was not expected because studies on friendship and kinship have often emphasised women's role in maintaining informal social networks (Crow & Allan, 1994), suggesting that paid friendship might be the option of choice. However the explanation may be found in the accounts that have been discussed above.

As has been shown, emphasising an employer – employee arrangement involved placing firmer boundaries of time and space around the work done. As has been argued, this perspective does accept a definition of the living space as a house rather than home, but it may also be seen as a way of carving out a space for a working relationship within the confines of a space where autonomy was more limited for women respondents who lived with their husbands. Men were in a stronger position with regard to autonomy in the home and could therefore define the place as a home while retaining influence with regard to getting jobs done. With 'caring' work defined as women's 'natural' domain, and the majority of personal assistants female, it was easier to reconcile informality in interpersonal relationships with an authority over work that ought to be done in the home. Women who lived on their own exercised more autonomy than those living with other household members and were rather freer to adopt a paid friendship approach.

Women employers presented these issues more frequently than men but they were not restricted to them. Personal assistants also gave accounts of changing relationships as a result of pressure from partners.

Bounding Paid Friendship

Pay is the boundary for paid friendship. The difference between social friends and paid friends has been described above, but the following case studies show this clearly.

Case Study: Alan, Matt and Jessica

While there were other male personal assistants employed, just one was interviewed as part of the eventual sample. Alan had employed Matt for 7 years with a break of 2 years, after which time Matt returned on a part-time rather than full-time basis. The arrangement had started very informally, with Alan seeking to introduce the families to one another. Matt pointed out:

‘One of the first things he did say was ‘you’ve got to meet all me family and it’s important for me to meet all your family for this to work.’ And I was really happy with that. I thought ‘well great, let’s meet each other, let’s all get together ...and there’d be a nice happy thing going on.’ (Matt, personal assistant to Alan)

They had initially introduced each other’s families to one another, but the process was not straightforward. It was evident from Matt’s point of view that their families were quite different from each other in terms of the ways that they interacted with one another and each family’s expectations of its members:

‘My family has never been like that. As soon as you grow up you move out, get a job and do your own thing. And my brother.... just because we haven’t spoke for two weeks doesn’t mean we’ve fell out, but if Alan’s family hadn’t spoke to each other for 2 weeks there’d be a big uproar. ‘Why’s so-and-so not rung?’ ‘I don’t know.’ ‘I rang him last week, why hasn’t he rung me? I don’t know, he’s probably fallen out with me. I’m not ringing him!’ And that’s how it is.....and I think ‘oh, god (laughs) get over it!’ But generally, as a whole,

yes, they're a great family. Just a very warm, loving family.' (Matt, personal assistant to Alan)

Further issues concerned Matt's relationship with his girlfriend:

'When I started working for Alan me hours changed....I was on a 24 hour call-out, so I couldn't really go out drinking with me girlfriend because I would have to go round there and pick him up if he fell over. So that created quite a bit of issues with me and me girlfriend. Then Alan's saying 'why didn't you invite Jenny over for the day? Well we didn't really want to go out for the day with me and Alan: she just wanted to spend the day with me.... so it's not really a good thing in my mind to involve family or close friends to who you work with, for the simple reason that it can cause a bit of uncomfortableness.' (Matt, personal assistant to Alan)

On one occasion Alan had asked Matt to help him to visit a house, outside of working hours, and although he initially agreed, Matt later refused to do this, preferring to watch a video with his girlfriend on his day off. A large disagreement ensued, culminating in Matt leaving his job and not returning for two years. Alan employed other staff before re-employing Matt and put the arrangements on a different footing:

'Alan's main thing now is his support and what he wants to do, which is great. Now if the support worker wants to involve the family, well that's fine. Alan's happy with that. He won't be saying 'look I need to meet your mum and dad because we need to get closer.' It's not really an issue....it's not really important any more..... And over the years we've both worked that out.' (Matt, personal assistant to Alan)

This provides an account of a very broad paid friendship preference that bordered on social friendship. It became a more bounded paid friendship. Alan continued to adopt a paid friendship stance despite the intervention of Matt's partner. He could do this, in comparison with the other employers discussed above because Matt's partner did not encroach on what went on in Alan's home:

'Certainly all the people I consider friends think of my P.A.s as friends, and my friends have become their friends. And my P.A.s' friends have become my friends. So, very close.' (Alan, employer)

The move from social friendship to paid friendship is summarised succinctly in the following quotation. Kinship is in the past tense and support is in the present.

In relation to the argument, Alan's mother Jessica remarked:

'So Matt worked for him for quite a while before he got another (job)..... And we were quite upset when Matt left to do another job. I mean it nearly killed Alan because I mean he was like a son to him. But he's back anyway, and he gives him a lot of support.' (Jessica, Alan's mother)

Marilyn

A rather different but related incident also illustrates the push from personal assistants to limit the boundaries of work. Marilyn, working as a P.A. for Kathryn, also lived with her mother, father and brother at the time of interview. Her mother had multiple sclerosis and Marilyn provided her with much of the assistance she needed at home. At one point adaptations needed to be done on her parents house in order make it suitable for her mother, but alternative accessible accommodation was not forthcoming and proved difficult to find. Kathryn offered to accommodate the family for a number of months and they all moved in while the alterations were being carried out. Marilyn described the strains that this caused from her point of view:

'So they moved in en masse, me mum, me dad, all our worldly goods, and three cats. It was chaos. Absolute chaos..... In all the years I've been supporting Kathryn, those three months were the hardest. Because initially, when they started work on the house, it was like a building site....All the furniture was in storage, half the time there was no electric and no water, so it really was roughing it.... If the building work was getting on me nerves any particular day then I'd sleep on the floor at Kathryn's, which meant that I was getting up in the morning, starting work, working all day with Kathryn, then staying around to do a meal for the four of us, spending what should have been my time off at Kathryn's and then putting Kathryn to bed, and then going to bed and then getting up. So I spent 24 hours a day in Kathryn's house and she found it very difficult to switch off. So if it was 8 o'clock at night and I was watching something on the telly and Kathryn wanted something doing, she was asking me to do it. In the end I had to say 'I'm knackered. Because I'm not clocking off. I'm on the go constantly from getting up in the mornings to going to bed at night.' And over the course of maybe three or four weeks, Kathryn became confident enough for my dad to do some of the support because it seemed daft on the nights that I actually stayed at home, coming back to Kathryn's to put her to bed when me mum and dad were still there and still up. So between them they sorted it out that Kathryn would get herself ready for bed and my dad would help her into bed. Which then took a bit of

the stress off me because it meant I could go home at 5 o'clock and could go and stay at a friend's and I didn't have to go back until the next morning. So that three months was the hardest for me, simply because there was no clear line between work and time off.... And I wasn't getting that time out. That might be my time out for going and doing a bit of shopping on me own or going to the library or just going for a swim or something on me own. But any free time I got at Kathryn's during that three months wasn't properly free time because my mum was there. So straight away I was going from supporting Kathryn to supporting my mum. Something as simple as finishing work at Kathryn's at 2 o'clock, and nipping to Asda and mooching round for half an hour before I went home and started doing things at home - that was my little bit of free time, my little bit of breathing space. While my mum was living with Kathryn I didn't get that. So really, that was the hardest time. There was a lot of crossed lines and crossed wires and grey areas during that time.'

(Marilyn, personal assistant to Kathryn)

Therefore personal assistants as well as employers were proactive with regard to determining the limits of friendship, including the limits of reciprocal favours, which here was more akin to work. Personal assistants as well as employers took the initiative.

New Household Members

Case Study: Amy, Joe, Anna and Eva

If relationships changed over time in relation to other people – the social networks of both employers and personal assistants - then difficulties could also arise when the composition of households changed. Amy was living on her own when she first began to employ personal assistants and formed friendships with the two women she employed, Lindy and Anna. After some time she met her fiancé Joe, who then moved into Amy's house. Joe found the presence of personal assistants rather intrusive and tried to reduce the number of hours they worked. On the other hand he appreciated the support and companionship they provided to Amy and also the assistance they offered at times when he and Amy went out together. It was acknowledged that Lindy had been put out by Joe's arrival:

'I think it was a bit funny with Lindy at first because.....I mean her and Amy are very close and she must have thought 'well, you know, coming in here.' It took a bit away from her relationship with Amy and I think for a time it might

have been a little bit awkward. But I think we adjusted to that.’ (Joe, Amy’s fiancé)

‘I think the reason that Lindy left was because...she’d been used to just her and Amy. I think because she didn’t like there being the extra work with Joe as well. I think that’s why she got another job.....Amy doesn’t know about that - it’s been said off the grapevine. (Anna, personal assistant to Amy)

All the instances discussed in this section have involved employers whose preferences involved a paid friendship stance in relation to personal assistance. While the advantages of this included more flexible assistance for employers, overlapping contact with other people in both employers’ and assistants’ social circles caused conflict at times, exerting pressure towards an employer – employee stance. Changes in these networks also influenced the assistance relationships and were resisted by assistants also.

One further issue, briefly touched on above, is considered next, because it forms a link between a consideration of the influence of personal social networks and the broader realm of ‘public’ sociability. Not all employers distinguished social and paid friendship and the reasons for this are explored next.

Disabled Parents and the Recruitment of Family and Friends

If the employers in the study managed their working friendships in ways that straddled the public and private worlds of employment and friendship, then most disabled parents clearly positioned their relationships with P.A.s in the private sphere, at least where contact with their children was involved. While fifteen of the employer respondents interviewed were parents, nine of this number had young children at home, and it is with these nine people that I am concerned in this section. Najmah and Angela both lived with their spouses and Chloe, Margaret, Mark, Lisa, William and Susan were either widowed or divorced. Carol, interviewed as a friend of Chloe’s was also a disabled parent of three young children and her perspectives are included here.

Security as a Parent

Disabled parents were clearly aware of debates about disability and parenthood and the risk that they might be construed as not being adequate as parents. The position of people living with spouses was more secure in that the family had a more traditional shape in terms of public acceptability. Angela and Najmah had both recruited personal assistants through their networks of friends. Najmah used assistance to participate in activities outside of the home; his wife undertook most of the work in bringing up the children. Angela used help to support the family and children and felt she had worked out a satisfactory arrangement in that her P.A.s would support her position as a mother to the children.

The situation of some of the lone parents was more problematic in that they felt their positions as parents were less secure.

‘I’ve always been a very independent person.....I had to struggle to keep hold of my children. I felt like they were being taken away from me and pressure was being put on. So I always feel that I have to prove to myself that I can cope andI always feel like I’m having to fight.’ (Chloe, employer)

Disabled parents were very aware that their competence might be judged harshly and were concerned that asking for help would be construed as inadequacy (see also the discussion in Chapter 2 for more details). Carol pointed out the problem of asking for help from the social service department:

‘As soon as you contact social services for help, it’s ‘child in need! Child in need! Young carer!’ ‘Excuse me! She does very little! She doesn’t actually care for me, she does the sort of jobs that I would imagine most parents would expect their children to do.’ It’s just that mine do it because they’ve always had to. But no, I’m not being fair in getting the children to do jobs. And I shouldn’t do, but it’s all because of me disability. So where do you draw the line? Do you teach them to do the jobs because they have to learn to do them, or do you not do it because it’s ‘oh god, social services will be saying I’m using them because of me disability.’(Carol, friend of Chloe)

If employers did get assistance, this was also felt by parents to cast aspersions on their ability to cope. Lisa, who was in dispute with one of her personal assistants at the time of interview was acutely aware that her estranged husband and his family

might use the fact that she received personal assistance as a weapon in their dispute:

‘The other side of the family.....say they wanted custody. I’m only talking hypothetically, but it might be an issue. Grounds to use against me to gain custody. ‘It’s the only way she could bring up a child, to have carers. How’s this going to affect her childhood as she grows up?’ (Lisa, employer)

Disabled parents hired people they felt that they could trust as personal assistants. Chloe, Margaret and Susan all employed friends they had known personally beforehand. Mark, who had custody of his son at weekends, employed his mother and sister to work alternate weekends. Angela, mentioned above, who was living with her husband, had employed her mother for a period of time when she was in hospital, specifically to look after the children.

Why Employ Family and Social Friends?

It was considered safer to employ friends and relatives. While employers did take on people who were initially strangers to assist at times when they were not responsible for the children, preference was given to family members and friends where contact with children was involved. Lisa was the only lone parent who did not, but she expressed a preference for employing family members; her problem was that she had no-one local she could call on.

The issue of control was very important for parents because of the need to be seen as responsible and in charge vis-à-vis their children, both by their children and by other people. At the same time the wish was to create and maintain a place that felt like home rather than a workplace. The apparent solution was to employ people who saw the place as a home where they were in charge, or at least where their position as a parent was not under threat. Employing family members was also mentioned as a good solution in the sense that it was felt to be more natural for the children. It meant that there was support without the need for ‘outsiders’.

Other disabled parents were in a slightly different situation. Susan employed the daughter of a friend but felt more relaxed about her role as a mother because her

son was older; 14 at the time of interview. She did not have the sense that her parenting was under scrutiny or that her son might be taken away. She was aware that he would continue to live at home for a few more years but would then leave home. William was a single father of two daughters, aged 10 and 12. He employed Ellia and had known her through her previous work for him when she was employed by an agency. His situation was also more secure in that following an acrimonious divorce from their mother, the children had been asked by the court to decide who they wanted to live with and they had elected to live with William. The courts had also stipulated that the two should not be separated nor could the children change their minds following their decision. Therefore an outsider coming into the home would be hard pressed to challenge their living arrangements.

Problems with Employing Family and Social Friends

Particular issues arose for parents who employed family members and people who were already close friends. These may be illustrated by looking at a case study.

Case Study: Chloe and Laura

Chloe employed Laura, a social friend who she had known for 20 years. She considered the advantage to be that was able to talk openly about any difficulties and to receive helpful advice from Laura. She valued the informality that came with this and felt relaxed that Laura already knew 'her ways'. She also did not feel concerned at Laura being present if, for example, she shouted at the children. One of the main problems was dealing with things not being done in the ways that she wanted:

'When she serves up food for the children she lobs it on. Now even though I can't see, the rice has got to be on the outside and the other food in the middle. Because you're trying to bring up the children....you're trying to set examples. And she'll say things like 'oh, don't make such a fuss – they're only kids – just lob it on.' (Chloe, employer)

Chloe said they had resolved these issues through discussion but these discussions were not easy for either of the women due to concerns about offending one another and losing the friendship. Therefore issues did not always get resolved:

‘That’s easily said in theory, I must admit that. Because there are some things I just *cringe* and I’m thinking to myself ‘don’t say anything’. So it doesn’t always work. Sometimes I start and I think ‘she’s looking at me a bit off, so I’d better not ask her to do anything.’ (Chloe, employer)

‘She’ll come in and she’ll say ‘oh, I feel really bad today. I just feel so tired.’ Then I feel guilty because I want her to do the ironing, I want her to clean the floor, and I don’t ask her to do it because I know what it’s like to feel tired. I know what pain is like so I don’t ask her to do things. I sit here and talk to her and we get no jobs done and I get frustrated. Then when she goes I get the mop bucket out. And that really causes me a lot of pain because I can’t bend down, I can’t clean the bathAnd that’s what the P.A.’s there for.’ (Chloe, employer)

It should be noted that Chloe was a new employer in the sense that she had only employed personal assistants for 5 months. She felt that she would do things differently in the future, that she would not employ a friend again, but was reluctant to end her friends’ employment. Dilemmas arose on a regular basis. As the mother of three boys, Chloe had asked Laura to be a godmother to her sons before she had started working for her as a personal assistant, an invitation that Laura had accepted.

Chloe: ‘It’s very difficult employing friends, because it’s crossing that barrier, isn’t it?’

Sarah: ‘What do you mean by barrier?’

Chloe: ‘Because you’re actually paying them for things. When does Laura do things because she’s getting paid for it and when does she do things as a friend?.....She’s their godmother so she’s coming to the confirmation. She doesn’t work on a Sunday. So do I make that Sunday a working day, or do I have it as a friend?...I don’t even like to think about it.....I’ll probably take the easy way out and have it as a working day. So that means she won’t come on Saturday, which means I won’t have the bath cleaned that week. Whereas if it was a P.A....’

Further problems that arose for parents who employed family and friends were that they could not be relied upon to guard confidences, especially mothers, who were used to speaking as they wanted with regard to their now adult children. During the

interview Shirley discussed several issues, such as the circumstances of Mark's divorce, which he clearly preferred not to have aired in public. Other issues mentioned included not dealing with children in the way employers wanted, again especially problematic in the case of mothers.

Strategies for Dealing with Problems

Several employers had anticipated the problems that could arise and taken action to circumvent these either before or after. Three were identified here: employing family members who were not that close, blurring the issue of employment and finding ways of getting out of the situation.

At the time of interview Angela had just ended her mother's contract of employment because she felt her mother was taking over instead of helping her in her parental role. Having considered that this might arise before the start of the arrangement, she had decided beforehand that because she was not very close to her mother anyway, it would not be a great loss.

Mark's strategy was to take precautionary measures at the beginning. Shirley, his mother, who was interviewed as part of the sample, was not clear that she was formally employed. She did not have a job description or formal contract, and thought instead that she was helping out but with her (quite considerable) travel expenses paid. This circumvented possible problems Mark foresaw when the arrangement would change in the future. Again, Mark was not very close to his mother, having spent a large proportion of his childhood in residential schools.

Chloe, whose situation has been discussed above, was in the process of re-negotiating Laura's job description (with her agreement) to provide her son with assistance instead. This essentially sidestepped the problem but it was one way of starting to address the mistake.

Summary

For a variety of reasons, disabled parents did not feel their position to be as secure as that of other employers who did not have young children. As a consequence

they tended to employ personal friends or family members in preference to strangers. While this lent some security in that they felt their children were less likely to be taken away or branded as ‘young carers’ there were particular difficulties associated with switching to a relationship based on the exchange of money and labour. Employers took precautions to minimise potential fallout, in the case of family members, or they tried to extricate themselves in the case of friends. Forming a paid friendship after formal appointment could work with careful management, but employing people who were already close friends was problematic unless people were prepared to forego the previous relationship in favour of a working friendship. Some employers, such as Lynne, who were not parents, were prepared to do this, but lone parents were not. This was due both to the need for social support as a parent and because of a sense of insecurity about their position as a parent. Direct payments to disabled parents are relatively new: many still lack information and access and support for ‘young carers’ is easier to obtain than support for parents. If their situation becomes more secure in relation to their children then it might be expected that they will have less impetus to rely on employing close family and friends.

Dating and Intimate Relationships

Of the employer respondents, seven (5 women and 2 men) were living with a partner or spouse. One woman was in a relationship with a partner who did not live with her, and the other 22 employers were single. A range of views were expressed concerning meeting new partners and intimate household relationships.

Employers’ Dilemmas

Elder single women tended to reject the desirability of forming new romantic relationships. There was recognition of the difficulties that could ensue as well as the extra workload involved because of what a new partner might expect:

‘When you’ve got the things like I’ve got, you need all your energy. If you’ve got to be thinking about somebody else all the time...I think I need all me energy to focus on being upbeat.....I don’t find enough hours in the day. So if there was somebody else there as well, it would cause friction. That

wouldn't help what I've got. Because stress is one of the worst things.... I was married for 20 years; I've got two lovely children, and I like me own space.'
(Jean, employer)

Younger employers were more likely to be actively seeking intimate relationships; Chloe's experiences have been discussed above, for example, with regard to finding potential partners and this instance also highlights a degree of uncertainty over the amount of help that might be expected of an assistant. Wherever possible, employers kept personal assistants out of the way when meeting another person for a date. As well as being concerned about personal privacy, employers were concerned that their partner might view the presence of P.A.s in a variety of unhelpful ways:

Sarah: 'And have you ever taken a P.A. with you when you've been on a date?'

Judith: 'No, never. (pause) I can see it being very awkward.'

Sarah: 'People who have to take a P.A. with them have handled it in various ways.....but I think dating is frightening enough anyway....'

Judith:...'it's terrifying! (laughs) And you can imagine people being kinky and saying 'do we get her as well!' I wouldn't do it because I don't need to do it.'

Lisa had picked up on disapproval from the man she went out with when he met her personal assistant:

Lisa: 'I have been in a situation where I've had a boyfriend, and the P.A. turned up....And he's picked up....she's not just a friend,... 'who is that woman? Because I've said 'she's a friend'. When I explain that she's a P.A. and she does bits and bobs for me, a bit of paperwork, comes shopping with me, it's been 'ooh, I don't like that'. I think it's quite off-putting. And made me think again.'

Sarah: 'Have you ever taken a P.A. with you when you've been out on a date?'

Lisa: 'No, I haven't. I suppose in new relationships people are insecure anyway. And it's like going into a three-way relationship. Like the jealousy aspect (laughs). And 'am I going out with this young woman or am I going out with someone who's being like my mother?' None of us like blokes who are mollycoddled by their mother; you think 'they can't be much'. Can't be much of a person if they let her do that. (laughs). It's very complicated.'

Some employers had had to take personal assistants with them when going on dates because there was no other option. Where possible personal assistants were

sent away for a while and then returned later on. Nevertheless the experience was still highly intrusive:

‘It’s horrible. That’s where you need to have a very good understanding with your P.A. - to be able to say ‘this is the score. I’ll text you or call if I need you’ or ‘can you go and do X, Y and Z.’ And for it to be all right...(But) even though it’s easier to talk about the negatives, the positives far, far outweigh all the negatives. If the P.A.s weren’t there, you couldn’t even get out of bed in the morning, so you need to have that perspective.’ (Mark, employer)

Other problems with dating concerned the need to consider the situations of personal assistants. At the time of interview, Kathryn was involved with a non-disabled man, and through her own choice, they lived in separate houses and she expressed ambivalence about continuing with the relationship. However she described an instance where she had gone on a date with a disabled man who also employed personal assistants:

‘One of the issues around (my friend) and going on a date, is that I’m always aware of the times that P.A.s come out. They’re used to 10 o’clock at night. Especially on a weekday I’m ready for bed. So (my friend) and I went out together during the day (laughs). We suggested doing something and he said ‘I’ll ask (his P.A.)’ and I said ‘I’ll ask (my P.A.)’ It was weird. With adults who are on direct payments, supposed to be independent, and we’ve still got to ask somebody’s permission to do something. So yes, I would say that there are major, major issues around that. Where you draw the line at where your privacy is I don’t know.’ (Kathryn, employer)

As well as the difficulties of having to involve P.A.s in this way, they had had to involve a personal assistant in helping Kathryn’s partner to get into bed, also experienced as embarrassing and intrusive. The relationship had not continued and Kathryn considered that the unease they had both felt was a major factor contributing to this. Although much has been said about personal assistants’ undoubted concerns with regards to these sensitive matters (e.g. Earle, 1999), less has been mentioned about the sensitivities of employers which merits equal consideration in this regard.

Robert described a more positive experience of going out on a date with a personal assistant present. He also noted the difficulties of the presence of a third person but considered a good balance had been reached:

‘It went quite well in that we were sat in a pub and the P.A. went and sat at the bar and talked to some friends while I sat behind with my date. If I needed him I could call on him. And you also have to consider the safety angle.’ (Robert, employer)

With regard to existing intimate relationships, Mark summed up the dilemmas involved succinctly:

‘There are three categories. First, as a P.A. user going out with someone who’s able-bodied. On one hand it’s great if your partner is prepared to support you, then you haven’t got to deal with all the P.A. issues. And there’s a down side that if you’re not careful your partner ends up becoming your P.A. and it all goes pear shaped. The other scenario is going out with someone who’s disabled but doesn’t use P.A.s, and in that scenario the issue is around not being aware of the needs of the P.A. user. And two’s company, three’s a crowd. If you’re living with someone, how far do you go in having P.A.s in to support you? And in the third scenario, where both of you use P.A.s..... On a physical level you need two P.A.s, or you need P.A.s around a lot of the time. But the downside of that is always being aware of that other person in your house, or wherever you are.’ (Mark, employer)

Assistants’ Views

Employers who were living with partners or spouses in the same household tended to keep personal assistants separate from them, as they did for other family members. This was presented as more or less unproblematic in situations that were relatively static in the sense that employers, assistants and others had worked out a balance concerning assistance and how this was managed. Some employers managed situations by presenting them as a *fait accompli*. Priti pointed out that her partner knew already that she had personal assistants before he moved in with her. Angela, Najmah and Wendy, all married, had firmly established household arrangements before they employed assistants. These arrangements were therefore a given situation and personal assistance was fitted in around them.

Amy’s situation with regard to her fiancé Joe has been discussed above and may be classed as an example of the second scenario described by Mark. Having moved Joe into her home, one personal assistant had recently left and the other, Anna, interviewed as part of the sample, expressed her concern at their friendship with

Amy having changed. However she also expressed doubts about the relationship *per se*:

‘I just think it’s Joe that pushes Amy to be more independent. He’s wanting her to work and I think Amy’s quite happy as she is. I think Joe he doesn’t understand that Amy’s only been blind 2 years. Say if you went and dropped Joe off outside a school, outside the gates, Joe would be able to get in the school on his own. If you dropped Amy off, she wouldn’t be able to get in. So they’re different and they have different needs.....It sounds an awful thing to say but I think that if they were both sighted, I don’t think they’d be together as a couple. I think Amy, before she met Joe, was very, very low, and thought that because of her blindness she would never find a partner. And I think she’s just jumped in with both feet. And I think at the moment she’s realising - everything’s rushed because the wedding’s booked for next year. Joe is very moody and sulky. If he doesn’t get his own way, he sulks. And Amy’s quite a strong person as well, and opinionated. So at the minute there are some cracks I think. They’re beginning to have little arguments. That’s a thing about the job I don’t like. Because you are in their home, they can be having an argument while I’m sat there. Well obviously it’s not nice for anybody to be in a room with two people that are having an argument. They don’t care if they argue in front of me, and I do find that a bit uncomfortable because I can’t say anything... and Joe will say to me ‘what do you think?’ I feel it’s difficult, especially if I’m supposed to be working for both of them, to give any opinion on whatever they’re arguing about.’ (Anna, personal assistant to Amy)

Although the tensions Anna felt had to do with changes in her working conditions and in her relationship with Amy, she also expressed hostility towards Joe as the cause.

Personal assistants could not necessarily be relied upon to support the intimate relationships of employers, especially where these disrupted their own friendship with employers. Priti, adopting an employer stance with regard to personal assistants, did not report these kinds of difficulties when her partner moved in with her, conceivably because there were not close friendships to displace.

Given the ambivalence partners felt about the presence of personal assistants, some employers recognised that a choice might have to be made between the two. Linda expressed this viewpoint:

‘I suppose if I started going out with somebody, he’d have to accept her as being with me as well Got to do. If he doesn’t then tough. Sorry, because

this person's more important to me. Because we might only go out for a while, and me P.A.'s more important to me. You can go and live together for a while, it's not going to say that person will stay with you. So me P.A.'s more important than men. Sorry. (laughs)' (Linda, employer)

In one instance a personal assistant, Laura, had refused to attend a speed dating event with her employer Chloe, on the basis that her husband would object. However it should be noted that some personal assistants did express concern about intimate relationships and what they might do to assist relationships.

'I've always thought Alan would be really suited if he settled down with somebody.....I wouldn't say it's awkward to talk about it, but nothing does get said about that. I think he's quite happy to just carry on as he is, but I think deep down he'd like a companion. And it's awkward for me to say 'I think you should get a companion'. And I would never do that. But if I could, I would try and help him think through that. If I could do.' (Matt, personal assistant to Alan)

Robert also talked of encouragement to go on a date from a personal assistant who he classed as a friend and appreciated assistance to get appropriate clothing that he could manage on his own for the occasion.

Summary

In summary therefore, dating and meeting new potential partners was a problematic and potentially difficult experience. Many employers would not have been able to meet others without assistance. However the presence of a third person was unwelcome from the point of view of employers and their partners, and could negatively affect how employers were viewed by their partners or potential partners. Personal assistants might also resent the appearance of another person on the scene, although others supported and encouraged sexual relationships. Employers and personal assistants did whatever they could to minimise intrusion but for some employers and their partners the degree of intrusion experienced jeopardised the relationship. Where people lived with partners and spouses, efforts to keep people separate prevailed.

Personal Assistants as Partners

Rae (1993) discusses an experience of a relationship ending following the appointment of personal assistants who assisted her partner and argues that because of the gendered nature of assistance work, disabled women may be placed at a disadvantage where their male partners recruit female P.A.s. Obviously personal assistance brought people into close physical proximity. Most single men were open to the possibility of forming romantic relationships in the future and there was a tendency to see personal assistants as potential partners. Three men had in fact formed such relationships with P.A.s – one attachment having culminated in marriage that lasted for a number of years – although no respondents were currently involved with P.A.s at the time of interview. Two male employers also expressed the opinion that employers should not ‘take advantage’ of assistants in this way. No women employers expressed a similar view, perhaps because no lesbian employers formed part of the sample and because of the gendered nature of assistance work.

One male employer did report that his ex-wife had left him: Mark and his wife had both employed their own personal assistants and Mark’s wife and one of his assistants had started an affair, precipitating their divorce. One (female) personal assistant expressed the opinion that she would see nothing wrong in forming such a relationship with her (male) employer, although her employer did not view that situation as a possibility at the time of interview.

Therefore the data from this study suggests that although there was a tendency for male employers to regard personal assistants as potential partners to a greater extent than women, it appeared that the presence of P.A.s might intrude or disrupt intimate relationships regardless of gender.

In two instances personal assistants formed intimate relationships with other family members living in the same household as the employer. This issue raised dilemmas for all involved, and could become awkward where the relationship ended but the working relationship between the employer and personal assistant continued. There were no instances where personal assistants had ceased to work as P.A.s but

continued with the relationship. Jackie, who employed Ann, expressed concern that Ann and her son might get married and that this could result in the loss of an assistant whose help she valued highly. A particular worry was that restrictions on the employment of family members might come into play and that this might cause the assistance relationship to end. In this instance the relationship had started after Ann began working as an assistant and Jackie asserted her claim:

Jackie: 'If Ann and Ewan do ever come to get married, I'd have to stop Ann. Which is not fair really. I think they should change that rule in a case like that, where I've got used to me carer. She's met me son, they're going out together, and if they get married I've got to stop me carer.'

Sarah: 'You could probably argue that.....I think that's changing now.'

Jackie: 'I hope so, because I really love Ann. I've got used to her and everything she does - she does me tax things... I'm not a stupid woman but at my time of life I don't want to be messing with all them forms. I reckoned me own up this time and I said 'is this right Ann?' And she checked it and said 'you're owed £106.43'. (laughs) I'd miss her. I don't think I'd want to take on somebody else actually.' (Jackie, employer)

Two of Jonathan's previous girlfriends had worked or were working for his mother. In one instance a girlfriend had been recruited by his mother as a result of this contact. Jonathan had moved away to a new area at the time of interview but the ending of the relationship meant the end of the working arrangement:

Sarah: 'Have there ever been any awkward situations people have had to deal with?'

Jonathan: 'Two of my ex-girlfriends were my mum's personal assistants. That got a bit uncomfortable. With one of them actually it was while I was going out with her she got the job and we broke up and she was still doing the job and things got very, very weird and basically she became unreliable and wasn't turning up when she was supposed to be there, and when she was there she wasn't doing a lot of work. That was kind of uncomfortable.'

Sarah: How did you deal with it?

Jonathan: I was down here. (laughs) I was so far removed from it!

Unsurprisingly, instances where family members and indeed employers formed intimate relationships with personal assistants were more characteristic of households where paid friendship relationships with assistants predominated.

This chapter has explored the ways in which personal assistance arrangements were located in networks of shifting connections and power relationships with

family members and friends, how they affected these relationships, were also influenced by them and the reasons why this was the case. The context here has again primarily been the private sphere, but in turn these relationships were formed in a broader context: they also extended into the public realm and back again.

Broader Issues Concerning Assistance in the Private Sphere

The discussion so far has focussed on private sphere relationships with family and social friends and on relationships with personal assistants in the home. In this section I will return to the discussion of Claire Ungerson's work, and consider how the findings from this chapter both add to and differ from her arguments.

There are ways in which the present study adds to Ungerson's findings. She notes the limited scope of her study in that it only involved interviews with personal assistants and obviously the present study gathered data from a far wider number of respondents, including employers and family members as well as personal assistants. Different forms of assistance, including that provided by private agencies, family members and personal assistants have been shown to have different meanings for the people involved.

Ungerson, while noting nuances, tends to place these different forms under the auspices of 'care', because she is keen to show how paid and unpaid 'care' work are merging. This obscures differences in meaning. As has been shown in the data above, personal assistants did not draw clear distinctions between working for an agency or working as a personal assistant, therefore it is not surprising that this did not emerge so clearly in Ungerson's data. Part of the reason for this is that she places her discussion within the sociology of work. It is taken as a given that the location is the personal assistant's workplace rather than the employers' home.

A fuller understanding may be reached by taking a broader perspective that encompasses a sociology of friendship as well as work. Because Ungerson is concerned with considering women's unpaid work in the home as part of a continuum with paid 'care' work, there is an emphasis on kinship. This approach has merit but the emphasis tends to minimise the central issue of the employment - friendship dichotomy described by respondents in both studies. Personal assistant –

employer relationships may be characterised primarily by friendship rather than kinship and respondents made clear distinctions between the two. This point leads on to some of the areas of contradiction between the studies.

One issue concerns the employment of relatives to do personal assistance work. Ungerson argues that employing relatives and friends is the option of choice for many because it can diminish the possibility of risk. As has been shown here, there were some very specific circumstances under which relatives were employed; namely the social marginalisation of the employers concerned. In particular, lone parents and ethnic minority employers were more likely to employ relatives. This was permitted at the time under what was termed 'exceptional circumstances'. Employers who either did not have children, or who had adult children, preferred to recruit people who were not family members where this was possible, because this then allowed them in fact to regain a position in the family that was valued as part of a more private part of their life (discussed in Chapter 7). Respondents in this study were asked about the alternative arrangements they would make if they were not receiving direct payments. Of the 30 employer respondents, 18 said they would have to rely on agency staff or other workers provided by social services and just 4 said they would rely on unpaid help from family or friends. Of the others, 4 said they would commit suicide, 3 had no idea, and 1 respondent said she would do without the help. This total number includes the disabled parents. Those who had employed relatives and social friends recognised the inherent problems of doing so (with one exception) and several employers pointed out that they would not make the same mistake again, so recruiting family members was hardly the option of choice that Ungerson presents. It may be noted that there is time lapse between the studies: from 1999 to 2006 so this may account for the disparity in emphasis. If so, this suggests that employers are moving away from and not towards the employment of relatives.

This is not to deny that the situation may change. In particular, the extension of direct payments to people with learning difficulties and the provision of lump sum payments such as through new initiatives currently being piloted may lead to increased numbers of family members being employed or deciding to pay themselves.

To return to the data, from the perspective of employers, personal assistance might be more correctly termed a change in a form of work rather than a hybrid form of care and work. Personal assistance was largely presented by employers and by family members as an alternative to agency workers, home helps and so on. It was not presented as a way of enabling family members to be paid except as a solution to some particular circumstances, of which assistance with young children was the most notable.

Despite the problems in Ungerson's analysis, her work has many strengths. She acknowledges the need for further research to balance her research into the experiences of personal assistants but provides a solid springboard for further clarification of the complexities involved in the intersection of home and work, or private and public relationships as commonly conceived. While not discussed here, due to the focus on European comparisons, her location of formal and informal relationships within a cross-cutting framework of policy interventions (Ungerson, 2005) is useful and informative.

Conclusion

This chapter has explored some of the complexities involved when employers' social networks are taken into account. It has pointed to the ways that both employers and personal assistants were located within structural kinship and friendship networks (Pahl, 2002a) and shown the influence of these. It has also explored how both employers and personal assistants negotiated the boundaries of paid friendship as distinct from social friendship. Specific structural locations, such as being positioned as a lone parent, led to particular forms of employer – personal assistance relationships. It has been shown that that there is more to personal assistance arrangements than simply a muddling of boundaries (Glendinning et al., 2000). Rather direct payments and personal assistance exist at a complex intersection of many influences. Another of these has to do with wider social participation and this is the subject of the following chapter.

Chapter 9

Public Sphere Participation

Introduction

Personal assistance, as has been shown both in this study and others (e.g. Glendinning et al., 2000) has the potential to widen the broader social horizons of employers, family members, friends and personal assistants. Most employers and family ‘carers’, even those who were the most socially isolated, were able to take greater part in wider activities that brought them into contact with others they had not met before as a result of direct payments. For some personal assistants the employment relationship was instrumental in that the money allowed them to finance daily living. For others the work had additional personal meaning in that they learned from the experiences and judged it useful in their own lives.

The contexts considered in this chapter mainly fall into what is termed the ‘public sector’ in the sense of Weintraub’s (1997) 3rd and 4th meanings of the term – the third meaning of ‘public’ being general sociability in the sense meant by Ariès (1962) and the 4th being the division between family and close friends and the wider economic and social order. They concern contacts with people who were sometimes, but not always, placed on the outer rings of some employers’ maps of social relationships, where such people might be professionals or work colleagues. Sometimes they concerned people who might not be placed on the maps used during interviews at all, as was the case for strangers. Five particular contexts will be discussed here: contact with members of the general public (strangers met casually or in passing), contact with professionals, with others in work and in educational (school) settings and participation in meetings with other disabled employers. Although these domains were important in that people participated in them more or less regularly, they held added significance in that they formed a context for the more important close relationships with family members and friends discussed in the previous chapter, as well as personal assistants who often were present in these places. All respondents came into regular contact with strangers, whether they interacted with them or not, all had been to school, all

except three (two young students and one 12 year old child who were in education) were working or had worked at some point in their lives. Some participated in service user groups which were more or less effective. All employers had some contact with professionals, as did family members and some personal assistants.

The discussion will move from the most formal, contact with professionals (Erault, 1994; MacDonald, 1995), to least formal settings (casual encounters), followed by consideration of intermediate places (work, education and service user groups). As will be shown, employers, personal assistants and to some extent family and friends presented themselves differently in different places. While this is usual for most people in the course of daily life, it raised particular issues for employers and personal assistants.

Personal Assistance and Professionals

The perspectives of employers, family / friends and personal assistants with regard to contact with social service professionals has already been discussed in Chapter 5. This section briefly builds on these points to add in the dimension of how relationships were presented in terms of the employer – employee and paid friendship dichotomy.

In dealings with funders and professionals, employers were aware that bureaucrats had the power to approve and withhold payments and to stipulate what funding might be used for, even though the offer of payments was now mandatory rather than discretionary. They were further aware that they received direct payments on the basis that they were deemed to be able to manage them; that professionals were in a position of power over them. The judgements of ‘care’ managers rather than employers were taken into account in determining whether continued payments would be made: appeal and complaints procedures notwithstanding. This required the demonstration of competence, which was the presentation of an appropriate employer – personal assistant relationship according to the frame of reference of social service departments. As has been shown in Chapter 5, local authorities wanted to offload responsibility by according employer status while maintaining control over arrangements. Employers were aware that it was important that their

relationships with personal assistants were seen to be about employment rather than friendship and this was the way that the situation was presented. Robert, a very experienced employer of 16 years, with a large team of personal assistants, and who expressed a firm preference for paid friendship relationships with P.A.s in his home, made these points at two different points in the same interview;

Sarah: 'What are the good aspects?' (to having personal assistants)

Robert: 'I think it's the relationship - it's that you need to have a friendship. It's intimate in one way because of the nature of the job. You've got to get on or else it won't work.'

And later;

Sarah: 'Are there any times when you would mention that he's a P.A. specifically?'

Robert: 'In things like meetings with social services I would.'

Support from P.A.s

Often there was a certain amount of collusion or shared understanding between personal assistants and employers about the need to present a certain face to professionals that might be different from the way they behaved in other circumstances. Asked how Alan, his employer, would introduce him at various times, Matt pointed out:

'If I'm in a meeting with social services I want to be seen as Alan's support worker. Because it's important they see that this is how it's working. Generally, on a day-to-day thing I don't like to be seen as Alan's support worker. I like to be seen as his assistant....Or if we're out having a drink and we meet a couple of girls, 'this is Al, I'm Matt (both laugh)' (Matt, personal assistant to Alan)

When meeting professionals, personal assistants often stayed in the background. Chloe had employed Laura, a good friend for 20 years beforehand. She made the point that even when Laura was silent in meetings with professionals, her presence was helpful. Additionally such meetings were instructive in that they helped Laura gain an understanding of the dynamics. What is also notable in the following passage is how she talked of Laura as 'the P.A.' - a more formal kind of address

than was used at other points in this lengthy interview, again pointing to the formal footing demanded by bureaucrats:

‘I think it’s been an eye-opener for the P.A. because, although they sit down and don’t say anything because they don’t know anything about it, you feel like you’ve got somebody on your side. It’s almost an advocate there, or a silent advocate. You’re not sitting there on your own: the P.A. is of silent use, if you know what I mean.’ (Chloe, employer)

Other employers had been more explicitly defended. Linda had been criticised by a member of staff at the local day centre and her personal assistant responded by sharply objecting to the man’s behaviour:

‘this bloke... just come out with such a mouthful at me, saying ‘you want to stay here, get rest, shouldn’t be going out all the time, and blah, blah, blah’, to me. And I went ‘I can’t do with this’, so I started walking away, and (my P.A.) had heard this, and said ‘you have got no right to tell Linda what she can and can’t do. She knows, if she’s tired and doesn’t feel right, she’ll say so to me. It’s got nothing to do with you.’ And I felt ‘that’s the first time someone’s ever stuck up for me’. Somebody says to him after, one of the blokes, ‘well, you’ve had your ears clipped back haven’t you?’ (Linda, employer)

Not all employers and personal assistants presented a united front in the instances where they were in conflict, for a variety of reasons. (For example, mention has already been made of an instance where Neil’s personal assistant called up a direct payments organisation to complain about a decision she disagreed with.)

Employers did not tend to involve assistants who were less supportive in meetings with funders and other officials. However it was also the case that employers who had more contact with local authority staff tended to be people who were more involved in campaigning and / or political work. These people tended to be asked to join more committees and groups, or had founded them and social services became involved subsequently. People who were active in campaigning also tended to invest much more in the education of personal assistants, so these aspects were linked. However the presentation of the relationship as an employer – employee arrangement was understood by all to be essential in these circumstances.

Confrontation with Professionals

Several employers spoke of difficult situations with doctors and other medical staff. Personal assistants might be present in these encounters and sometimes there was a need to explain who they were. Many resorted to saying that they were 'carers' because the staff did not know about personal assistance and because doctors were usually in a hurry. Admitting who the P.A. was, and why they were there, automatically implied lack of independence and competence. Employers pointed to the fact that there had been scant publicity about direct payments, in stark contrast to widespread media coverage of the 'plight of carers'. Medical staff and indeed local authority staff did not recognise disabled people as employers. Instead there was a strong sense that they were seen as 'people in need of care' or as 'vulnerable people', and often assumed to be incompetent in comparison with other patients or 'customers' (Albrecht, 1992; Hugman et al., 1997). Competence needed to be proven, or demonstrated in these encounters. Because of this, interactions were often confrontational. Jean had to go to hospital urgently on one occasion. She was driven there by a neighbour, and described their reception:

'(We) get to the hospital and this doctor kicked off..... 'Can she do this?', you know, 'can she do this?', talking to the lady, '.....what medication is she on?' I kept answering, and he kept going like that. Well in the end, the lady, who was also a nurse herself, just said to the doctor 'I'm sorry, but the lady can answer for herself', and walked away. It were the only way how to handle it, and he had to speak to me. That wasn't a nice experience.' (Jean, employer)

Although personal assistants and family members / friends could assist employers with these experiences, their presence created dilemmas both in terms of the way others perceived the employer and in terms of privacy with regard to the disclosure of information (see also Petronio et al., 2004). However the dilemma about explaining the presence of assistants was dealt with differently in other contexts. I shall now turn to the question of everyday encounters in public settings with a variety of members of the public to consider the representation of personal assistance in a different domain of the public sphere.

The ‘General Public’: Employers’ Views

The focus in this section is on the public as a general area of sociability (Weintraub, 1997) – that is, other people who included strangers and acquaintances rather than closer friends or relatives, as defined by respondents. Disability Studies literature has been consistent in pointing to the problem of disablist attitudes among members of the public (Goffman, 1968; Keith, 1996) and the data in this study did not contradict these accounts. There were some positive comments and these are presented first because the alternative, the question of how disablism was dealt with, largely shaped the question of personal assistance in this context.

Meeting People

Employers described instances where members of the public were helpful and friendly. Carol spoke about the assistance she received from transport staff while using both buses and trains, and Judith mentioned the friendliness of people on the streets of the small town where she lived. Wendy felt that there were sometimes advantages to using a wheelchair in that she could sometimes get away with things and flirt more openly with men in a way that non-disabled women could not do. Several employers took a proactive approach to talking to strangers they met in the course of daily life and spoke of the value of this in terms of expanding their horizons.

Almost all employers participating in the study had decided to take on more leisure activities that took them out of the house. Typically these included starting evening classes, shopping, going to fitness centres, cinemas and theatres and / or pubs and clubs, and this in turn allowed contact with more people. In circumstances where employers regularly met the same people over time, new and positive relationships were formed with people who became friends in some instances. Personal assistants sometimes encouraged employers to increase their range of activities and the employers in this study appreciated this. These actions included encouragement to take up swimming, joining clubs and simply going to the shops with the personal assistant rather than staying at home while these chores were done.

‘When we go (to the pictures) it’s been like over 50s.... They all know me now. If somebody’s stood there, and they see me coming, they’ll say ‘oh, we’ll move and let you sit here’ and we get talking. ‘Which film are you here to see?’ You get to meet these people.... If you miss a week it’s ‘have you not been so well, love? We kept the space for you here for you.’ (Linda, Employer)

Employers turned chance encounters into positive experiences, especially in places where they might see people on an intermittent but regular basis. Alan used a swimming pool at weekends:

‘..there’s an accessible changing room which I choose not to use, so we go in the normal changing rooms and most of the neighbourhood use them. I meet lots of people that way..... people being what they are. This lad’s having to dress me and some people just back off conversation. They get scared away - and some people ask. It’s also good as well.’ (Alan, employer)

Access and Friendship

Some employers noted changes in the way disabled people were treated on the streets in comparison with past experiences. This was attributed to improved physical access allowing people to get out more. In turn this meant non-disabled people were more accustomed to the presence of disabled people, so changing perceptions of disabled people themselves:

‘ I think things are getting better... the younger fraternity of disabled people are getting better. But the older fraternity... doctors, nurses, parents, whoever supported them - they’ve never allowed them to live their own lives I think the younger people are becoming a lot better because they’ve had a better experience. It’s still difficult.... but I think some younger people are being allowed to live their own lives like the rest of them.’ (Frances, employer)

While some employers noted positive changes, barriers of access remained in terms of gaining entry to public spaces although these were slowly changing with the implementation of measures to comply with legislation. On the other hand some employers were able to make representations about this through personal assistants:

‘When (Alan) used to go to the post office, he’d sit outside in his wheelchair. Matt would go in. And he’d say to him, ‘tell them because they’ve got this step, I can’t come in this place.’...A lot of shops don’t like it, because they don’t like paying. But it’s by law now. They’ve got to do it.’ (Jessica, Alan’s mother)

Access difficulties were problematic in terms of developing relationships in the private sphere. As Najmah pointed out;

‘I meet lots of people in the Pakistani shops and in the town centre. You always bump into someone you know. In the area where we live I know everybody. I meet people and get invited to their houses but the problem is that they are not wheelchair accessible’. (Najmah, employer)

Evidence from research into relationship formation and maintenance shows that people’s friendships are strengthened when the activities which people take part in are extended to a broader range of contexts (Adams & Allan, 1998). Invitations into the home are a powerful way of strengthening acquaintanceship into friendship, especially as homes are increasingly important places for socialising. Therefore access issues limit the depth of relationships as well as inhibiting the formation of new social relationships.

Disabling Attitudes

All employers without exception reported disabling attitudes expressly directed towards them by strangers on the street and in other public places. These experiences have been widely reported and discussed by a wide range of authors (e.g. Goffman, 1968, 1969; Keith, 1996; Murphy, 1990) and will not be reiterated in depth here. It is important to mention respondents’ experiences however, because they form an important context for the public participation of employers, family members, friends and personal assistants.

Being pitied was widely reported, especially by and in relation to women and in situations where there was not great potential for conflict such as when passing people in the street:

'I'm not embarrassed about the way I look... I just accept it..... People nudge each other and say 'look at her'. When I go to (see a friend) there's always a couple of women sat on a bench saying 'she's here again. She's come to see (her friend). Isn't it a shame? She's got a bonny face and all.' (Jackie, employer)

People reported being treated as if they had other impairments as well as those they did and resented this:

'The way people treat you out there, on your own, is absolutely diabolical. They have this inbuilt radar that seems to say 'she's disabled - she's deaf, daft and stupid.' (Frances, employer)

'I've had people saying, 'they shouldn't let people like you out'. It makes me laugh, because I'm just as intelligent, and I don't feel any worse than anybody else.' (Jean, employer)

Hostility was encountered in situations where conflicts of interests arose. While conflicts arise in many public situations, criticism singled employers out as different, using personal challenge and / or condescension:

'Went in the baker's, grabbed a loaf, there's two ladies being served, and I'm waiting in the queue. And as I come to hand the lady me loaf, a hand comes over me shoulder: a bloke. 'Oh, you don't mind' he said, 'I've got to get back to work. Some of us have to work all day'. I was furious. I turned round and I nearly threw..... I was so annoyed. 'Why do you assume that because I'm in wheelchair that I'm not working? I've got to get back to work as well.' I said 'I've got about 4 minutes to do it in so yes actually, I do mind.' It's not about 'excuse me....' And the other thing I don't like is if they say 'oh come on love, you can go before me!' because then they're assuming that the half dozen people behind me don't object to me going first. I'll wait in the queue, the same as everybody else.' (Frances, employer)

Being avoided or ignored by others;

'I think people in social settings are very uncomfortable with a person in a wheelchair. I don't think people always know how to react to you. Children will be saying 'oh, mum, why....what's...' and their mum will be saying 'oh, sssshhh'.' (Angela, employer)

So far I have offered a very brief resumé of what were very important issues universally reported by all respondents, without exception. This is not to minimise

the prevalence of disablist attitudes, but to allow for a more extended discussion of how and why employers, personal assistants, family members and friends dealt with these situations and the implications for personal assistance. Employers dealt with these incidents in a variety of ways – by ignoring the behaviour, by confronting it and by using it as an opportunity for educating people; the latter being seen as especially appropriate for children. Most employers used all three strategies, according to the mood they were in and their judgement of the situation.

Public Assumptions About Personal Assistants

Employers often went with other people into public places, whether with a family member, friend or personal assistant or both. In situations that involved interacting with members of the public – shops were cited as a particular and frequent example, people consistently addressed the other person(s) rather than the employer. Sometimes this could lead to conflict. Amy had enrolled as a member of a fitness club. When she attended, the staff there insisted that Lindy, her personal assistant, remained with her during the session:

Amy: 'I had a problem with the gym last year....I was on the exercise bike.....and for that hour I didn't really want Lindy to be there. She could come home and do some shopping or hoovering... and then come back after an hour and pick me up. Now they wouldn't allow Lindy to leave. They said she had to be there at all times, and it got into a right farce.'

Lindy: 'It was the way that he approached it. He was telling me wasn't he?'

Amy: 'Yes, he came to you rather than coming to me, and it got a bit further because I actually went to a solicitor. So I were not standing for it. I won't stand for anything if I feel I'm being discriminated against. I will say so.'

It wasn't just a matter of chance that members of the public spoke to the person accompanying the employer. They also made a judgement about the relationship between the employer and the other person, whoever they were. This assumption was that the employer was in need of 'care' or assistance and they made a value judgement about the relative importance of each of the parties:

Sarah: When you say the things that you've had to put up with, what kinds of things?

Jackie: People say 'I wonder what's wrong wi' her?'I'm getting out of t' wheelchair and people will say to Rita, 'is she all right? Can she manage?'

They don't say to me 'are you all right?' They talk over me to Rita, as if the brain's not working. And at first I used to get a bit upset about it; now I don't. I just say 'yes love, I'm fine.'

'Care' in this context was seen as a one-way process where one person was considered dependent on the work of another, often conceived as altruistic, virtuous and /or overworked. While authors have developed more nuanced definitions of 'care', which in particular seek to position the concept in a wider framework which escapes notions of dependence (Williams, 2001), this was not the understanding of 'care' on the street. Being in receipt of 'care' was not something to be proud of, both because of the assumptions by members of the public that they were dependent on the other person and the way these assumptions translated into feelings about their own situation and internalised oppression (Mason, 1992a):

'I think it's pride really. I don't like to say I've got a carer. I don't like to admit it if I'm being honest, because it makes me feel inadequate... I've always been a very independent person.' (Chloe, employer)

Circumventing Public Assumptions About 'Care'

Employers also often used the strategy of saying nothing or just referring to the personal assistant by their first name, leaving others to draw their own conclusions.

'If I bumped into anyone casually, I don't actually say 'this is my personal assistant'. Often there's no need to introduce them. Yes....I think people just sort of automatically assume that I'm with a friend.' (Angela, employer)

'And I don't think you need to tell people it's a P.A. Because I just don't think it's relevant. And I think it's more comfortable for them and for me, because you don't have to discuss it with other people if it's not relevant to the situation.' (Frances, employer)

'Other people, they don't need to know.' (Aurang, employer)

The recurring point that other people did not need to know echoed throughout the interviews. However when employers introduced personal assistants to other people, they introduced them as friends and this was a deliberate strategy. As Najmah pointed out:

Najmah: 'I introduce them as a friend because if you say 'carer', they see the situation with other eyes.'

Sarah: 'How do you think they see it?'

Najmah: 'If I say that they're a carer, they will think that I need a carer with me; that I need care.'

There were three main reasons why employers did not counter these perceptions and attitudes with the assertion that personal assistants were employees. Firstly, as mentioned above, members of the public did not know what a personal assistant was:

'If you introduce them as a P.A. then that's too complicated. You have to think. People don't really understand what a P.A. is.' (Frances, employer)

Explaining the concept of personal assistance was not easy (see Laura's account of trying to do this in the section on personal assistant's views, below). Secondly, in light of the hostile attitudes described above, there was no certainty that members of the public would support the concept of Independent Living and their position as an employer. While some might, there was a likelihood that many would not. Wallis (2000) has pointed out that relationships with personal assistants are open to a very wide variety of interpretations, including the view that personal assistants are servants, generally not something that is socially acceptable. Employers recognised this by avoiding mention of the work. On the other hand they were not prepared to step into the role of being 'looked after'. Thirdly, presenting personal assistants as employees was felt to potentially undermine a positive relationship with personal assistants, particularly in the case of employers who had ambivalent views on 'being a boss'. As has been noted above, consistency was a feature of the paid friendship stance:

Sarah: 'And how do you introduce your P.A.s to other people?'

Lisa: 'Actually as 'this is my friend' or something like that....For me it's making my life natural as well...It's very unnatural to have an assistant, like a high-powered business person...so for me, it helps to say oh, it's a friend' and I think it's nicer for the P.A. as well, because it makes them seem more natural and at ease. Not just a skivvy – there's a friendship involved as well.'

Almost all employers adopted the same strategy regarding personal assistants and members of the public – assistants were introduced as friends where there was a need to explain their presence. A few employers would add an explanation about the work done but only one employer, Priti, referred to the person with her as an assistant only. Therefore even employers who adopted an employer – employee stance in the home would often refer to the assistant as a friend when in public.

Where this was violated, employers felt strongly about the situation. They considered it to be a status issue in that it presented the personal assistant as being in a more powerful and distant social position:

Lisa: 'I suppose it's the vibes I get off the P.A.....as if to give themselves self-importance.... to make themselves look better. When I talk about a personal assistant I'll say 'it's just a friend.' People can put on self-importance can't they? And I think there are occasions when that happens. And that makes me feel small and stupid.'

Sarah: 'Can you give me an example of when they've done that?'

Lisa: 'I think one occasion is when we went to the Christmas concert. And she bumped into a friend of hers who said 'oh, what are you doing here? I'm just here with my daughter's friends'. 'I'm working' she said. And I thought 'that wasn't necessary, she could have said it afterwards'. It just made me feel really pathetic, like a user. It just wasn't pleasant.'

Kathryn acknowledged that characterising personal assistants as friends when in public situations did cause problems for P.A.s.:

'I think they actually find it more difficult than I do. Because I just call them a friend. Sometimes Marilyn's been asked 'is that your mum?' and she finds it rather funny. She says 'oh, actually, it's me boss,' - it's not nice because actually I don't see them as employees. I see them as friends who I am able to pay for being there for me.' (Kathryn, employer)

Therefore, whereas social contact with close friends and family tended to exert a pressure towards a relationship characterised by an employer – employee stance, contacts with strangers and acquaintances exerted a push in the opposite direction, towards paid friendship, at least as far as employers were concerned.

A brief mention may be made of an exception. Priti introduced her personal assistant as such rather than as a friend. She used their name and then added that

they were a P.A. Taking a firm employer – employee stance in the home, she followed this through in the public sphere. As mentioned earlier she emphasised limited engagement with personal assistants wherever possible, feeling that their presence could inhibit being able to meet new people and her relationships with others. Limiting personal assistants' presence enabled the issue of who they were to be avoided. If social friends referred to assistants as friends she considered this misguided.

The perspectives of personal assistants are reviewed in the following section.

The 'General Public': Personal Assistants' Views

Personal assistants were very aware of the attitudes of some members of the public towards employers. Furthermore they were aware of differences in the way that they and their employers were viewed.

'I think they probably feel sorry for Amy.' (Anna, personal assistant to Amy)

'I would say they pity her more than they treat her with respect. Whereas I suppose I get respect but I get treated as a - I don't like the word normal, I hate it. But if you could say that - I get treated as a normal person and she gets sort of pitied.... And it's 'sorry love, I didn't realise you can't see.' (Laura, personal assistant to Chloe)

They also understood that members of the public might assume that they were family members:

'I don't think members of the public see it as a job. I would imagine that a lot of members of the public would just assume that you were family. Probably because people always associate caring jobs with a uniform. And that's the big difference with direct payments.' (Marilyn, personal assistant to Kathryn)

Being Identified

Most personal assistants preferred that employers did let other people know that they were working. While they did not say so, it might be speculated that this was

in order to accord them some status as an employee and possibly some distance from the employer:

Sarah: 'Do you think it makes a difference if people know that you're a carer?'

Ellia: 'I think they're intrigued. Usually they know. Might just think I'm his friend. Some want to know a bit more about me but if William's introducing me to somebody he usually says 'this is Ellia, my carer.' Or if he forgets, I usually say it...'

Sarah: 'Do you prefer that when she introduces you she explains who you are?'

Emma: 'Do I prefer it? Yes. I think so. Just because it explains who you are really. What you're there for. Especially if they don't know you. Yes, it does.'

However Matt, Alan's personal assistant, expressed a different opinion;

Sarah: 'And do you think it makes a difference if people know that you're a support worker?'

Matt: 'It does, yes. When I'm out with Alan having a drink I don't like to be classed as a support worker. I'm Alan's friend.'

It might have been preferable to Matt to identify himself as a friend rather than an assistant in social situations. As discussed above, Jessica, Alan's mother, noted the stigma attached to men working as assistants with regard to gendered cultural expectations about working roles and had noted the criticism male assistants had attracted in pubs from other men. Identifying himself as a friend to other people allowed a way out of this problem.

Identifying Employers

Assistants were rather uncertain about the wisdom of presenting themselves as employees and they implicitly understood the connotations attached to 'being looked after':

'If I said 'this is Amy, my employer', then she'd probably be all right with it. But if I said 'this is Amy who I look after', she could take it wrong way and be a bit miffed I think. I say 'this is Amy' because if I see anybody, me friends and me family know obviously what I do for a living so they know who she is.' (Anna, personal assistant to Amy)

Personal assistants let others know about the work they did when employers were not present and employers deemed this preferable also. It enabled the issue of employment or 'care' to be avoided in day-to-day encounters.

One personal assistant, Laura, had tried explaining her work role to a shopkeeper:

'I said 'you know I work for her, don't you?' He says 'why? What does she do?' I said 'I'm the P.A.' He said you're a P.A?' I went 'yes, but don't worry. I'm not like a secretary P.A. I help her round the house and do her shopping and stuff.' He was like really confused because when somebody says you're a P.A. you automatically think of somebody in a general manager and secretary type of situation..... When I've said it, people sort of look at me as if 'well you're not in a suit' type of thing, because if I'm going to be cleaning I don't go nicely dressed. I go in me everyday clothes, which Chloe expects me to.'

(Laura, personal assistant to Chloe)

Even though they preferred to have their work acknowledged, personal assistants generally went along with the idea that they were a family member or friend. Therefore there was a certain degree of ambiguity in dealing with members of the public.

This issue was important because members of the public consistently saw personal assistants as being the more competent party. All assistants had experience of having questions directed towards them rather than the employer, and they developed strategies for handling this. In shops, for example, these included standing back when payment was to be made, avoiding eye contact with shopkeepers, working out in advance what help if any, was to be offered to employers during the transaction process, and redirecting the attention of shopkeepers:

'Quite frequently they will talk to me. 'That will be £26' and I'll say 'Wendy's paying'. Then they'll look at Wendy and talk to her and realise that she does have a brain and she can talk....That can be quite annoying at times. But then on the other hand you can get some that are really nice and they'll go out of their way to help.... but there are more ignorant people than there are helpful ones. (Samantha, personal assistant to Wendy)

Many personal assistants mentioned they had not understood how unpleasant some people could be until they had started working as a personal assistant; that it had opened their eyes:

‘Me, they’re all right with. But I usually get browned off because they’re not nice to Jean. So it’s opened my mind that way. Makes you think more.’
(Emma, personal assistant to Jean)

Personal assistants could be important mediators for people with visual impairments, unless the people they came across took the initiative to introduce themselves. Anna, who felt uncomfortable about some of her employer’s behaviour sometimes chose not to make another person’s presence known to Amy because of this:

Anna: ‘Sometimes if I say ‘oh, such a body’s there’ and she’ll start saying things, sometimes quite rude or nasty things out loud, so they will be able to hear her. But she thinks it’s funny. She’s not bothered because she can’t see their reactions. And it is quite embarrassing for me because I can.’

Sarah: ‘How do you deal with that?’

Anna: (laughs) ‘Well, there’s not much I can do. A lot of times maybe I’ll think if such a body’s there, and I think she might say.....I won’t say ‘oh such a body’s there’. I don’t mention it.’

This was unusual though. Other personal assistants took an active role in making links with other people. Laura, Chloe’s assistant, made sure that she pointed out people Chloe knew when they passed on the street, often describing their appearance when she sensed someone recognised Chloe. Matt pointed out that Alan now was more proactive in talking to strangers because he did so himself.

The ‘General Public’: Family / Friends’ Views

Family members and friends concurred with the views already expressed with regard to the behaviour of others they might meet and on how employers were seen. They expressed criticism of strangers who were hostile or unpleasant. The issue of who they were and how to be introduced was less problematic as there was no discrepancy between their wishes and those of their relation or friend.

One further point may be made however. There was a tendency for other people to view their presence as saintly and altruistic. This applied in particular to the two men interviewed who made specific mention of this:

‘They always think I’m a saint. Generally it’s like ‘oh, you’re so good for doing this for your mum’, or, on some occasions, for your girlfriend, which I think is highly amusing.’ (laughs) (Jonathan, Kathryn’s son)

Mike, who continued to give substantial help to his wife Wendy, graphically expressed the dilemmas involved in being treated in this way and a longer extract from the interview is included here:

Mike: ‘Everyone likes to be praised but for me, I know that if there’s two, three people in a room and one person walks out, one or two people slag off the person. It’s just normal life; it’s what people do. But if I was in a group of people and I walked out, I know that none of them would dare slag me off because all the others would say ‘he’s looking after our Wendy’. And sometimes I don’t like that, because it does leave you out of that circle.’

Sarah: ‘Like on a pedestal?’

Mike: ‘Yes! I am, definitely. Because I can’t do no wrong. Even if I did upset somebody, or I did something wrong, they would not bring that up or talk about it to somebody else, because they know how highly I am regarded in the families, and that other people wouldn’t back them up with their arguments. And it’s a privileged position if you want to call it that but sometimes I wish I didn’t have it.’

Sarah: ‘There’s a down side to it as well isn’t there? Yes.’

Mike: ‘Yes. And if I ever did let anybody down, I think it’d be such a dramatic fall. If I had an affair - bloody hell! From being up there, I’d be the worst bastard in the world. Because ‘how could he do that to Wendy; she’s in a wheelchair’. It’s not going to happen. I don’t even think about it. But I know it’s a huge fall - it’s like me brother, he had an affair. ‘Oh bloody hell, he’s a prat’. He’s split up and this and that. But then he’s forgiven. Now if I did it, I don’t know whether I would be forgiven, because of Wendy. So there’s that expectation on you as well.’

Sarah: ‘Yes. People can treat you.....’

Mike: ‘I’m hero or zero - there’s no in between. If I did anything bad, they wouldn’t say ‘oh well, he’s strayed. It’s only once; everything else has been all right.’ But with me it’s either hero or zero. And there is no ground in between.’

None of the women interviewed mentioned being seen as saintly. Again, the assumption was made that they were a member of the family or a friend, but no particular comments on this were made, reflecting views that women might be expected to assist relatives but men were somehow ‘special’ for doing this.

To summarise the issues this far, participation in community life raised the issue again of whether this was friendship or work, or public or private ground. Most employers asserted paid friendship as the defining relationship with personal assistants. Personal assistants mostly preferred that their work be recognised but did not push the issue because they were working for the employer. Recognition of the aspect of work placed personal assistance firmly into the bracket of 'caring' as far as the public was concerned, and employers did not push this issue because of lack of support for Independent Living. Instead they avoided it by referring to friendship. Family members experienced being seen as 'special' and disliked being given superior status to their relatives. On a daily basis, employers, family members / friends and personal assistants were mounting challenges to public perceptions and new relationships were formed where people met others on a regular basis through common interests.

Work and Employment

Four employers did work for which they were paid (Alan, Kathryn, Priti and Robert). Each of these people worked in middle class professions on a full-time basis. The two men were self-employed and the two women were employed by organisations, and all worked in fields that related to disability issues. Amy was due to start part-time work in a professional occupation, as a youth worker, one month following the interview. Other employers worked on an unpaid basis. Frances and John did voluntary work that was highly responsible and took up much of their week. Chloe, Jean, Lisa and Mark had set up and were involved in running or participating in voluntary organisations concerned with disability issues. Therefore people were employed, whether paid or unpaid, in a very narrow field of work. Most of the employers interviewed would have welcomed more opportunities for working.

Personal assistants did accompany employers to work and they did driving, note taking, preparation of refreshments, filing and administrative work and so on. Two personal assistants had changed their job roles in relation to their employers' employment: Matt was in the process of going into business with Alan, his

employer, on an equal footing, to set up a direct payments brokerage organisation – something he was looking forward to – and Marilyn now assisted Kathryn with administrative duties at work. Although most work colleagues knew of the working arrangement with regard to personal assistants, in some instances, such as when attending conferences, personal assistants could be described as ‘friends’ or ‘personal assistants’, according to the circumstances.

Keeping in the Background

Assistants worked in the background. Where employers worked in familiar buildings and with colleagues who were known, then many employers would ask assistants to do other jobs at home or elsewhere while they were working, and only be present at the times they were needed. Priti and Alan used mobile phones to call assistants at times they were needed during the course of the working day and others made arrangements for assistants to be ‘on call.’ There were various reasons why personal assistants might not be present. Firstly, where employers worked in familiar buildings they made environmental adjustments to remove barriers and arranged for assistance from colleagues so that assistants were not needed. Secondly it was not possible for assistants to be present in some instances. Frances noted that in some meetings it was essential that no-one additional was present because of the need for keeping information discussed confidential. Thirdly, there was a preference to keep assistants out of the way because they could hinder work. For example, John noted that some personal assistants were not interested in what he did and could appear bored in meetings and Priti found it difficult to work when someone else was sitting in the room doing nothing.

Where personal assistants were present during the working day, then most employers made sure they were silent and did not participate in discussions. One of the main issues concerned personal assistants joining in with comments to colleagues:

‘Marilyn had interrupted me and I really found it totally inappropriate. And I got in the car, and I just turned around and went, ‘don’t you fucking do that to me ever again!!!’ And she retaliated in the same sort of manner and ‘why!! What do you mean!!!’ and went ‘rrrrrrrh!’ and I told her what I thought and

she went ‘right!! I won’t!!! What did you say was for tea?’ And it just totally changed. It was like out, in the open and said it.’ (Kathryn, employer)

Employers expressed concerns that personal assistants might make contributions on subjects they knew little about and either make themselves or the employer look foolish. Assistants were briefed beforehand on how to dress and to behave in particular circumstances. There were occasions however when disputes arose, when personal assistants were deemed to have behaved wrongly and when this happened, employers were quick to point out the problem:

‘I had to rap that lady’s knuckles the other day...because she’d gone off out when I went in to me meeting, without me knowing she’d gone off out to the shops. It was the second time... and I said ‘I’ll not tell you a third time.’
(Frances, employer)

There was some matching of assistants with circumstances – it was often the more trusted and longer-standing assistants who were involved with work, rather than newer employees. This was felt important because of employers’ standing and reputation with colleagues. Work situations, in contrast with contacts with professionals and members of the public, could necessitate quick changes of face and role, and employers deemed it important that assistants could handle this in ways that did not undermine them at work. Assistants were called on to distinguish public and private spheres, the degrees of public and private matters within the public sphere and to safeguard boundaries. Robert described some of the subtleties involved:

Sarah: ‘And do Peter and Hugh (personal assistants) get involved with the other people at work?’

Robert: ‘Yes, they talk to the staff. It’s different, because I’m the boss. The staff are my staff, so there’s a different role and relationship there. But the staff get on well with the P.A.s.’

Sarah: So would P.A.s be involved in meetings, say if you were discussing policy?

Robert: ‘No, they wouldn’t get involved in speaking in meetings, unless it was for something specifically that they were asked to comment on. They keep in the background.’

Sarah: Has that ever happened?

Robert: ‘Not in a meeting. It’s happened when I was talking to someone else and one of the consultants asked Peter what he had to do for me. Peter said it was confidential and personal, which was right....it’s personal needs and

nothing to do with work.... I took it up with the consultant in question and I said that he shouldn't have asked it....It bugged me. I went to see Kathy, as chair of the organisation and as a friend. She wanted to make a complaint to the director, to say that it's not on. Peter wasn't nasty, but he stood his ground and I'm very proud of him for doing it that way. And he was right.'

In summary therefore, employers who worked were particularly concerned that personal assistants supported their work and behaved in ways that reflected positively on their standing in the organisations. One way of ensuring this was by choosing experienced assistants they could rely on to accompany them, and the other was by putting in place clear guidelines for behaviour.

Personal Assistance and Schooling

This section is particularly concerned with the experiences of parents in relation to young children's schooling. Several respondents had children who were in school and reported a range of experiences in relation to this. Employers wanted to support their children as parents while being aware that their children might be on the receiving end of teasing or criticism from other pupils. As Annette, William's 12-year-old daughter pointed out:

Annette: 'I don't like really bringing my dad to school. Like Ellia (personal assistant) coming as well. I try and ask my mum.'

Sarah: 'Why is that?'

Annette: 'Because no one else has got a dad that's disabled.....I won't be embarrassed if he did,....it's what they would say really.'

Sarah: 'What kinds of things do you think they would say?'

Annette: 'Well, there's a lot of people who show off a lot in my class.

So.....they would ask me loads of questions, and whatever I say, they would tell somebody else and it would probably go round the school.'

Sarah: 'How do you deal with difficult situations like that?'

Annette: 'I change the subject, I just don't tell them.'

Lisa credited her daughter with dealing with handling situations with diplomacy:

Lisa: 'It's complicated for her explaining it to her friends.'

Sarah: 'How does she do that?'

Lisa: 'She's wise enough to know about the state of each individual person. To suss out who's able to take your confidence. And there'll be some children who'll be in the playground (who) just won't understand the meaning of

it...but her best friends, the friends that come here, and know me, will understand.'

Parents' situations varied. Angela felt that she was seen as a mother by the other parents at the school gates, and enjoyed discussing topics such as forthcoming school plays and so on. She took an active part in school committees and felt that gradually teachers and other parents had understood the contribution she was able to make. Particularly the older and younger school pupils had behaved positively towards her:

'I'm known now around the school... With some of my son's friends it's 'cool wheelchair' - it's a scooter. But it's quite a streamlined one, quite niftythey love the colourand in that sense that's actually helped me....they've asked me how it works. It's made it easier. I'd much prefer for somebody to ask me than to nudge each other. I find it less embarrassing, and less bothersome. And for them. I think often you can tell if somebody is or knows somebody who's disabled. Because they're not frightened of you.'

(Angela, employer)

Introducing her personal assistant was more of a personal challenge, as Angela needed to explain to the teachers that the assistant would have to pick up the children at times. However the fact that her personal assistant was also involved in running crèches and after school clubs made it easier in the sense that the assistant fitted into the surroundings and was known for her work with children by other parents. The personal assistant was therefore more likely to be identified in this way rather than as a 'care' worker.

Lisa experienced more difficulties in getting to know other parents, something that would have been helpful to her as a single parent. She felt that not being able to make eye contact had made it this more difficult. Although she wanted to attend school events to support her daughter, she chose those where she felt she would appear in a better light, such as the school play, avoiding sports events because she would not know where to look. She gave a graphic description of the dilemmas involved and her points are quoted at length because they provide an illuminating account of the decisions she made in balancing the effect of disablism on her daughter with her desire as a mother to support her daughter's participation, and the ways that personal assistance changed the situation:

'I don't want her growing up and looking back and thinking 'oh, my mum sat on the settee while I was with strangers'. That would be terrible. So I've always made a point of going to things.... like the nativity play. It's incredibly hurtful, because that's the whole thing, isn't it? You see their little faces and all the mistakes they've made.....looking at it is more than all the other things. So although it's pretty difficult to do, I've always done it, because then Penny can say 'oh yes, my mum was there' and we can say 'do you remember when we went to such a thing?' ... I haven't gone to sports day, because that is too distant. You're stood back from it, for a start and it's not a focussed thing, like a play. You're sitting there and it looks as if you're taking it all in. You are, but it looks better as well. With sports day, I'd be there and I wouldn't know where to focus. She could be here and I'd be looking over there, and that would be hurtful for her. She'd be looking at me in the crowd, knowing that I was away with the fairies sort of thing (laughs). So it's selecting what is good for both of us. I've been to school events (but) I still don't talk to them – they (other people) make themselves as small as they can when you walk by. As quiet as possible. And at Christmas fair it's just noise, crowds, stalls, and you haven't got a clue what's on them, and you want to take control, to say to your daughter 'oh, let's go and look at such a thing' and be in control that way, rather than wait for her to say 'oh mum can we go to this'. First time I went to one of those, it's the third party people - teachers, and other people like that, directly addressing her - 'oh take your mum over to such a place....perhaps your mum would like a cup of tea'. And they automatically talk to her! And you think, 'well, I've only had a conversation with you yesterday about homework. I can talk to you and understand what you're saying.' And it's just their embarrassment and inadequacy.... I can't take it personally because otherwise you'd just roll up in a ball. But from my daughter's angle, it must be so hurtful for her to think that people can treat her mum like that. But the last year we had it, I actually arranged it so the P.A. came with us. And it was a totally different experience. Because she could run off and play with friends or do what the other ones did, which was just to potter around the stalls and sit and have a cup of tea like the other children do. Instead of always having to be with me, and people assuming that it was her role to do things for me. It was a totally different experience.' (Lisa, employer)

Chloe, who had three disabled sons had challenged the school policy of not allowing one of her sons (who had a visual impairment) out at break times. Initially he was kept inside and later confined to a corner of the playground. She had intervened to make sure he was allowed to run around with the other children because she was concerned that he wouldn't make friends if kept isolated.

Assistance was variable with regard to help for children. Margaret had succeeded in getting personal assistance to help her son with his homework, but noted that in some other areas this was seen as not being appropriate by the local authorities

involved. Before this had been agreed, she had had to constantly ask teachers about the work that had been set.

The discussion so far has highlighted how different public contexts were handled in a variety of ways. The decisions here did not break down in a straightforward way in terms of presenting an employer – employee relationship or paid friendship stance. Rather, all involved made a series of decisions with regard to how they would deal with specific instances, taking into account the attitudes of other people, including stereotyped assumptions about who people were, the specific circumstances involved, and the likely effects on others. These findings build on classic studies (e.g. Goffman, 1968, 1969) by adding personal assistance into the picture.

Given the complexities involved in all these varied circumstances, it may be self-evident that opportunities to exchange ideas with other employers would be highly valued. Opportunities to do this varied across different areas.

User Led Organisations / Service User Groups

As mentioned in Chapter 4, in several geographical areas user groups of people in receipt of direct payments had been established and they were organised differently. In Area 2 the existence of the group pre-dated the availability of direct payments and employers who had a large degree of control over the agenda actively attended meetings. In Area 1 a group had recently been established at the instigation of the social services department and they largely set the agenda and took control over the proceedings. In Areas 5 and 6 administrative organisation of direct payments had been delegated to an organisation of disabled people but there was no active service user group. The views of employers in each locality were consistent with regard to these organisations and will be compared in turn.

In Area 2, where an active group had been established, reports of involvement were very favourable and respondents found discussions useful:

‘At first I didn’t like them (meetings). I found them intimidating and...but I’ve found that I really do like them now. I think it’s because it’s like comparing notes almost.... I’m not out there on me own. And I think for the people who are just joining the scheme to realise that it’s not easy getting it going, but there are other people there to support you if you want... you know that the other people understand, you know that if you are having problems or if there’s an issue, it just gives you a space without the P.A.s being there. Or without criticism...it gives you a safe environment. You can share things.’
(Angela, employer)

People attending these meetings felt that there were real opportunities to exchange thoughts and concerns but also to have an input into the ways that decisions were made. Employers had raised concerns that were important to them and had been able to set the agenda in terms of what was discussed as well as influence such things as the provision of information that was more directly related to actions taken by the local authority.

Opinions were very different in Area 2. Here there was criticism of the way that meetings were run and the subject matter discussed. Both employers and personal assistants attended meetings, although during the meetings the employers and P.A.s might discuss issues in smaller groups. Several rather disparaging comments were expressed:

‘To be honest, I’m not going to the next meeting. I think they’re a load of idiots..... I think they talk to you like kids. I think they should look at more what people have got problems with. I think it’s just a way of wasting time really. The meetings, I don’t get much out of them at all.’ (Janice, employer)

This having been said, the social services departments’ control over meetings was contested. While employers did not specifically object to personal assistants being present at this point it might be conjectured that some objections might be raised in the future. At issue at the time was control over the agenda. Some weeks after this interview some service users present offered to chair meetings as a way of exercising more influence over the discussion.

In Areas 5 and 6, employers expressed satisfaction with the support they received from the organisation of disabled people contracted to provide assistance. However

they did not at this time have any contact with other people using direct payments and therefore no informal ways of discussing issues and concerns.

Sarah: 'Do you have contact with other people who have direct payments?'
Wendy: 'No, I don't. I'm a great advocate when I'm going out and about - I was in (town) recently and people there, they start talking about care, and I get really on the bandwagon about direct payments. I started talking about where they should go, what they should do, who they should ask and what they're entitled to. So they were very grateful and I'm promoting it whenever I'm out. But actually, in all honesty, I know of one person that's on it. And it was me that got her on it.....that told her about it. She has MS. But apart from that, no I don't.'

In fairness to the organisation involved, there was a plan to set up meetings of service users so that a point of contact could be made. Often this was the only way that employers could meet others in a similar position to themselves. In no instances did organisations responsible for providing support make available contact lists of other people using payments or make other arrangements for people to be in touch with one another independently.

Employers therefore found service user groups to be an effective means of support where they had control over the agenda and priorities of the group. This was not an automatic 'given' but something that was often actively contested. The competence of local authorities was questioned in particular:

'In (Area 4) there are a load of bloody idiots on the direct payments team. They ask me daft questions. I was saying to them 'does it include payroll?' and they said 'no, only care costs.' I asked her if the oncosts were included and she didn't know.' (Robert, employer)

The reason why control had to be fought for was because service user opinions were frequently discounted. Social service staff considered the perspectives of service users to be 'private' and therefore not admissible in a supposedly 'public' workspace. Kathryn, herself an employer of personal assistants, was also employed within the social services department on the direct payments team in another area. She described how her views were seen as invalid:

‘There are some times when working for social services and being a service user have a big disadvantage. Because I can totally see the user’s point of view, and when it comes to the recipients’ point of view I can also see.....and I have a couple of times overstepped the boundaries and had my knuckles rapped for it.....‘You don’t do that. Your private opinions aren’t worth anything in social services.’ But when I went for me interview, I made it very, very clear that I wouldn’t forget me roots and where I came from. If it wasn’t for being a service user, I wouldn’t be in the right place, have the right temperament and everything to actually do the job for which I’m employed.’
(Kathryn, employer)

When arrangements worked well, participation in groups of employers represented a way that employers could create a safe environment, as Angela described.

Concerns related to dealing with the administrative requirements such as accounting – and by implication, maintaining the integrity / boundary of the home - what money could be spent on, and with the logistics of managing personal assistants: the issues that have been discussed in this thesis. These issues were also on the priority list of local authority staff keen to establish disabled people’s status as employers although within limits. Other issues that were of concern to employers, such as managing personal assistants and how to arrange things such as going on holiday, were on the agenda in some areas but not all, depending on the degree of control exercised by employers over the subject matter of the meetings. This being said, during the course of the study, the movement was toward greater control over meeting by employers, even if progress was slow.

It should also be noted that a few employers, especially those who had been on direct payments for some while, felt there was not much point in attending meetings, and preferred to be getting on with other things:

‘A lot of people, once they get on direct payments think ‘sod the service users group’ and they’re off doing their own thing.....There’s 16-20 people on direct payments in (Area 2) - let them do it now. I’ve done my bit - I feel I’ve made a difference, I’ve made a breakthrough.’ (Alan, employer)

In this instance, it was not that Alan had no contact with other direct payment users, more it was the case that he had a supportive and active network of his own, and one that was rather freer of control and influence from the social service department.

For other employers, these meetings did represent the focal point for collective action, despite the frustrations and difficulties of making progress, and meetings with others in similar situations were an important way of strengthening the effort. This final section raises again the question of public participation and boundary disputes concerning what was deemed to be a private issue or public matter.

Conclusion

This chapter has considered the question of social relationships in some parts of the public sphere as commonly conceived. It has sacrificed depth for breadth. The main intention has been to illustrate the differences in how employer – personal assistant relationships were portrayed according to context. For example, employer – personal assistant relationships were presented as formal arrangements to social service departments but characterisations of friendship took precedent on the street. These are at opposite ends of the spectrum with reference to the typology introduced in Chapter 6. It is an irony that an employer – employee relationship such as that on show to social service administrators often rested on an underlying paid friendship, through collusion. Both of these forms of relationship, or their manifestation at least, may be in part explained in terms of power, whether that is the power to give or withhold funds as in the case of social service departments or the power to discount on the basis of an ideology of dependency and ‘care’ as was the case on the street. Nevertheless the slow attrition through challenge to everyday practices that resulted from participation in the public sphere did make a difference, whether this took the form of ramps appearing outside shops or personal assistants gaining insight into practices of discrimination and oppression.

The following chapter will broaden this discussion by considering issues that arise from the findings presented in this thesis.

Chapter 10

Conclusion

Introduction

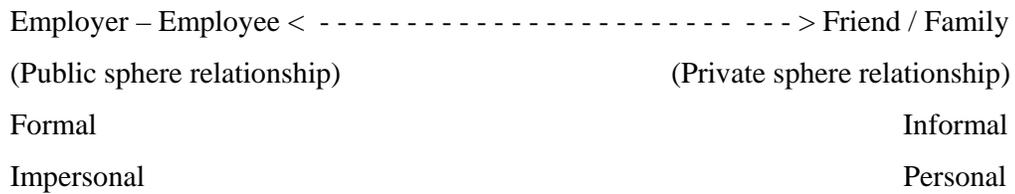
Details of the main points arising from the preceding chapters have been provided in the form of summaries and conclusions. Therefore this chapter will build on the discussion so far rather than offer a repeat of earlier statements. Instead, I will comment on further points that arise out of the data, discuss the implications and relate issues to broader questions of sociological theory and policy. In so doing, I will use the term social relationships in a rather wider sense than the way it has been used so far: to refer to social patterns rather than interpersonal relationships. The main areas I will discuss here are friendship and the meaning of kinship, labour market relations, questions of autonomy, needs and rights, and finally public and private domains of social life. The intention here is not to suggest solutions but to map dilemmas and broader resonances with this study.

Relationships with Personal Assistants

The concept of paid friendship has been proposed as a way of describing a distinct and consciously selected form of social relationship. As an ideal type, the features that distinguish it from both social friendship and paid employment have been discussed. Because of the absence of the concept of paid friendship, sociologists have tried to make these lived relationships fit into other pre-existing categories such as paid work or social friendship. Because it has not fitted, it has been judged that something is wrong somewhere. Given the long – standing tradition of discounting the perspectives of disabled people within sociology (Barnes & Oliver, 1993) it has been a small jump to concluding that the inadequacy lies in disabled employers rather than sociological concepts.

While paid friendship has been conceived of as an ideal type, it is important to reflect back again on how this ideal type relates to lived experience. The typology

outlined in Chapter 6 was used as a means of unravelling the complexities of employer – personal assistant relationships:



However the model may be modified in an important respect. Paid friendship rests on a fundamental understanding that jobs will get done, something typically attributed to an employer – employee relationship (meant here in common sense terms). It is the manner in which jobs get done and the definition of the physical space that is different. As such, paid friendship may be seen to build on and to some extent exists over and above the employer - employee stance. It may therefore be represented schematically in another way:

Paid Friendship relationship (associated with increasing personal control and autonomy)



Employer – Employee relationship (associated with decreasing personal control and autonomy)

This is not to deny instances where employers may simply be looking for friends as a result of isolation and loneliness and seek personal assistance relationships to fill a void. It is simply to assert that paid friendship can be and is a conscious preference for many employers and personal assistants (the majority in this study) who reconcile the inherent contradictions of personal assistance in the home in this way. It may be expected to increase as experience of direct payments increases. The employer – employee stance remains as a fall-back position. This is furthermore not to assert that paid friendship is a superior or more sophisticated way of reconciling the dilemmas of personal assistance. As has been seen, there are a whole range of factors that might lead employers to make an employer -

employee stance the option of choice, including problems associated with felt intrusion into personal space, the degree of precision and predictability wanted in terms of what is done and how, the amount of assistance received, as well as the reciprocal impact of other interpersonal relationships, both those of employers and those of personal assistants.

In this study, because home relationships were an important focus, the question of gender unsurprisingly became an important explanatory factor in understanding the data. (It may be surmised that questions of ethnicity would have equal force had it been possible to recruit more respondents.) The predominance of the employer-employee stance among women, combined with their accounts of why relationships took the form they did, bears testimony to this. It is in this light that Marfisi's (2002) questions about the dichotomies of personal assistance may be seen as an issue of gender in the home and of disability with regard to lack of support for Independent Living.

The Meaning of Kinship

Disabling attitudes were apparent in some family relationships. Sheila (Janice's personal assistant) gave an account, for example, of how family members had been told by others to ignore Janice if they saw her in the supermarket. Other family relationships were warm, supportive and highly attuned to oppression and discrimination. These instances question the necessity of consciously omitting family and friendship relationships as an area of study and leaving concerns to professional and medical researchers. However this could amount to an argument that it makes sense to think about these connections because family members and friends are not so bad after all.

Informal, i.e. unpaid 'care' is located firmly in the study of kinship relations within sociology. Successive studies have pointed to the corrosive effects of long-term unreciprocated assistance as corrosive of family relationships (e.g. Lyons et al., 1995; Parker, 1993). They all assume, even if negative consequences ensue, that the people involved still constitute families. Government policies are designed to ensure that support is given so that families don't 'break down' – often seen as

evidenced by family members refusing to assist their relatives or harming them. In these studies and policies, families are taken as given, even if they are seen to be working well or not working properly. Sociological debates have hinged on the forms that families take, consequent problems of definition and the arrangements that accompany these (Beck & Beck-Gernsheim, 2002; Silva & Smart, 1999; Smart & Shipman, 2004). It is assumed that external indicators such as differences in gendered working patterns have implications for attachments and solidarities. How agreements are reached are also the subject of intra-familial study (Finch & Mason, 1991; 1993).

The respondents in this study raised a different issue, concerning the meaning of relationships. It was clear from accounts that people drew distinctions between being a 'proper' family member and the receiving and provision of long-term assistance to one another. The data from this study has shown that the process of becoming a private sphere 'carer' and 'receiver of care' may be reversed by direct payments and that it is resolved in the direction of family membership.

Labour Market Relations

There is more of a difficulty when 'care' becomes translated into the public sphere. When it intersects with broader societal agendas it may be translated into institutionalised oppression (Finkelstein, 1998b). While women have largely been given the visible task of providing publicly funded 'care' to disabled people, they may also be fulfilling agendas of keeping disabled people off the streets or out of employment (Abberley, 1987). In this sense, Ungerson's work, which has been of great value here as a way of developing my arguments, may be seen as staking a claim to the work of service provision on more advantageous terms for non-disabled women. An explicit concern with power relations and an argument in favour of better conditions for poorly-paid assistants (Ungerson, 1997) develops into an assertion that "any future research should take account of historical work on the relationship between masters and mistresses and their domestic servants" and that "there are certain aspects of these new types of employment that are reintroducing a traditional hierarchical type of employment, particularly where

workers are very easily exploited.”(Ungerson, 2005:203). The data from this study questions this, as indeed does Ungerson’s earlier study (Ungerson, 1999).

In the long run, it may be argued that the removal of disabling barriers and a successful challenge to disabling attitudes would remove the need for much personal assistance and for ‘care’ more generally. In the interim the current availability of personal assistance has opened up opportunities for more disabled people to move into the public sphere, including employment. At the moment the move is towards taking more control over the shape of services: all employers in this study (except one) worked, whether earning wages or not, in occupations concerning disability. The challenge therefore is twofold: maintaining direction in contexts where systems are set up with other agendas such as the reduction of welfare costs (as detailed in Chapters 3 and 5), and maintaining commonality of purpose when the systems are set up to ‘care’ for clients. Aspirational support (Finkelstein, 1998b) may be difficult to provide where systems may define people as ‘unable’ to work (Shakespeare & Watson, 2002), regardless of aspiration or support to exercise autonomy. As I have shown in Chapter 7, albeit in the context of home life, the opportunity to contribute, not on the basis of compulsion or arbitrary standards but on the basis of aspiration, is one of the dividers between ‘care’ and reciprocity; clienthood and humanity.

Autonomy and Rights

Autonomy may be thought of as being in a position to exercise influence and having control over everyday living (Barron, 2001). It is a social relationship: autonomy vis-à-vis others. Although Disability Studies authors have sought to separate being able to do things for oneself from notions of independence, as Ellis (2005) argues, state policies increasingly expect that people receiving welfare provision should be active in overcoming dependency. Privileging autonomy in the movement for civil rights can feed into government notions of ‘promoting independence’ (Ellis, 2005: 701) in the traditional sense.

Civil rights have underpinned actions by the disabled peoples movement in preference to needs (Oliver, 1996b). In liberal democracies, freedom has largely

been conceptualised in terms of negative rights, that is, a right to not be impeded in doing as one sees fit with regard to the use of property and its disposal. The concept of rights developed together with capitalism and reflects low cost strategy to the state (Noonan, 2004). Claims to resources on the basis of need, such as the campaign for a comprehensive disability income (Disability Alliance, 1987) may be contrasted with a strategy for civil rights, the latter representing a theoretical claim to those resources.

Within the disability movement, rights have often been formulated in terms of human rights – an assertion of access to resources on the basis of humanity rather than classic liberal rights concerning the control of assets (Morris, 2001a). This is different from the notion of assistance as an asset to be appropriated and disposed of at will. Asserting a right does not equate to realising the resources themselves (Barron, 2001; Noonan, 2004). With direct payments, the means to accessing the resources is actually predicated on the demonstration of a form of functional competence, at least in the way it is realised by the state. A claim to direct payments does not mean people will get them

The question of needs as used in social policy gives a perspective on disability as a social relationship and the conflation of impairment and disability by professionalised services (Harris, 2004). Subverting the meaning of the word ‘needs’ cuts off claims to resources at the point where they intersect with others on the grounds of common interest in securing requirements for living. Needs become redefined to denote inadequacy in those making the claims. It is a small jump to assert another meaning for need – the ‘need’ for what professionalised services can provide. The way out of the conundrum that is presented is demonstration of a particular form of autonomy – the ability to manage payments and personal assistants and one that cannot be demonstrated by all the people seeking redress.

Returning to the study, the requirement to present an employer – employee relationship to ‘care’ managers was not accidental. It was reported by all respondents. People presented this face even if it did not accord with the more personal connections and social relationships they formed in the course of daily

life. It was the presentation of an acceptable form of autonomy, one that did not recognise social relationships of equality.

While the discussion of gender and the shape of employer – personal assistance relationships has been primarily presented as an issue of inequality in private sphere household relationships, it can also be seen in another light here. As has been shown, women faced more difficulties securing resources; they got less help for fewer hours, even though many sought support for a wider range of things such as running households and assisting other people. Their resources with regard to assistance were less certain and for some at least rested on additional requirements to demonstrate competence, in looking after children for example. Implications of losing direct payments were therefore more severe. With less power in this respect, so the ‘need’ to show autonomy and competence as defined by social service departments is strengthened. The potential for external definitions to extend deeper into the private space of home is increased. As Rae (1993) points out, if technology is available, it might be preferable.

Public and Private Spheres

The last few points have raised the final main issue that I want to discuss. Throughout the thesis the concepts of public and private have been used as a typology for discussing particular forms of relationships and domains. While different formulations have been noted, the terms have been used in a fairly commonsense way. It has been assumed that the home, family and close friendships are largely private and that the wider world - encompassing a general world of sociability, work, school and so on - is public. However the following discussion will consider again the nature of the divide and the light that may be cast on it from this study.

By way of illustration, I will refer to a point made earlier in the thesis and which passed without comment. Anna, a personal assistant to Amy said that her job did not feel like work because they were ‘always going shopping.’ Above, this was used to illustrate the point that she characterised their relationship as paid friendship. It also illustrates another point however. For Anna, going shopping was

part of her private sphere, associated with her home life, and was an activity where she exercised a great deal of control. This is why her job did not feel like work. She would make a note of items in the shops when on these trips and either come back for them later or buy them while she was with Amy. For Amy, her employer, the boundary was constructed differently in that this was part of her public arena, where her presence might be commented upon positively or negatively by others, and where she did the same thing. Employers spoke of instances where people told them to get off the streets, or that they 'shouldn't be allowed out'. Amy's presence outside the house was 'public' property in that other people felt at liberty to pass comment in a way they did not for Anna. It was not automatically a place where employers exercised control and freedom of movement in the sense of being welcome.

Debates about public and private often centre on gender issues. Here this has been taken out of the equation – both people are women. They are also doing the same thing – going shopping. While there is no question about Anna being out on the street, Amy's situation is contested. Here I am not concerned with where the boundary between public and private may lie 'in reality'. I would like to set this aside for the time being. The point is that regardless of how shopping in the town is characterised – public or private – participation by each person elicits different responses. Comments such as 'you shouldn't be allowed out' represent a push into a more private sphere. They are attempts to limit spaces of activity and to draw a more circumscribed sphere of autonomy for Amy than for Anna. It is in this sense that autonomy may be seen as a social relationship that is constrained by disability.

If this argument is granted then this brings into question the notion of public and private as inextricably descriptive of location and activity. Rather, the boundaries, as in this example, may be drawn differently for different individuals and groups of people. It makes more sense to conceive of public and private as contested spheres that are asserted and granted or not as a result of privilege and power. People telling Amy to 'get off the street' did not expect to be sanctioned for this, while they might be if they did the same to Anna. It follows therefore that this destabilises the common sense notion of what constitutes 'the private' or 'the public'.

Social privilege and position confer the ability to define a larger private sphere and one that is freer from outside influence and scrutiny, as well as more control within that private sphere, by being able to define what happens in it. An example from this study would be the ability of local authorities to shield from view decision-making processes regarding eligibility for funds (private within the public). Here the private is not synonymous with personal privacy. It is the exercise of power in the so-called public sphere.

With more privilege, the divide moves further into the realm that others might define as being wholly public. The private gets larger. Beckett and Wrighton (2000) discuss these issues in relation to assessment procedures experienced by disabled people, noting how aids will be granted for household activities but not for those deemed to be 'public' in common sense terms. Moving the participation boundary further out, one respondent in this study (Brenda) found it easier to get driving help for ostensibly going to church than for visiting friends. 'Public' funds are used to circumscribe activity and to define a smaller 'private' domain than for non-disabled people as well as to construct boundaries around the 'public'.

Disability Studies has largely ignored questions about how public and private spheres are defined. The wish to use the tools of justice and civil rights characteristic of the public sphere has meant that the divide has largely been accepted as given. The argument I am presenting is that safeguarding of the private sphere is also needed. Another way to challenge disability is to expand the private as commonly conceived. Many of the more advantaged employers who took part in this study were doing this by defining their living space as a home. It is not therefore surprising that this provoked a response.

Conclusion

This final chapter has sought to make connections across public and private divides and to draw out themes from the chapters to illustrate links. I have also tried to situate the thesis within some broader areas of sociological debate to show the resonance for other areas of study. It is my hope that the complexities involved

with direct payments have not been glossed over but that the myriad influences shaping these developments have been traced. It has been my privilege to try to do this.

APPENDIX 1

SUMMARY OF RESPONDENTS

1. EMPLOYERS

Name	Gender	Age	Ethnicity	Impairment	Household	Nos. P.A.	Time P.A.s	Hrs P.A. pw
Jean	F	58	W British	Rheumatoid arthritis	On own Divorced	2 direct 2-3 agency	1 yr. 4 months	70
David	M	53	W British	Spinal injury	On own Divorced	2 direct	9 months	168
Tom	M	49	W British	Spinal injury	On own Divorced	2 direct	9 months	30
Linda	F	50	W British	Rheumatoid arthritis	On own	1 direct 1 agency	6 months	34
Lisa	F	38	W British	Visual: no sight	With daughter (9) Divorced	2 direct	10 months	14
Margaret	F	31	W British	Visual: partial sight	Son (6) Daughter (2) Widowed	1 direct	5 months	8
Sylvia	F	77	W English	Arthritis Leg amputations	On own Widowed	1 direct	1 year	25
Angela	F	37	W British	Stroke	Husband Sons (9 & 4 yrs.)	3 direct (1 P.A. is mother)	2 years	56

Name	Gender	Age	Ethnicity	Impairment	Household	Nos. P.A.	Time P.A.s	Hrs P.A. pw
Alan	M	42	W English	Muscular dystrophy	On own	5 directly	7 years	168
Kathryn	F	45	W English	Spinal injury Depression Short-term memory loss	On own Divorced	2 directly 1 employed through A.T.W.	4 years	32 plus assistance at work via employer
Janice	F	67	W English	Friedreich's ataxia	With husband	1 direct Informal arrangements	2 years	9.5
Wendy	F	33	W British	Tetraplegia	With husband	4 directly	4 years	51
Chloe	F	39	W British	Visual: partial sight	With 3 children Widowed	2 directly	6 months	20
Ruth	F	66	W British	Motor neurone disease	On own Divorced	4 directly	2 months	49
Robert	M	47	W English	Cerebral palsy	On own	6 directly	16 years (through a Trust until 1993)	168
Christine	F	55	W British	Multiple sclerosis	On own	2 direct 1 agency	18 months	47
John	M	47	W British	Quadriplegia	On own	9 directly	7 years	168
Jackie	F	63	W English	Arthritis	On own	3 directly	2 years	16

Name	Gender	Age	Ethnicity	Impairment	Household	Nos. P.A.	Time P.A.s	Hrs P.A. pw
Priti	F	30	Indian British	Cerebral palsy	With partner	7 directly	8 years	49
Susan	F	32	W English	Leg injury	With son (14)	1 directly	3 months	5.25
Najmah	M	26	Pakistani British	Not known: wheelchair user	With wife and 3 children	2 directly	10 months	46
Mark	M	32	W British	Cerebral palsy	On own. Custody of son every other weekend. Divorced	4 directly	12 years: 8 years through direct payments	96
William	M	38	W British	Leg injury. Bipolar disorder 2, short-term memory loss	With two children (12 and 9). Divorced	1 directly	1 year, 5 months	42 (actual hours worked 60)
Graham	M	62	W English	Paraplegia	With wife, also disabled	3 via agency	3 months some time previously	30
Aurang	M	24	Pathan British	Leg amputations	On own	1 directly	4 months	40

Name	Gender	Age	Ethnicity	Impairment	Household	Nos. P.A.s	Time P.A.s	Hrs P.A. pw
Judith	F	49	Black British (Jamaican)	Brittle bones, restricted growth	With friend, former P.A.	1 directly	5 years	35
Amy	F	31	W. British	Visual impairment: no sight	With partner	2 directly	2 years	45
Lynne	F	68	W Anglo / Irish	Meniere's syndrome, paralysis, osteoporosis	On own	1 directly	1 year	21
Neil	M	24	W British	Spinal muscular atrophy: type 2	On own	6 directly	2 years	148
Frances	F	61	W English	Polio, skin cancer	On own	7 directly	5 years	168

2. FAMILY AND FRIENDS

Name	Gender	Age	Ethnicity	Connected to Employer	Relationship to Employer	Household
Jessica	F	63	W British	Alan	Mother	Living with partner
Jonathan	M	23	W British	Kathryn	Son	On own

Name	Gender	Age	Ethnicity	Connected to Employer	Relationship to Employer	Household
Carol	F	42	W British	Chloe	Friend	With 3 children
Grace	F	62	W English	Janice	Friend	On own
Mike	M	36	W English	Wendy	Husband	With partner, Wendy
Eva	F	53	White British Christian	Amy	Mother	Living with husband
Shirley	F	55	W Welsh	Mark	Mother	Living with partner
Joe	M	28	W British	Amy	Partner	Living with partner, Amy
Annette	F	12	W English	William	Daughter	Living with father, William, and sister
Naomi	F	34	W British	Jean	Daughter	Living with partner

3. PERSONAL ASSISTANTS

Name	Gender	Age	Ethnicity	Connected to Employer	Previous / other work	Household	Time P.A.	Hours worked p.w.
Matt	M	25	W English	Alan	Factory work / Builder	On own	7 years with break of 2 years	24
Marilyn	F	26	W English	Kathryn	'Private sector' care agency	With parents	4 years, with change of support role	35 (during working hours)
Sheila	F	52	W English	Janice	Shopkeeper	With partner	3 months	9.5

Name	Gender	Age	Ethnicity	Connection	Previous / other work	Household	Time P.A.	Hours worked p.w.
Anna	F	30	W British	Amy	Fitness centre worker	With husband and daughter	1 year	29
Laura	F	36	W British	Chloe	Supermarket worker	With husband and daughter	18 months	20
Ellia	F	29	W Italian	William	'Care' worker	Living with father	Nearly 2 years	Officially 42 (actually 60)
Emma	F	39	W British	Jean	Residential home for elders	Living with husband and daughters	2 years	32 - 33
Kate	F	32	W British	Jean (also Jean's daughter-in-law)	Community artist	Living with husband and daughter	2 years	12-14
Samantha	F	41	W British	Wendy	Childminder	With 2 sons	4 years	45 hours but may be more or less

Notes on the tables above:

Ethnicity: Descriptions are taken from respondents' own accounts. Pre-given categories were not offered and people were asked to provide their own.

- Connection: This is provided so that the reader may cross-reference the connections between employers, family / friends and personal assistants.
- Nos. P.A.s: This refers to the numbers of personal assistants employed by each employer, and whether they were employed directly or via a third party such as an agency.
- Time P.A.s: With regard to employers, this shows the time involved since they had first employed a P.A. directly. With regard to personal assistants, it shows the time that the individual concerned had been working for the specific employer they worked with at the time of the interview. These may or may not coincide for reasons of the time lapse between interviewing the connected respondents and job change.
- Hrs. P.A. pw: This refers to the total number of hours of personal assistance that employers received per week. Typically employers reported the official allocation that had been made by the social services department.
- Household: This describes whether people were living on their own or with others.
- Previous /
Other Work: In all cases this refers to previous employment where just one line of work is listed. Where two are listed this refers to employment prior to becoming a P.A. first and then employment carried out at the same time as working as a P.A.
- Hrs worked
pw: This refers to the number of hours personal assistants worked each week. P.A.s typically reported the actual hours worked rather than those for which funding had been given to the employer.

Appendix 2**Letter to Potential Respondents**

Sarah Woodin,
Address

Tel/fax:
e-mail: spl9slw@leeds.ac.uk

Date

I am writing to ask for your help with a research study I am doing, about direct payments and what life is like for people who have personal assistants.

I am a student at Leeds University, and am doing this work as part of a thesis, which I will complete in 2-3 years time. I plan to interview about 30 disabled people in area and I very much hope you will be interested in taking part. A number of disabled people have helped me by giving their views in the past, and if you are one of these people, many thanks, and I hope you will be interested in taking part in this study as well.

Interviews will last for about an hour and will be arranged at a time and place convenient for you. I will be pleased to answer any questions you might have for me, and to explain more about the study.

If you are interested in taking part and making your views known, could you let me know by contacting me (details are above), by the I look forward to hearing from you,

Yours sincerely,

Sarah Woodin

APPENDIX 2

INTERVIEW QUESTIONS

SCHEDULE OF QUESTIONS ASKED OF EMPLOYERS

Direct Payments: Present Arrangements

1. Who do you employ at the moment?
2. Do you employ people directly or through an agency?
3. How long have you employed them?
4. What hours do they work?
5. What kinds of work do they do?
6. What are the good aspects?
7. Are there any difficulties with how things work now?
8. If you weren't getting direct payments at the moment, what kinds of arrangements do you think you'd make?

Mapping Exercise

See details on p.86 and p.285

For People in the same Household

9. Do you live with anyone else?
10. How long have you lived with them?
11. Have you lived with other people before?

About All or Some of the People Placed on Map

12. How do you think of X? As friend, family or in another way?
13. How often do you see them?
14. When do you contact them or they contact you?
15. How do you keep in touch?
16. What are the kinds of things you do together?
17. How would you say that your relationship with X has altered?
18. How would you say that it has stayed the same?
19. Are there any times when X has been particularly important to you?

20. Are there any times when things have been difficult?
21. Do you help each other out? If so, how?
22. What was your relationship like, say (6 months before employing P.A.s)?

Personal Assistants and Others in the Same Household

23. What is it like having a personal assistant in the house?
24. When does (person you live with) have contact with your P.A.(s)?
25. When your P.A.(s) first started, how did you go about making it work, with the people you live with?
26. How did you go about working things out with your P.A.(s) when there were (changes to your household)?
27. How have things developed since that time?

Relationships between Personal Assistants and Others on the Map

28. What kinds of arrangements do you make with your P.A.(s) when you see X? What do you ask them to do?
29. Is it always like this or are there times when you arrange things differently?
30. When your P.A. started how did you guide them about what they should do?
31. Do you do the same things now?

Education, Work and Voluntary Work

32. Do you do any education, work or voluntary work at the moment?
33. Do you have contact with other people there?
34. How often do you see them?
35. Do you just see them there or are you in contact at other times or in other places?
36. Do you help each other out? How?
37. Have there been times when X has been very important to you?
38. Are there any times when things have been difficult?

39. When you are there, is / are your P.A.(s) also usually there?
40. Are there times when P.A.s aren't with you?
41. Do you advise you P.A.(s) about what to do when you're there?
42. Can you think of a time when you've made a different arrangement?
43. Are there times when arrangements work better than others? Why is this?

Meeting New People

44. Are there times when you meet people casually?
45. How do you go about meeting new people?
46. Are there places that you go out to on a regular basis? With whom / on own etc?
47. When have you met new people when your P.A.(s) has / have been there?
48. When have you met new people without your P.A.(s) there?
49. Have you found any difference in the way that people behave towards you when you have a P.A. there and when you don't?
50. How do you introduce you P.A.(s) to other people?

Intimate Relationships

51. Some people have said that meeting new partners or going out on dates needs some thought. What are your views on this?
52. Have you ever taken a P.A. with you when you've been on a date?
53. How did you handle this situation?

Social Networks

Thinking of all the people you are in contact with;

54. How do people get on with each other?
55. Are there times when people get on well?
56. Have there been any difficult times when people haven't got on so well?
57. Is this the same as say (6 months before getting direct payments)? Are there any ways that things have altered?

Getting Funding

- 58. How was it you came to get direct payments?
- 59. How definite were they about what the money was for?

Previous Arrangements

- 60. Before getting direct payments, what kinds of help did you have?
- 61. Did you have any formal help? By that I mean where the person helping was paid in some way.
- 62. Did you get any help from people who weren't paid?
- 63. Were there things that were good about that arrangement?
- 64. Were there things that were difficult about it?
- 65. How did the whole arrangement work?

Changes over Time: Personal Assistance

- 66. Since getting direct payments have you always employed the same people?
- 67. (If no) Who else have you employed? What were the reasons for the changes?
- 68. Have your P.A.(s) hours always been the same or have they changed?
Why?
- 69. Are there any arrangements for practical help that you have now that are the same as before you got direct payments?

Managing Personal Assistants

- 70. Lots of people have said that it takes a while to sort out the best way of working when you take on a new P.A. What have you found?
- 71. Are there times when you prefer that your P.A.(s) takes an active part in what you are doing? Thinking about social / education / work occasions.
- 72. When do you prefer that your P.A. takes more of a back seat and is less involved?
- 73. Have you ever had to handle any difficulties with managing a P.A.?

74. (If employing more than one P.A.) Do you prefer that your P.A.s are in touch with each other directly or that they make arrangements through you? Why?
75. Are there times when you would prefer do things with just your P.A. there rather than other people such as friends or family?
76. Do you find that having a P.A. gives you more or less free time?
77. Do you see yourself as an employer or as something else?
78. Do you think that there is a difference between a carer, a support worker and a personal assistant? Or are they the same thing?
79. Do you think there are any rights and responsibilities that people have towards each other?
80. Do you have any contact with other people who use direct payments?

Personal Details

Questions re: address, age, contact preferences, ethnic identity etc.

Missing Information

81. Sometimes it's easy to miss out the most important questions. What have I missed out that I should have asked?
82. How could the interview be improved?

SCHEDULE OF QUESTIONS ASKED OF FAMILY MEMBERS AND FRIENDS

For Family Members

1. Can you tell me about the people you see as your immediate family?

Contact with Respondent

2. How often do you see X?
3. What are the kinds of things you do together?
4. Are you in contact in other ways?
5. How do you keep in touch?
6. Are there any circumstances where you give particular help to X?
7. Are there ways that X helps you out?

Contact with P.A.s

8. What kinds of work do P.A.s do?
9. When do you have contact with P.A.s?
10. What is it like having a P.A. in the house? Yours? / X's? For you? / For X /
For others?
11. What kinds of arrangements do you make with P.A.s when you see X?
12. Are there times when P.A.s are there?
13. Are there times when P.A.s are not there?
14. Do you think there is a difference between when P.A.s are there and when
they are not? (How? Why?)
15. Is there a difference between a carer, a support worker and a P.A.? Or are they
the same thing?

Relationships Before Personal Assistance

16. Can you tell me what your relationship was like, say X years ago?
17. In what ways has it stayed the same?

18. In what ways has it developed?
19. Did you use to give X any help on a regular basis?
20. If this the same or different now?

(If Assisting)

21. Was there any other informal help?
22. Was there any formal help? By that I mean people who were paid in some way.
23. Were there things that were good about that arrangement?
24. Were there any things that were difficult about it?
25. How did the whole arrangement work?
26. Are there any arrangements for practical help now that are the same as before direct payments?

Getting Personal Assistance

27. How did it come about that X got personal assistance?
28. What were your views on it at the time?
29. Do you still think the same way about it?
30. What are the good aspects?
31. Are there any difficulties with how things work now?
32. Have there ever been any awkward situations that people have had to deal with?
33. How have difficult situations been sorted out?
34. Are there any times when things have worked particularly well?
35. How did getting personal assistance affect your relationship with X?
36. How did you and X go about working things out when the personal assistant(s) started work?
37. How have things developed since that time?

Relationships with Personal Assistants

38. How do you get on with the personal assistant(s)?

- 39. Any that you get on with particularly well?
- 40. Any that you find or have found difficult?
- 41. How have you dealt with any difficulties?

Contacts through Personal Assistants

- 42. Have you met any other people through (any of) the P.A.(s)?
- 43. Are you still in contact?

Meeting New People

- 44. Are there any times you meet people casually when you're with (employer)?
- 45. How do people behave towards you? How do people behave towards X?
- 46. Are there any difficult situations that you've had to deal with?
- 47. How did you deal with these?
- 48. Are there any times when things have worked particularly well?

The Whole Network

- 49. Thinking about all the people in the family / network, do people have much contact with one another?
- 50. How do people get on?
- 51. Any times when people get on particularly well?
- 52. Any times when things are or have been difficult?

Personal Details

This section involved asking practical question re: address, age, contact preferences, ethnic identity etc.

Missing Information

- 53. Sometimes it's easy to miss out the most important questions. What have I missed out that I should have asked or that you think it's important that I should know?

54. How could the interview be improved?

SCHEDULE OF QUESTIONS ASKED OF PERSONAL ASSISTANTSContact with Employer

1. Who do you work for at the moment?
2. Are you employed directly or through an agency?
3. How long have you worked for X?
4. What hours do you do?
5. What kinds of work do you do?
6. What are the good aspects?
7. Are there any difficulties with how things work now?
8. If you weren't working as a personal assistant, what kind of work do you think you'd be doing?
9. What do you think are the most important aspects of a P.A.'s job?

Relationship with Employer

10. How would you describe your relationship with X?
11. What parts of the job work well?
12. What parts could be improved?
13. Are there any times when you've helped out informally? (Done things that aren't part of your job?)
14. Are there any times when X has helped you out informally?
15. Do you think you work makes a difference to X's quality of life? How?
16. How does your work help your quality of life?

Contacts through Employer

The following questions were asked in relation to (as applicable): the household, education, employment, voluntary work, socialising with family and socialising with friends.

17. Can you tell me about people you have met through X?

18. How often do you see them?
19. What places do you see them?
20. What kind of role do you have when you see them?
21. Are there times when you have taken an active part in activities?
22. Are there times when you have stood back?
23. Are there times you can think of when things have gone particularly well?
24. When have you felt most comfortable?
25. Are there any times when you have had to deal with awkward situations?
26. Have you ever been given any advice on how to behave or what to do in difficult circumstances?
27. Has X ever met any of your family or friends? On what occasions? How do / did people get on?
28. When wouldn't you want them to meet? Why?

Meeting New People

29. When do you meet people casually when you are with X?
30. How have strangers behaved towards you? Towards X?
31. Are there any occasions when things have worked out particularly well?
32. Are there any situations that have been tricky to handle?
33. How have you sorted out difficult situations?
34. Have you even been on a date with X?
35. How did you handle it?

Explaining to Other People

36. How does X introduce you to other people?
37. Do you think it makes a difference if people know you are a P.A.?
38. How do you introduce X to other people?
39. How do you describe the work you do to other people? Friends? Family?
40. How do you think members of the public see a P.A.'s job?
41. Do you think there's a difference between a carer, a support worker and a P.A., or are they the same thing?

Changes over Time

42. Many people have said that it takes a while to sort out how to work together when you start working as a P.A. What have you found?
43. Do you think of yourself as an employee? As a friend?
44. How has this developed over time?
45. Have any things improved over time?
46. How have you sorted out any difficulties?
47. Has the job altered in any ways since you started?
48. How do you think things are likely to go in the future?

Personal Details

Questions re: address, age, contact preferences, ethnic identity etc.

Missing Questions

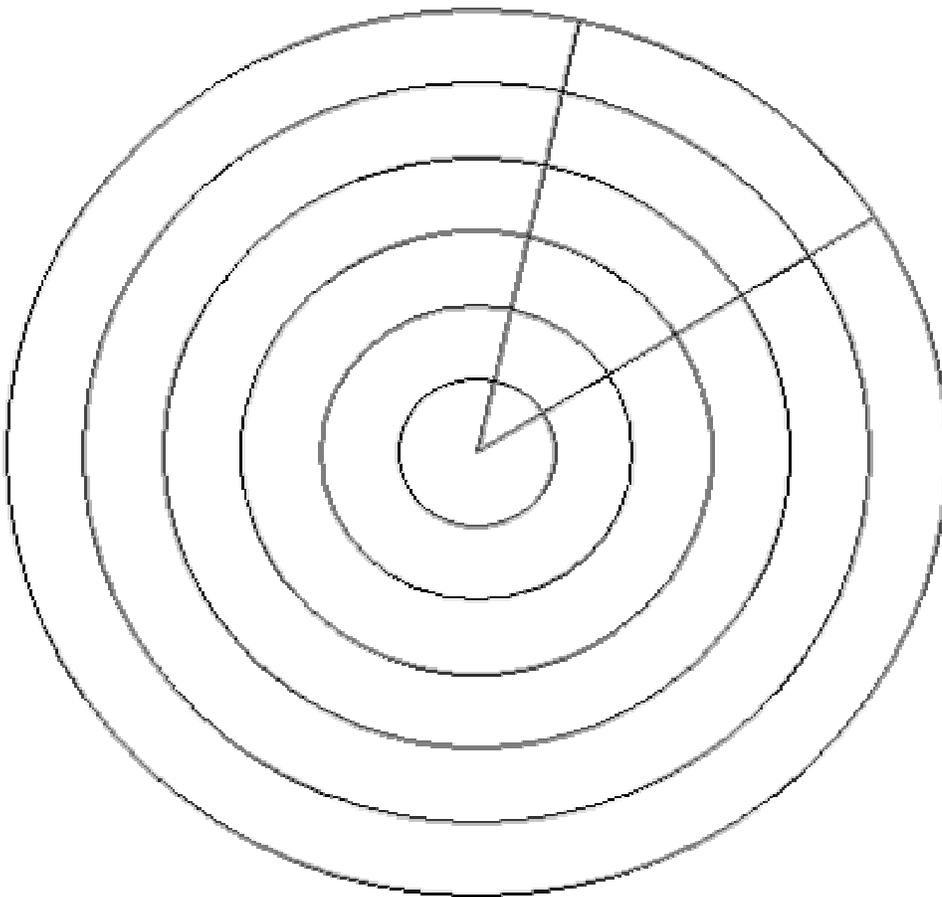
49. Sometimes it's easy to miss out the most important questions. What have I left out that I should have asked, or that you think it's important that I should know?
50. How could the interview be improved?

Appendix 2

Methods

Chart used for Mapping Social Relationships During Interviews

The diagram below is a scale version of a larger chart used when asking employers to map their social networks. Employers were asked or assisted to write the names of people on post-it notes and to place these on the chart according to how personally close the respondent considered them to be. A descriptive numbering system from 1-6 was used with visually impaired respondents. The number 1 or innermost circle represented a position for those people respondents felt closest to; the number 6 or outermost circle represented the position for those felt to be most distant. The segment represented a position for people considered important but where the relationship was considered problematic in some way.



Appendix 3

A Note on Terminology

Employers

Finding a generic term for the description of people who received direct payments was difficult. Some authors favour the term 'recipient', thereby defining the main relationship as between the disabled person and the service system. Here this was rejected because of the primary focus of the research.

The term employer, which is used here, has some limitations. It describes the main relationship as between the disabled person and the personal assistant, and thereby ignores possibly more important relationships between disabled people, their families and friends. Obviously disabled people had a range of relationships with family members, who were described in a variety of ways and specific descriptions are used where possible. However these are not generic terms. 'Employer' is also unsatisfactory because of the variation in ways that respondents described their status and relationships: not all disabled people identified themselves as employers. With these caveats, the term is used in this thesis.

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