

Changing social relations: A study exploring the  
roles, responsibilities and relationships of  
employers with learning difficulties and their  
personal assistants.

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## Abstract

Cash payments in the form of direct payments have become an essential tool in the distribution and provision of social care support. This development has been hailed to represent 'a potentially revolutionary challenge to [the] unequal relationship between providers and receivers of care' (Glasby & Littlechild 2002: 137), which has shifted the position of social care recipients from 'service users' to commissioners, developers and managers of their own support and created the role of personal assistant. This thesis explores this challenge through the experiences of newly created 'employers' with learning difficulties and their personal assistants, within the discourses of independence, choice, control and empowerment which stand as central principles within the personalisation agenda (DH 2007a; DH 2007b). The personalisation agenda is argued to be situated within the at once competing and complementary analysis of the Independent Living Movement and New Labour's analysis of the 'new global realities' (Cerny & Evans 2004), which requires a re-negotiation between the citizen and the state. These direct employment relationships represent one of the critical points at which our relationship with the state is in the process of flux. It is this, our relationship with the state in social care, heralding new forms of responsibilised citizenship in the form of citizen-consumers (Clarke et al 2007) and citizen entrepreneurs (Scourfield 2007), in combination with the changing social relations of support in the form of personal assistants, that is of interest. Drawing on disability studies and feminist analysis situated within the political economy, this thesis explores, with equal interest, the experiences of employers and personal assistants. Whilst it is clear from this project and others (Gramlich et al 2002; Stainton & Boyce 2004; Prideaux et al 2009) that directly employing personal assistance offers the opportunity to create a personalised support arrangement, however questions emerged around the equality of that opportunity and implications for a workforce which has historically remained low status, low paid and unsupported (Ungerson 1997a). These questions brought into perspective how 'empowerment' is experienced and



encouraged an analysis in which support relationships are characterised as much by 'interdependence' as 'independence', questioning the extent to which the 'commodification' (Ungerson 1997b) of support represented the value, or lever of empowerment. Rather, it was the personal and informalised aspects of these relationships that offered value and which returns us to a recognition of the social in the personal.

# Contents Page

|  |     |
|--|-----|
| Accessible Summary   | vii |
| Chapter 1: Introduction  | 1   |
| <b>Part I: Changing Relations</b>  |     |
| Chapter 2: Discourses of direct payments   | 8   |
| Community 'care' & the politics of disability  | 11  |
| Valuing people, normalisation and personalisation                                    | 24  |
| Direct payments as a 'technology of citizenship'                                     | 35  |
| Changing relations: from 'care' to 'assistance'                                      | 42  |
| Chapter 3: Methodology   | 53  |
| Research interests   | 53  |
| Participants: Employers, personal assistants and supporters                          | 55  |
| Ethics & analysis  | 61  |
| Introducing the participants   | 81  |
| <b>Part II: Emerging themes: contingencies of 'empowerment'</b>                      |     |
| Chapter 4: Beginnings  | 88  |
| Chapter 5: Roles   | 110 |
| Personal assistant as practical  | 117 |
| Personal assistant as personal   | 122 |
| Personal assistant as a 'technology of citizenship'                                  | 127 |
| Negotiated 'support', 'doing', 'independence'<br>and 'resistance' in the 'community' | 139 |
| Chapter 6: Responsibilities  | 143 |
| Becoming a 'responsible' employer  | 148 |
| Personal assistants in conflict: responsible 'to' and 'for'                          | 166 |
| Responsibilities: questions of empowerment   | 184 |

|   |         |
|---|---------|
| Chapter 7: Relationships  | 188     |
| Working relations   | 196     |
| ‘Friendly’ relations  | 201     |
| Formalising the informal  | 206     |
| In-formalising the formal   | 211     |
| Negotiated boundaries   | 217     |
| Commodification and (de)commodification of support                      | 227     |
| <br>Part III: Discussions and Conclusion<br>                            |         |
| Chapter 8: Personal & Social Lives                                      | 232     |
| Taking the responsibility   | 238     |
| Social relations of support – the informal and the professional         | 243     |
| Working together  | 246     |
| Suggestions for practice  | 250     |
| Chapter 9: Conclusion: Searching for the personal<br>and the collective | 255     |
| <br>Part IV: Appendices<br>   |         |
| Appendix I: Accessible leaflet and consent form                         | 261     |
| Appendix II: Personal information assistant leaflet                     | 269     |
| Appendix III: Supporters information leaflet                            | 272     |
| Appendix IV: Consent form   | 275     |
| Appendix V: Topic guides  | 277     |
| <br>Glossary  | <br>279 |
| <br>References  | <br>282 |

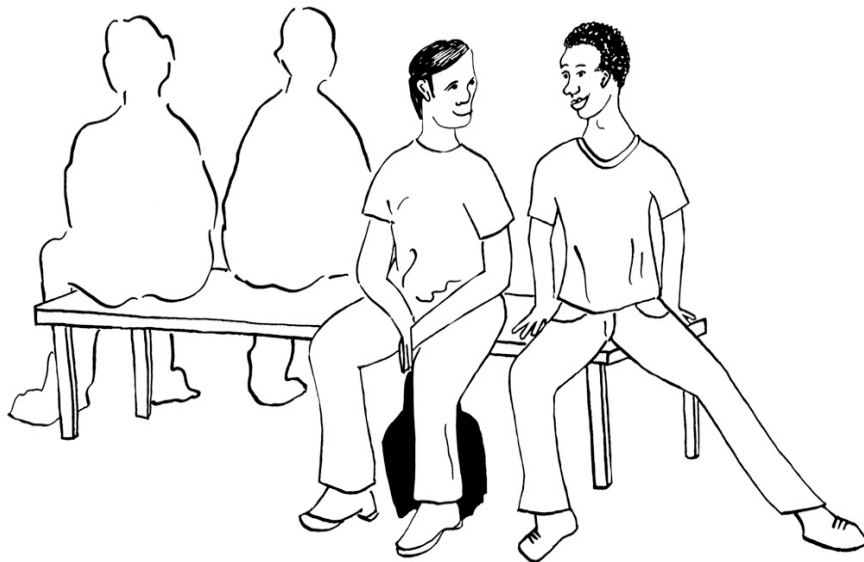
## Acknowledgements

I would like to take this opportunity to thank John Brown and Ian Buchannan for their support and supervision of this project over the last 3 years and the ESRC for funding the project. I would also like to express my gratitude to the local People First group who through their battles to highlight the legitimate demands of people with learning difficulties have taught me the meaning of self-advocacy and reminded me of the importance of research that explores, questions and is theoretically engaged, but equally counts and offers the possibility of change. Needless to say (and has been said many times) thank-you to my family (and friends) who have been of immense emotional and practical support when things have been hard and of particular importance, my sister, Helen, who, through her endless enthusiasm for new ideas, both supported and challenged me intellectually, for which I am very grateful. Finally and most importantly I would like to thank everyone who took part for sharing, so freely and generously their experiences, without whose contribution this project would not have been possible.

## Author's declaration

This thesis is presented as my own work – with the guidance and supervision of John Brown and Ian Buchannan. None of this thesis has previously been presented or reproduced in any other form.

‘Changing Relations’ : A project about people with learning difficulties and their personal assistants.



This is an accessible summary of the final report. Some of the words may be difficult and you might want to ask your supporter to help.

This is a project about:



Direct payments

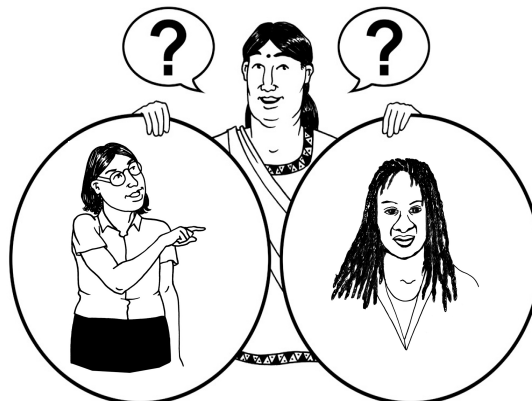


People who employ their own personal assistants - employers.



And people who work as personal assistants

This project is interested how it feels to employ a personal assistant and how it feels to work as a personal assistant.



## What happened?



This project was done by Katie Graham as part of a PhD course at the University of York.



A PhD often involves a big research project which normally takes 3 years to do.



This project talked to 24 people to find out what it is like to employ and work as a personal assistant.

## Who was interviewed?

To help understand how direct payments work and what it is like to employ a personal assistant different people were interviewed:



Employers



Personal assistants

And supporters, who were either:



The employer's family



Or the employer's care manager



## What were the interviews like?

All involved were asked similar questions about:



What is it like being an employer?



What is it like working as a personal assistant?



What is good about employing or working as a personal assistant?

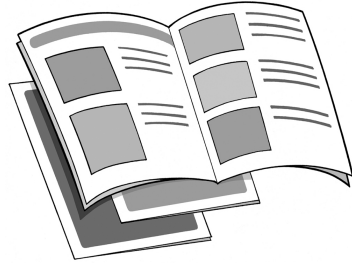


What is difficult about employing or working as a personal assistant?



What would make it easier or better?

## Why is this project important?

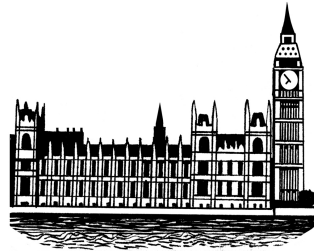


This section looks at the history of direct payments.

It also looks at different people's ideas about why direct payments are important including:



Self-advocates



The government



And academics

## Direct payments



Direct payments were introduced in 1997 after the government passed the Community Care (Direct Payments) Act 1996.



Direct payments mean that people can now employ their own personal assistants.



At the beginning it was difficult for people with learning difficulties to get a direct payment.



But now everyone is being encouraged to take a direct payment through personal budgets.

# Valuing People



Valuing People papers are a group of Department of Health papers about how to make the lives of people with learning difficulties better.

The most important ideas in Valuing People are that people with learning difficulties should have access to:

Rights



Independence, with support



Choice



Inclusion



# Personalisation



Personalisation is the new word the government has used to describe changes in social care.



Personalisation is about individuals in their communities.



Making choices



And taking control and responsibility for their life. A part of this maybe employing a personal assistant.

Research  
Question  
?



How can direct payments help people with learning difficulties have independence, make choices and take control of their support?

## Personalisation sounds good. Are there any problems with personalisation?



Some people are worried that personalisation means that people will become isolated and lonely.



Personalisation can mean taking control of your life. Some people have good family and friends to support them.



Some people do not have as much support to help them take control, make choices and manage their support.

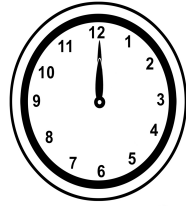


Other people are worried that personalisation could lead to inequality.

# Personalisation and personal assistants



Personal assistants are an important part of the personalisation agenda.



Personal Assistants often work only a few hours a week for their employer.



Personal assistants are managed and paid directly by their employer.



Some research has shown that most personal assistants enjoy their work.

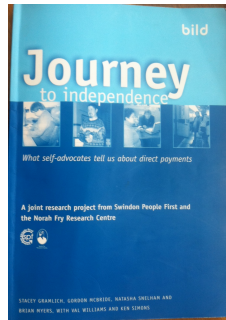


This research also said that personal assistants enjoy getting to know their employer.



How can personal assistants work to support the independence, choice and control for their employers?

## Being an employer



A project called *Journey to Independence* done by self-advocates said that direct payments can make a positive difference to peoples lives.



But they also said that employers need more support to manage their direct payment and personal assistants.



They also found that being part of a self-advocacy group helped to give people the skills and support they need to manage their personal assistants.



Good accessible information is really important for people employing their own personal assistants.



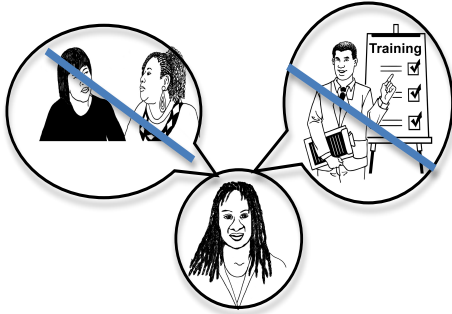
And good support services are also really important to make the most of a direct payment.



## Being a personal assistant



*Journey to Independence* also thought about personal assistants needs.



They said that personal assistants need good support to work well. Personal assistants often do not have any support or training.



Other people worry that personal assistants have low wages.



And some people think that personal assistants do not have good employment rights.



Trade Unions are organisations which protect workers rights and support them when things go wrong.

Most personal assistants are not members of a trade union.

## Employers and personal assistants: What does the research tell us?



Direct payments and employing your own personal assistant can work really well for some people.



Some people need more support to make direct payments work for them. At the moment there is not enough support for employers.



Some personal assistants really enjoy their work.



However, some personal assistants do not have access to the support and training that they need.



How do we make sure that everyone is supported?  
How do we make sure that the benefits of direct payments are experienced equally?

There were 4  
general  
research



## Research Questions

These questions came from research that people have already done and ideas in government papers such as Valuing People.



1: How can direct payments help people with learning difficulties have independence, make choices and take control of their support?



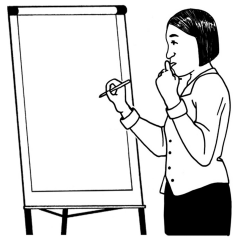
2. How can personal assistants work to support independence, choice and control for their employers?



3. How do we make sure that everyone is supported?

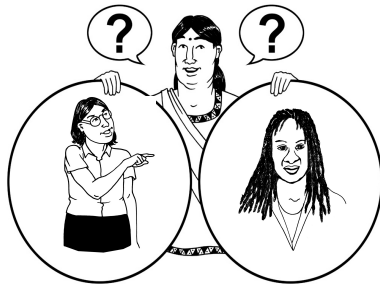


4. How do we make sure that the benefits of direct payments are experienced equally?



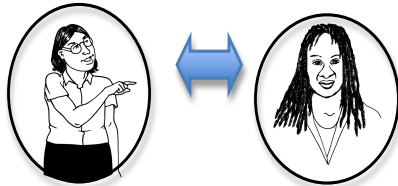
## What did we learn from this project?

The people involved in this project talked about lots of different things. Three particular things stood out:



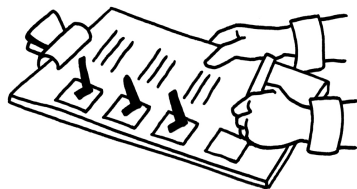
### Roles

What is it like being an employer?  
And what is the role of the personal assistant?



### Relationships

This about the how employers and personal assistants work together.



### Responsibilities

This section looks at the responsibilities of being an employer and personal assistant.

## Roles: What do personal assistants do?

Personal assistants and employers talked about the different types of support personal assistants offer. These include:



Support at home:

Shopping



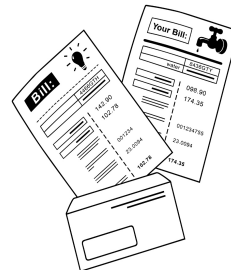
Cooking



Cleaning



Bills





Support outside of home

Socialising



Work



Holidays



“having a laugh”



Personal assistants do lots of other things as well, like supporting people to appointments, support with e-mailing, working on allotments and some personal care support.

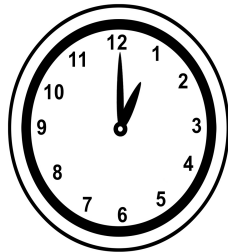
## What makes a good personal assistant?



Employers talked about what they think makes a good personal assistant.



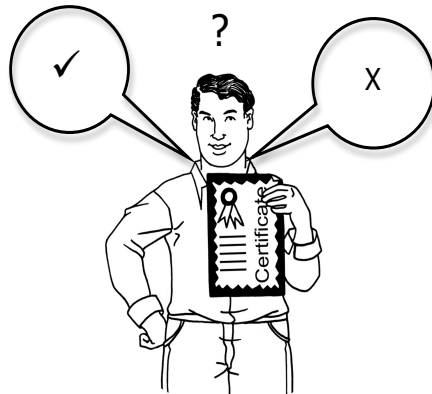
A clean CRB check



Reliable. Employers said that it was important that personal assistants come on time.



Trustworthy: People said that it is important that personal assistants are respectful of confidentiality.



Experience: Some people like to employ people with qualifications. Other people prefer not to employ experienced people and preferred to train them themselves.

Personality: Many of the employers talked about the personal qualities of their personal assistants. These personal qualities included:



Someone who has similar interests



Someone who can listen



Someone who invites you out with their friends and can get on with your friends.

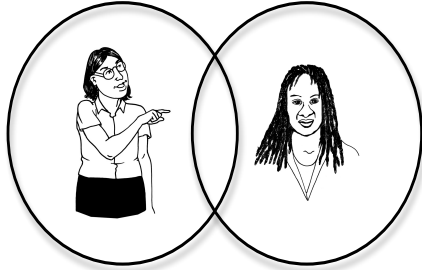


Someone you can get along with.

It was really important to many of the employers that they employed personal assistants who they had things in common with and someone they could get along well with.



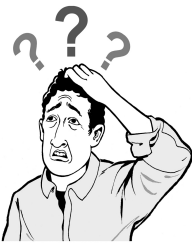
## “It’s a two-way thing”



Employers talked about working with their personal assistants as being part of a team – “it’s a two-way thing”.



However, some personal assistants were not clear about how they should be working.



When people talk about independence what do they mean?



Some personal assistants were concerned that they were ‘doing’ too much for their employers.



Rather than ‘supporting’ their employer to do things themselves.

## Relationships: getting along with your personal assistant.



People talked how they get along with their personal assistants.



Some people employed their friends to work as their personal assistants.

However some people found that this caused problems.



People were worried that it would be difficult to tell their friends what to do if they were working as their personal assistant.

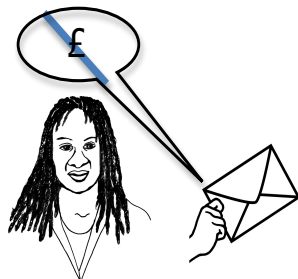
## Different people had different relationships with their personal assistants



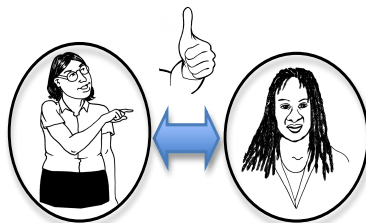
Friendly: Everyone said it was important to be friendly with their personal assistants.



Family: Some employers employed a family member to support them.



Some personal assistants had close relationships with their employers and offered to help even when they were not being paid.



Other personal assistants said that they enjoyed getting to know their employers and that it “doesn’t feel like work”

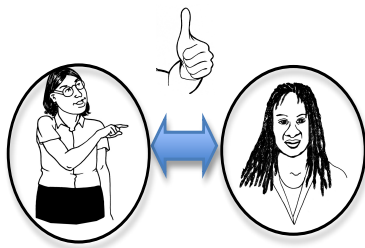
## It's good when everyone's involved

One employer said:



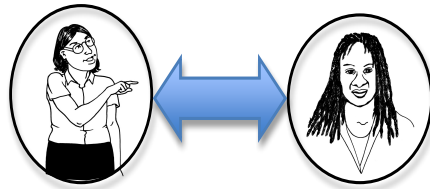
“I think when, the best bits for me is when they say they enjoy what they do...when the personal assistants say I really enjoyed that what we did today, I'm really glad you chose to do that and that really makes me really happy because I've done something for me, cos I've also involved them as well”

A personal assistant said:

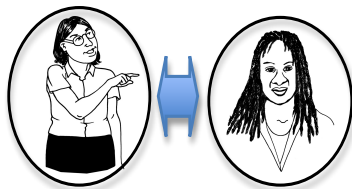


“I have really enjoyed getting to know [my employer], it's the most personal job that I have ever had, you can really get to know somebody, understand their ups, their downs, understand how she ticks as well, that's been really really good”

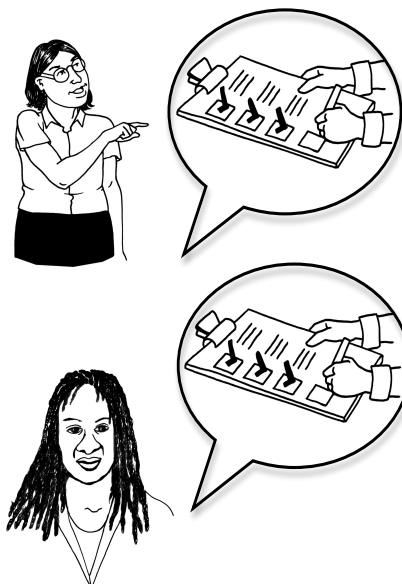
## Making sure everyone is happy



Everyone said that getting on well with your personal assistant is important, but some people also thought that it is important to keep some distance between the employer and personal assistant.



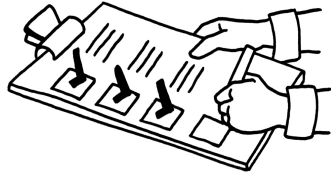
And that getting too close can cause problems.



A clear description of the job of employer and job of personal assistant can be helpful in avoiding problems.

## Responsibilities: becoming a responsible employer

Employing a personal assistant means taking some responsibility for:



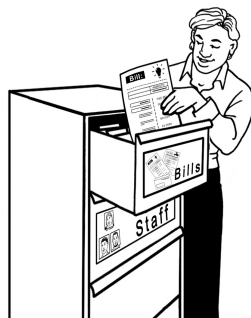
A personal assistant's job description.



Paying their personal assistants including tax and national insurance contributions.



Training their personal assistants.



In many places an Independent Living Service helps with these tasks.

This project found that there is more to employing a personal assistant than paying them.



Employers wanted training and support to be employers.



And employers wanted training opportunities for their personal assistants.



Some people found training courses for their personal assistants themselves.



Others trained their personal assistants themselves offering their personal assistants an induction.

## Working alone: being a personal assistant can be a hard job.



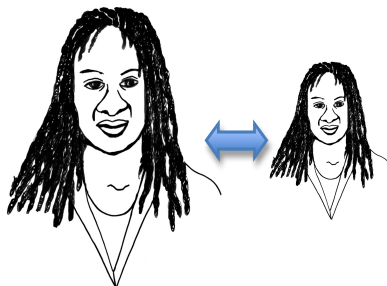
Both employers and personal assistants felt that being a personal assistant can be a difficult job.



Some personal assistants felt they needed more support to do their job well.



At the moment there is not any support for personal assistants.



Some people have a senior personal assistant to offer support to other personal assistants.



## Being a responsible employer and being a responsible personal assistant



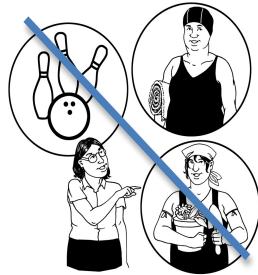
This project found that being an employer can be difficult.



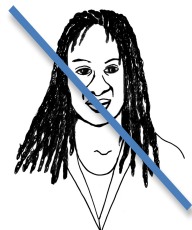
And being a personal assistant can also be difficult.



Both employers and personal assistants need support.

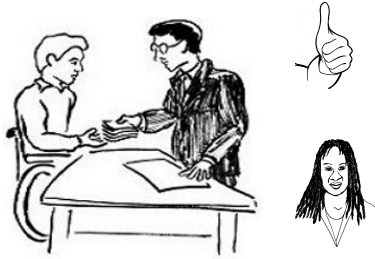


If employers do not have the support they need then direct payments may not offer people as much choice and control as they should.



If personal assistants do not get enough support they may not be able to work as well as they would like to.

## Conclusions: Personal solutions



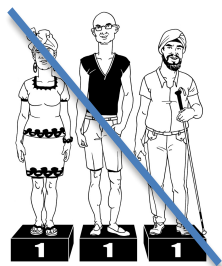
Direct payments and employing personal assistants can make a big difference to people's lives.



However, employing a personal assistant can be difficult and employers and personal assistants do not always have the support they need.



Different people need different levels of support.

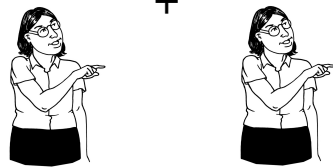


If support is not based on each person then some people will not get the most from direct payments and this could create inequality.

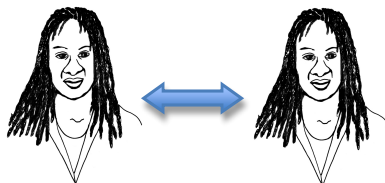


This is the last section is about what could make life better for employers and personal assistants.

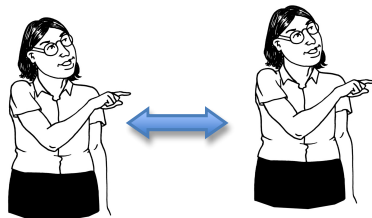
Here are 3 suggestions of things that might help:



1. People putting their budgets together.



If employing more than 1 personal assistant this might offer peer support for employers and personal assistants.



## 2. Inclusive circles of support



Circles of support can be useful to support employers to manage their personal assistants.



At the moment circles support the person. Would having a member of the circle to offer support or supervision to personal assistants be possible?

+



Or would this take control away from the employer?



3. The importance of funding self-advocacy groups to campaign for fair support for everyone.



I would like to thank all of the employers, personal assistants and supporters who took the time to speak to me for this project.



By Katherine Graham 2011. An accessible summary of the changing relations project.

# Chapter 1

## Introduction

In 2002 a direct payments user with learning difficulties<sup>1</sup> talked about the potential of direct payments to escape 'service land':

This gives you a chance to get out of service land. In service land everything is labelled clearly, so they can stay in full control of everything (your life), no risks involved. Service land has crates (labels, and what they choose for us) – these are only options but may not be totally suited to us

(a direct payment holder in Gramlich et al 2002: 18).

Direct payments enshrined in the Community Care (Direct Payments) Act (1996) offered people who formally used services the opportunity to directly employ their own support. This opportunity to directly employ support has been hailed as '...a potentially revolutionary challenge to [the] unequal relationship between providers and receivers of care' (Glasby & Littlechild 2002: 137) offering opportunities for self determination beyond the 'crates' or labels used in 'service land'. Various cash for care schemes are in place throughout Europe and the USA (Ungerson & Yeadle 2007a) and represent a broader shift towards user control and the commodification of 'care' (Ungerson 1997b) and one which is set to be further developed through personal budgets (DH 2010).

These previously unequal relationships formed through traditional forms

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<sup>1</sup> People with 'learning difficulties' have been labeled in different ways in different countries at different times. As disabled people redefined 'people with disabilities' to emphasise the 'disabling society' (Oliver 1983), people with learning difficulties chose people first and through this a general consensus emerged that 'difficulties' should be used in preference to 'disability' as it reflects the social model of disability and acknowledges that people's needs change over time ([www.peoplefirstltd.com](http://www.peoplefirstltd.com)). Valuing People (DH 2001) uses the term 'learning disability' and it acts as a signifier of eligibility to receive services. However, reflecting this preference for 'people with learning difficulties' it is this term which will be used throughout.

of 'care' in residential settings and community environments through private, voluntary or local authority home support often failed to respect and respond to the needs, wishes and aspirations of the people they aimed to support (Beresford 2001) and it is through the transfer of cash payments that these support relations are intended to be altered.

The rise of the Independent Living Movement sought to challenge these unequal relationships and relocate the debate away from responsibility to provide a minimum level of maintenance support, towards a system based on a discourse of rights. Morris writes:

The new system of direct payments—with all its imperfections, which include the fact that, at the moment<sup>2</sup>, it is not to be applied to people over the age of 65—is an important stage in the achievements of a civil rights movement. I would argue that social researchers have a moral responsibility to collaborate with this movement in any work which they develop on issues which are not of mere academic interest but which concern people's rights to choice and control in their lives.

(Morris 1997: 60).

Morris situates the achievement of direct payments as a stage in a civil rights battle which, she urges, should be approached in collaboration with those for whom the opportunity to have rights, access to choices and control has been denied. The rights based discourses of the Independent Living Movement (Morris 1993b) throughout the 1980's and 1990's chimed with a political and economic analysis which sought to reappraise the methods and motivations of the welfare state. This meeting of the discourses of rights, from the Independent Living Movement, and the introduction of more consumerist discourses fitted neatly into, not only Conservative political principles, but also New Labour's analysis of new global realities (Cerny & Evans 2004) and as

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<sup>2</sup> This stipulation was extended in 2000 to include older people (Clark et al 2004).

such Spandler (2004: 190) argued that direct payments represent 'a complex confluence of new right, New Labour and welfare user movement ideologies and demands' (Spandler 2004: 190).

Former Prime Minister Tony Blair clarified this new approach to public services in the social care green paper, *Independence, Wellbeing and Choice*:

"We are proposing to put an entirely different dynamic in place to drive our public services: one where the service will be driven not by the managers but by the user."

(DH 2004 in DH 2005a: 20)

This new dynamic and relationship between the public sector and users of services reflected a new analysis of the contract between the state and the individual founded on a belief that the social rules had changed. The boundaries and obligations of the post war social contract of the welfare state had shifted. Emergent citizen-consumers (Clarke et al 2007) in all areas of life now exist in a reflexive project where the 'natural' order of things has been called into question (Giddens 1994). Changes in social care and the increasing conditionality of welfare (Dwyer 1998) place social care research in the centre of this re-negotiation of the relationships, rights and obligations of the state and the individual. This research project is situated within this analysis of the reflexive project exploring these changing relationships and developing identities of people with learning difficulties from 'users of services' to designers, developers and employers of their own personal assistants.

Direct payments are positioned as a powerful tool in the transfer of power from the public sector to the user (Leece 2010) and now act as a key tool in the development of the personalisation agenda. Leadbeater, an enthusiastic and influential advocate of personalisation, defines the 'simple' yet potentially transformative agenda as:



Privatisation was a simple idea: putting public assets into private ownership would create more powerful incentives for managers to deliver greater efficiency and innovation. Personalisation is just as simple: by putting users at the heart of services, enabling them to become participants in the design and delivery, services will be more effective by mobilising millions of people as co-producers of the public goods they value.

(Leadbeater 2004: 19)

In spite of, or perhaps due to the simplicity of the idea of personalisation, Ferguson (2007) argues that the value of the personalisation agenda (for politicians and policy makers) lies in its ambiguity, arguing that whilst representing a tool of empowerment it is also intrinsically linked to the New Labour project of individualisation, responsabilisation and the privatisation of risk. It is within these ambiguous discourses of choice, control and empowerment, located and facilitated within an open market, that this project also has an interest in the people who are employed to facilitate and enable these values.

Therefore this project seeks to explore, not only, the experiences of people with learning difficulties who have chosen to take a direct payment and directly employ their own personal assistants, but in tandem the experience of working as a personal assistant for an employer with a learning difficulty. Hasler et al (1999: 5), much quoted in government literature, emphasised that direct payments are ‘...[A] means to an end and that end is independent living’. However, as Scourfield (2005) suggests the ends may be clear, but the means to meet those ends are less so. This project builds on questions about how those ends are met in the context of increasing numbers of direct payments users choosing to directly employ their own personal assistants (Prideaux et al 2009; Manthorpe & Hinde 2010). In achieving the ends it is critical to consider the context in which lives are lived.

Ungerson (1997a) sought to problematise a system which whilst offering

apparent autonomy to one group of people may, advertently or inadvertently place another group, in this case, the social care workforce, in a potentially vulnerable position. In response to Ungerson's work Morris argued:

Any work on direct payments and the labour market, of the kind referred to by Clare Ungerson in her paper, should be informed by the work and action which the Independent Living movement has developed over the last 20 years. It is unfortunate that her paper has taken the work of another researcher (myself) and substituted it for an understanding and acknowledgement of achievements of the Independent Living movement. This is deeply insulting to the people whose social action and social theory have, in promoting their human and civil rights, changed the whole way that we think about disability and community care.

(Morris 1997: 57)

Heeding Morris' concerns, but simultaneously remaining concerned about the creation of a workforce with few rights (Ungerson 1997a; TUC 2008), this project begins with the premise that the material conditions of all involved are vital and that the juxtaposition of one group over another denies the shared experiences and concerns of people who employ and work as personal assistants (Spandler 2004). In practice front line workers are a part, if not a large part, of the means to the end of independent living yet we have limited knowledge about what it is like to be a personal assistant and how – and of particular interest to this project – personal assistants seek to support people with learning difficulties as direct employees.

In the development of cash payments and the personalisation agenda there has been little mention of personal assistants in terms of their role or how they are to facilitate the 'ends'. The positive impact of direct payments for disabled people has been well documented (Stainton & Boyce 2004; Prideaux et al 2009), however this has been less well

explored for people with learning difficulties (Arksey and Kemp 2008). Skills for Care (Eborall et al 2010) estimate that in 2009 the personal assistant workforce to have been made up of 263,000 people with projections of the workforce expanding to between 495,000 and 722,000 by 2025. *Think Local, Act Personal* (Putting People First Consortium 2011) and *Capable Communities and Active Citizens* (DH 2010) offer the context for further reform and intention to extend, not only the opportunity, but the expectation that people will choose to take a direct payment and directly employ their own personal assistants in future.

Given this potential increase in demand for personal assistants and a lack of understanding of the experiences of people who have learning difficulties and employ their own personal assistants (Hastings 2010), this project seeks to explore these relationships from both the perspectives of the employers and personal assistants in an attempt to understand the nature of these employment relationships, how they are negotiated, and the expectations and support needs of all involved.

Part I seeks to explore the conceptual and theoretical framework surrounding direct payments. Chapter 2, *Discourses of direct payments*, draws on disability and feminist analysis and constructions of 'care' within the context of broader social policy reflections upon the theoretical and policy discourses of choice, control and empowerment to enable an exploration of the positioning of the employer and personal assistant amongst these at times competing discourses. Chapter 3, *Dual perspectives*, focuses on methodology and process of the research project situating the project within the context of inclusive research methodologies (Walmsley & Johnson 2003) and the importance of accountability of the research project (Stalker 1998).

Part II forms the main body of the research organised into three themes, with an introductory chapter, *Beginnings*, introducing the participants in their own words. Chapters 5, 6 and 7 explore the three primary themes

of roles, responsibilities and relationships which collectively illuminate the complexity, joys and tensions at play in these new relations of support.

The final section, Part III, aims to tie the strands of Part II together with an analysis of personalisation and self-directed support that is as much about interdependence as it is about independence. The personalisation agenda's focus upon the 'individual' with individual responsibilities and obligations to society downplays structural and social inequalities, and whilst emphasising the community, marginalises the importance of the collective. This concluding section offers an exploration of the implications of the findings in the Roles, Responsibilities and Relationships chapters suggesting that the contingencies of empowerment are significant in the experience of directly employing personal assistants, specifically that opportunities to make choices and take control are unevenly distributed and in agreement with Fyson (2009) often dependent upon the social capital of the employer. This chapter also draws out one of the contradictions of the personalisation agenda in the professionalising and in-formalising<sup>3</sup> of the role of personal assistants and finally a recognition that support and assistance is built on relationships. Ideas of independence and control are challenged through preferences to 'work together', these in combination led to an exploration of practical ways to embrace the personal whilst celebrating the interpersonal and exploring ways of reconnecting with the social.

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<sup>3</sup> In clarification - In-formal or in-formalising has been used throughout to refer to a movement towards the 'informal' rather than complete transition between the formal world of personal assistant work and the private sphere of 'informal' support.

# Part I: Changing Relations: Literature review and methodology

## Chapter 2

### Discourses of direct payments

Direct payments through the Community Care (Direct Payments) Act (1996), in combination with the earlier Independent Living Fund<sup>4</sup> (Glasby & Littlechild 2006), were the first incarnations of cash payments in the UK. Since the implementation of the Community Care (Direct Payments) Act cash payments have been configured in different ways. In 2008 the final report of the Individual Budgets Pilot Programme (IBSEN) reported findings from a large scale, Department of Health funded, piloting of individual budgets (Glendinning et al 2008). Individual budgets, which the evaluation explicitly explored, represent a development of the single social services budget (a direct payment) broadened out to include social care as well as housing support, equipment funding and employment based funding streams such as Access to Work and are a particular type of pooled budget. Recent developments have focused on the implementation of personal budgets which commonly describe a budget which is allocated from social services, rather than a pooled budget (Carr 2008). Personal budgets represent a holistic change in the assessment and allocation of funding through a self-assessment and resource allocation system (RAS)<sup>5</sup>. This self-assessment process seeks to further alter the relationship between the local authority, care manager and the person looking for support services through individual planning and commissioning of support. Personal budgets therefore represent a shift

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<sup>4</sup> The Independent Living Fund was founded in 1988 and closed down to new recipients in 1992 and throughout its existence demand far exceeded expectation (Morris 1993).

<sup>5</sup> This project does not explore either self-assessment or the development of RAS systems as these more recent developments were not fully in place during the period of this project.

forward from direct payments which may have been agreed for very specific needs, for instance alterations of property, but have been largely used for personal support (Pearson 2000; Manthorpe & Hindes 2010)<sup>6</sup>. Therefore direct payments represent an evolving strategy for the distribution of social care funding.

The original legislation conferred a power rather than a duty to offer direct payments, which offered significant discretion to the local authority with eligibility dependent upon the person being considered 'willing and able' to manage the payment (DH 1996: 10-11 in Gramlich et al 2002: 9). Consequently, although not specifically denied access to direct payments in the legislation, people with learning difficulties were largely excluded from the opportunity to self-direct their own support (Glasby & Littlechild 2006). The 'willing and able' caveat has since been redefined and local authorities have a duty to offer direct payments to all social care users and eligibility is judged on the difference it could make rather than the onus being on the direct payment holder to take total responsibility for the payment (DH 2004b). This was significant for people with learning difficulties in their pursuit for the civil rights fought for by disability activists.

Direct payments were sought and offered as a solution to the problem of poor quality and inflexible services for social care users. The limitations of the initial direct payments legislation through the Community Care (Direct Payments) Act (1996) are testament to the power of the disability

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<sup>6</sup> Due to the semantic confusion about the differences between individual budgets and personal budgets they are only specified, within this thesis, when referenced in relation to a particular method of combining the funding (as in individual budgets) or the methods of assessment and self-assessment (as in personal budgets) in all other cases the term direct payment is used. The direct payment reflects the means of people receiving their funding from the local authority regardless of route. Direct payment has also been chosen over cash payment (which may reduce confusion) as this is how many of the participants in the project describe their budget and this project is primarily interested in the relationships that evolve out of directly employing personal assistants rather than the means by which their funding was granted.

movement and the lack of political mobilisation of other user groups. The 'willing and able' caveat led commentators to note, particularly in relation to people with learning difficulties, that, where a person with a learning difficulty could manage to convince the local authority that they are 'willing and able' to take a direct payment they may inadvertently talk themselves out of eligibility to receive services at all (Williams & Holman 2006).

As such, direct payments represent one of the most significant policy developments in social care in recent years emerging from the site of conflict between the traditional practices of institutional 'care' and the rights of disabled people to live autonomous lives, but these developments have been experienced unevenly. The uptake of direct payments by people with learning difficulties has historically been low (DH 2007a). The rights at the foundation of the disability rights movement, although theoretically also applied to people with learning difficulties, have presented more complex questions of support than the 'assistance' imagined in some of the literature surrounding disabled people's experience of employing support. Direct payments are embedded not only within the emancipatory aims of the disability movement and ideas of 'independence', 'choice', 'community inclusion' as pre-cursors to 'empowerment', but also hinged upon the workings of local care markets of support and assistance. As such the underlying discourses of direct payments have been subject to analysis from various quarters. The following literature review explores the development of thought around direct payments from the perspectives of disability studies and at times conflicting feminist work on 'care', through an analysis of the current changes in social care centred upon the development of direct payments within the personalisation agenda, drawing upon the, at times unproblematised use of the highly contested concepts of 'independence', 'choice' and 'community inclusion' as levers of 'empowerment'.

## *Community 'care' & the politics of disability*

The self-advocate in the 'Introduction' described the opportunities direct payments offer to escape 'service land' and the 'crates' or labels into which people with learning difficulties have been placed, through attempts to resolve what has been constructed as the 'social problem' of disability. The identification of disability as a 'social problem' has been a theme evident throughout the development of community care. The first part of this section outlines the development of legislation, which granted very specific types of support within institutions and the community, moving on to a discussion of community care in the field of disability studies and feminist analysis of 'care'.

Walmsley & Rolph (2001) suggest that the history of learning difficulties has to a greater and lesser extent been characterised by community care and mechanisms of 'care' and 'control' in the community. During the 1900's, although institutions were common, familial support continued to play a significant role in caring for people labelled as 'moral defectives' under the Mental Deficiency Act (1913). The categorisations of the Mental Deficiency Act (1913) remained for many years, only to be overturned in the Mental Health Act (1959) and institutional care (or control) continued to be the primary means to 'protect' people with learning difficulties and society at large. At this time, and in spite of growing awareness of the atrocities of Nazi Germany the ideas of the eugenics movement were still freely expressed. Tredgold writing in 1952 argued that people as defined under the Mental Deficiency Act 1913:

...are not only incapable of being employed to any economic advantage, but their care and support, whether in their own homes or in institutions, absorb a large amount of time, energy and money of the normal population that could be used to better purpose'

(Tredgold 1952: 92 in Race 2002: 33).



However, it would be misleading to suggest that these ideas were wholly socially acceptable and there was an equally powerful movement towards a re-conception of learning difficulty. The initial focus upon control, containment and 'protection' of society as a whole gave way to increasing recognition that people with learning difficulties:

...are an integral part of the human race...the extent to which we guarantee to them the maximum freedom which they can enjoy and the extent to which we help their families to give them the love they need, is a measure of the extent to which we ourselves are civilised.

(National Council for Civil Liberties 1951 in Concannon 2005: 29).

A growing commitment to community based support in line with the National Council for Civil Liberties' call for a more respectful and civilised approach to people with learning difficulties paved the way for a commitment to support for people in their own communities.

*Better Services for the Mentally Handicapped* (DHSS 1971) represented the first attempt to address the needs of people with learning difficulties and the final disentanglement of learning difficulty from the realm of mental health, a vital step forward in the development of improved support, as Stephen Thornton acknowledges:

...when you combine mental health and learning disability, mental health always takes the time, the crisis, staff shortages ... Learning disability just trundles along

(interview with author in 2005 in Walmsley 2006: 79).

This is evidenced by the key concern highlighted in *Better Services for the Mentally Handicapped*, specifically that development in learning difficulty services had been slow. The paper identified future targets including the movement of people from institutions into smaller community based residential accommodation and services. *Better*

*Services for the Mentally Handicapped* emphasised that 'home should be homely', mixed with potential to pursue individual interests (DHSS 1971: 35). Furthermore a label change was once again proposed, mental handicap, which was chosen '...in preference to any of the alternative terms because this helps to emphasise that our attitude should be the same as to other types of handicap' (DHSS 1971: 1). This change and commitment to homely residential services was clearly a huge leap forward and was a life changing experience as Mabel Cooper who lived in St Lawrence's Hospital near Croydon has said:

A lot of people, especially like me, we always think if they didn't have enough money to keep us outside they would say, "Right, you all have to go back in the hospital" and open them again. It's important they knock them down and then people like me and a lot more will know that won't happen. I think it worries a lot of people like me because they are still standing there because they could say "OK, we're going to open all that again and all the people what were there go back up there". Of course it saves them a lot of money. I know they have turned a lot of St Lawrence's off, they've built houses on there. Some of it's gone, but there's still a lot there.

(in Atkinson et al. 2003: 29).

Mabel's fears were not unfounded, community care and the dissolution of the large institutions, although popular and clearly evidenced as necessary through Goffman's *Asylums* (1961) and Morris' *Put Away* (1969) indictment of lives in institutions, was thought to lead to financial savings, an assumption which has been questioned (Dalley 1988).

Community care as a policy objective has often been cited as a source of tension and conflicts; at once liberating, from institutional care and expedient, developed to fit the political inclinations of the time, as Jones, Brown and Bradshaw (1983: 102 in Morris 1993b: 4) observed:

To the politician, 'community care' is a useful piece of rhetoric; to

the sociologist, it is a stick to beat institutional care with; to the civil servant, it is a cheap alternative to institutional care which can be passed to the local authorities for action – or inaction; to the visionary, it is a dream of the new society in which people really do care; to social services departments, it is a nightmare of heightened public expectations and inadequate resources to meet them.

This combination of emancipation, political expedience and financial concerns has led commentators to describe 'community care' as a slippery term (Bornat et al 1993) which whilst proffering emancipatory rhetoric, perpetuated smaller scale institutional style residential and day 'care' and continued dependence upon informal support. The collective provision of traditional services and aspects of community care have been effectively critiqued by disability activists and the Independent Living Movement, a critique which (in spite of having foundations in a very different place) fitted neatly with Conservative politics of the 1980s and 1990s. During this time the traditional values of the welfare state were challenged and re-framed to be the problem. This ideological stance represented a shift away from state responsibility towards the responsibility of the individual or the family unit and rested upon the assumption that it is open markets, rather than state monopolies that can best meet the needs of individuals in society. Beresford suggested that:

[T]he political new right condemned large-scale state welfare as costly, wasteful, bureaucratic, centralizing and inefficient; extending the power of the state at the expense of individual freedom and choice, advantaging the dependent at the expense of the productive and undermining market principles and competition, in turn weakening the creation of wealth and taking money from wealth created

(Hayek, 1982; Marsland, 1992; Deakin, 1994 in Beresford 2005: 467)

This vein of analysis of the state of welfare provision prompted further

reformation of social care provision with the passing of the National Health Service and Community Care Act (NHSCCA) (1990). *Caring for People* (1989) which laid out the plans for the forthcoming NHSCCA argued that:

Stimulating the development of non-statutory service providers will result in a range of benefits for the consumer, in particular: a wider range of choice of services...which meet individual needs in a more flexible and innovative way

(DH 1989 in Hoyes & Means 1993: 96).

The NHSCCA legislated the purchaser/provider split and transformed social work into care management, creating an environment where services were purchased by the care manager on behalf of their service user in response to an assessment of their needs (Means et al 2003) and simultaneously placed social care 'users' as 'consumers'. The state had never monopolised social care provision, private providers always existed, however the number of private nursing and residential providers increased from 23,000 to 193,000 between 1970 and 2000 (Carey 2008). This created a 'quasi-market' (Le Grand, 1997) where the motivation appears to be less about welfare rights than financial concerns (Dwyer 1998).

Community care as a preference to institutional care was clear, however care in the community became a byword for care 'by' the community (Finch 1993: 8). The importance of '*by the community*', emerged out of the inability of underfunded social services to meet the expectations of the disability and Independent Living Movement and added impetus to feminist researchers to consider the gendered nature and expectations of women to sustain the whole 'spectrum of care' (Finch 1993).

The growth of what came to be termed 'informal care' (Morris 1993a), placed expectations on families to provide 'care' and perpetuated relationships of 'dependency' between disabled people and their families.

Therefore, certain aspects of underfunded community care were welcomed neither by disability nor feminist activists. Baldwin and Twigg (1991: 129) write:

...sexual divisions in caring which currently disadvantage women are closely bound up with other aspects of their subordination – crucially with their status in the labour force, where low pay and part-time work confirm the ‘common sense’ of identifying them as carers.

Linking expectations to be carers with their position in the labour market feminist concerns were primarily focused on kinship care. Graham (1983) explored the gendered nature of ‘care’ as intrinsically linked to the way we define social relations. Graham introduces the concept of caring as a ‘labour of love’ primarily involving women and arguing that the states of labour; the activity component, and love; the identity component, do not always co-exist. The caring relationship, the ‘labour of love’, is expected to continue even when love may not be present. As such the state plays an instrumental role in the maintenance of women as carers, and generates a culture that recognises that:

...substitute services are not “care” as they lack the very qualities of commitment and affection which transform care-giving work into a life-work, a job into a duty

(Graham 1983: 29).

Therefore, Graham (1983) argues that it is through the experience of caring, the combination of identity and activity, that women can become accepted in the private area of the home and the public arena of the labour market through formal caring work as nurses, teachers, carers and social workers.

Through this work Graham’s position towards formal care is made clear, and has been extended through the interpretative categories of ‘caring for’

and 'caring about' (Dalley 1988). Dalley (1988) draws upon the work of Graham (1983) and Parker (1981: 17) and their work on 'tending'; the separation of feeling and doing; in an attempt to clarify the contested concept of 'caring'. She identifies a distinction between the acts of 'caring for', which represent the tasks of tending to another person and 'caring about' which refers to the emotional aspects of care. Dalley argues that these should be separable, however, the act of separation is discouraged by society's expectations of women as mothers and nurturers. Therefore women's family work of 'caring for' is a 'natural' continuation of her presumed predisposition to 'care about' her family (Dalley 1988). The work of Graham (1983) and Dalley (1988) exposed the results of community care policies and their influence over women's lives.

For disability activists community care resting on informal care and feminist analysis placing family members in need of support as a 'burden' only act to further entrench traditional understandings of disability and 'care' which revolve around and reproduce dependency and disempowerment. Morris (1993a: 38-9) equates any use of 'care' as akin to control:

The custodial nature of the role of carers as paid workers (which has traditionally been particularly strong within residential / institutional provision and has been carried over into domiciliary services) has heavily influenced the way that family members have become identified as carers. Those who have a personal relationship with a disabled person and who provide them with some form of help have been constructed as 'informal carers'. The word 'informal' is used to distinguish them from carers who are paid to help as a job but the common definition of 'carer' is much more heavily associated with the 'taking charge of' definition of care than it is with the 'caring about' definition.

Feminist analysis of care and women's formal and informal roles in line

with the recognition of the essential role informal 'care' plays has lent strength to the carers' lobby (Harris 2001) and informal care work as an expression of citizenship obligation has been recognised through successive carers strategies (HM Government 2008; HM Government 2010). As at any point in the development of community care, family (or informal) carers continue to play a role that is at once legitimised, recognised and problematised.

Morris (1993a) draws on the power dynamics of 'caring for' and 'caring about' in relation to the 'custodial' nature of informal and formal 'caring' or 'care work'. This power dynamic described within the distinction of 'caring for' and 'caring about' has been applied from the 'informal' to the 'formal' care-work setting. Wærness (1984: 70-72) advocates a conception of care, which dispels the distinction between formal and informal care. She argues that the important factor in the caring relationship is not whether it is performed in the home or institution, or if the care provided is waged or unwaged, but the power relationship between the carer and cared for. Wærness identified three kinds of care: 'personal services', 'care-giving work' and 'spontaneous care'. Each of these implies a different type of relationship between the carer and person cared for. Personal services was used to describe a relationship whereby the person cared for is of a superior status to the carer and involves care work which the cared for could provide for themselves. Care-giving work describes a relationship of 'dependency', where the person cared for has become 'dependent' through disability or illness. Wærness contends that this relationship is typically reliable and consistent. Finally, spontaneous care, which is not reliable, but '...arises impulsively and spontaneously' (Ungerson 1990: 14 on Wærness 1984). As with each of the types of care, Wærness suggests that spontaneous care is as likely to occur within the public or private spheres of care. Ungerson (1990) has identified certain difficulties with the different types of care, as she suggests it is more likely that caring relationships evolve rather than remain fixed over time. As such, she suggests that, for example, a spontaneous care gesture

could become expected by the receiver and thus become subsumed within personal services category of care. However, as Ungerson (1990) states, the importance of Wærness' typology of care is that it offers a challenge to the dichotomy between formal and informal care in combination with exploring the power relations at play within 'caring' relationships.

Whereas British feminist thought throughout the 1970's and 1980's focused on the 'burdensome' potential of care, a trend founded in the social and inter-relational aspects of care offers broader and wider ranging analysis of the 'ethics of care' (Fine & Glendinning 2005). This collection of work had begun to argue for a political ethic of care, which places care and caring relationships in their wider context. Sevenhuijsen (1998: 150) argues for caring solidarity:

We need caring solidarity not because the 'needy' are dependent on the solidarity of the 'strong', or because the 'strong' need to defend themselves against the looming threat of society's corruption by the 'needy' – an idea which has fast been gaining in popularity in recent years – but because everyone in different ways and to different degrees needs care at some point in their lives.

Implicit in caring solidarity and a political ethic of care are notions of interdependency whereby care is not reserved for the 'needy': rather it readily occurs in many aspects of human interaction (Sevenhuijsen 1998). Sevenhuijsen emphasises the interdependency of us all, however others have preferred to focus dependency as an intrinsic part of life. Kittay (1999) argues that to ignore or avoid approaching 'dependency' and 'dependency work' diminishes our ability to understand these relationships, rather she would argue, an engagement with 'dependency' re-enables a vision of how the spectrum of care is experienced and worked. Kittay (1999: xiii) draws out dependency in order to shed light on interdependency and:



Rather than denying our interdependence, my aim is to find a knife sharp enough to cut through the fiction of our independence.

In these respects Sevenhuijsen and Kittay have used 'care' to place it within broader contexts of rights and justice. As such 'care' has been posited as a useful analytic concept (Daly & Lewis 2000).

In spite of its potential analytic uses many have refuted the utility of the concept of care with its association with dependency as representing a return to the 'repression of those already marginalised' (Silvers 1997: 24). Richard Wood in 1991, the then director of the British Council of Organisations of Disabled People wrote:

Let us state what disabled people do want by stating first what we don't want. WE DON'T WANT CARE!

(quoted in Shakespeare 2006: 139).

'Care' therefore, in the context of disability activism equates to dependency. Independence as a constructed concept challenged by Kittay has been problematised and more clearly defined by Brisenden (1989: 9 in Morris 1993b: 23):

Independence is not linked to the physical or intellectual capacity to care for oneself without assistance; independence is created by having assistance when and how one requires it.

A rigid and common sense definition of independence of doing something alone or without help is countered through assistance. Within this re-interpretation of terms the social model of disability sought to raise awareness of the distinction:

...between the physical impairment and the social situation, called 'disability', of people with such impairment. Thus we define impairment as lacking all or part of a limb, or having a defective

limb, organism or mechanism of the body and disability as the disadvantage or restriction of social activity caused by a contemporary social organisation which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities.

(Oliver 1996: 22)

This distinction between impairment and disability has been critical in the development of the social model of disability (Oliver 1983) and it is through this radical redefinition of impairment and disability and a rejection of care that personal *assistance* could emerge (Shakespeare 2006).

The social model of disability (Oliver 1983, 1990) and Independent Living Movement (Morris 1993a), have been influential in the UK. The Independent Living Movement emerged from disabled people's attempts to leave residential care. Morris (1993b: 21) described the four assumptions behind the broad movement as:

- That all human life is of value;
- That anyone, whatever their impairment, is capable of exerting choices;
- That people who are disabled by society's reaction to physical, intellectual and sensory impairment and to emotional distress have the right to assert control over their lives;
- That disabled people have the right to participate fully in society.

These assumptions, although designed to be inclusive to people with learning difficulties and critical in the development of personal assistance, yet have had a difficult history with people with learning difficulties. Simone Aspis, a self-advocate said

People with learning difficulties face discrimination in the disability movement. People without learning difficulties use the medical

model when dealing with us. We are always asked to talk about advocacy and our impairments as though our barriers aren't disabling in the same way as disabled people without 'learning difficulties'

(in Campbell & Oliver 1996: 97).

Goodley (2001) further highlights Aspis' questioning of the relationship between 'learning difficulties' and impairment. Whilst disabled people have separated the impairment, and the disability flowing from it, people with learning 'difficulties' have been '[T]hrown into the category of naturalised, irrational 'other'' (Goodley 2001: 211). As such Goodley (2001; 2011) has sought to re-approach analysis of impairment to deconstruct the remaining essentialist link between impairment and the individual model to enable recognition of the social construction of impairment. The activism and campaigning of the disability movement, through an analysis of the social model, have elicited developments, including the development of direct payments, which have been of benefit to people with learning difficulties. However, simultaneously another strand of thought and action has been pervasive in the lives of people with learning difficulties. Gillman et al (1997: 690) sum up people with learning difficulties' experience of the social model, in direct contrast to disabled people, who have successfully:

...fought the colonisers of disability (e.g. medical and allied professionals) for the right to define disability on their own terms, the fight against the colonisers of learning difficulty is of a different order; it is a fight against the denial of humanity itself...hence *people first*

(Gillman et al 1997: 690).

Whereas disabled people highlight the disabling environments, emphasising shared experience and the collective, people with learning difficulties' self-advocacy movement has advocated *People First* which may reflect another, more individualised, approach to exclusion and

inclusion. Approaches to services for people with learning difficulties, although they often nominally acknowledge the social model, are hinged on the more individualised model of normalisation. Wolfensberger's ideas of normalisation and later Social Role Valorization (SRV) took root during the 1970s and 1980s and have been influential in the development and management of services and support for people with learning difficulties (Race 1999; Yates et al 2008). Normalisation and SRV look outwards to the community for socially valued roles and internally to the individual to effect change and therefore can be argued to assume conformity as a condition for acceptance (Brown & Walmsley 1997). Increased emphasis upon the community not only served the ideological perspectives of the presiding governments, but also supported the normalisation strategy which encouraged the:

...utilisation of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviours and characteristics which are as culturally normative as possible

(Wolfensberger 1972: 28).

Normalisation approaches place value upon culturally normative practices and have been commonly used as a service evaluation tool, potentially reflecting professionals' concerns rather than those of people with learning difficulties (Chappell 1992). However, advances in community participation, the potential for positive change and person-centred planning have all been attributed to the development of normalisation approaches in services for people with learning difficulties (O'Brien & O'Brien 2000). Nevertheless, where the social model comes into difficulty so too, when applied to people with learning difficulties, it can be argued, does normalisation:

As Foucault showed us, these impairments and the 'impaired individual' are emergent as objects of thought only within specific systems of knowledge. However, normalisation/SRV cannot acknowledge their status as constructed and contingent because of

the manner in which it conceptualises them

(Yates et al 2008: 250).

The very conception of the individual in a community and current essentialist constructions of 'learning difficulties' have made it difficult for normalisation to move beyond the individual (Yates et al 2008) and engage with the possibility of a social construction of impairment (Goodley 2001; Goodley & Rapley 2001). For disabled people who had begun to challenge the assumptions of institutional 'care' and medical constructions of disability successfully, 'community care' did not offer a significant challenge to the power wielded by social services through processes of assessment (Morris 1993b). Similarly the explicit emphasis upon informal care with a 'normative core' of reducing expenditure limited the possibilities of the 'empowerment' rhetoric claimed to be at its core (Rummery 2002).

### *Valuing people, normalisation and personalisation*

Where the 'empowerment' rhetoric failed to deliver through community care policies, people with learning difficulties had additional and specific influences over how policies, which seek to empower, were and are enacted. The significance of normalisation within community care for people with learning difficulties lies not only in its impact, upon the development and evaluation of services (Wolfensberger 1983 in O'Brien & O'Brien 2000), but through the importance attached to the fulfilment of socially valued roles, and as such the premise upon which support has been and continues to be offered. Traditional day services for people with learning difficulties (currently being re-provided into community settings) were developed as adult training centres which were dominated by industrial work-based occupations, some with the appearance of mini production lines. This emphasis upon work was minimised with the

release of Pamphlet 5 which declared that:

...day centres would no longer be insular and segregated settings dominated by industrial work, but centres of excellence that would facilitate a two-way flow between the centres and the community. Whilst work training and occupation would continue to play an essential role in the overall programme, the intention was to provide greater opportunities for integration in education, employment and leisure pursuits for all who could benefit, but essentially, still maintain a source of expertise and alternative resources for those unable to fully meet the challenges of ordinary community life.

(Henley 2001: 936).

Adult Training Centres became Social Education Centres blending occupational activities with more individual programmes suited to an individual's needs. These shifts in best practice within day centres have continued. In recent years O'Brien's service accomplishments, which stressed community presence, mainstream facilities, choice over life, opportunities to develop skills in order to reach potential, respect and community participation, have remained influential (1987 in Thomas & Woods 2003). In combination with the work of O'Brien, the King's Fund has released numerous critiques of and models for day services, notably the *Changing Days* project (Wertheimer 1996). *Changing Days* advocated community involvement and person-centred approaches to enable a move away from building-based services towards involvement in 'ordinary activities', education, employment and leisure pursuits outside of segregated services.

These ideas of an ordinary life necessitate doing 'ordinary' activities, having 'ordinary' friends and necessarily in this vein of thought having an 'ordinary' job (DH 2009e). *Valuing People* (DH 2001) outlined a vision for the future of learning 'disability' services ascribing to principles of the social model, normalisation as well as medical models of learning

'disability' with an emphasis upon labelling based on IQ. Whereas day centres were once perceived as spaces of learning and development *Valuing People* re-defined these centres as outdated institutions harbouring 21<sup>st</sup> Century exclusion, isolation and institutionalising practices with 'some...offer[ing] little more than warehousing' (DH 2001: 19). Day centres became places which were re-defined as offering poor support which created dependency and restricted possibilities of making real choices and taking control.

Services for people with learning difficulties have been, historically and arguably remain, low on the political agenda and in the early stages *Valuing People* (DH 2001) was to be nothing more than a strategy paper, but on hearing that there might be some governmental support for the paper it was elevated to the status of a White Paper (Walmsley 2006). Nevertheless there was little direct funding attached to the project, which in itself is a vague and confusing document which was likely to lead to regional variations in its implementations. *Valuing People* (DH 2001) has been described as '...an uneasy amalgam of the progressive and the neoliberal, the romantic and the practical...' (Burton & Kagan 2006), but offered a new direction in terms of a more participative response to the policy process (Walmsley 2006). The National Forum for people with learning difficulties was established, and a strategy to develop Valuing People Partnership Boards which were intended to offer the possibility of more local participation in the development of the agenda. The strategy is a strategy of values and 'vision', rather than being prescriptive and directive. As such *Valuing People* offers a collection of what could 'loosely be called aims' (Walmsley 2006: 94). This 'vision'<sup>7</sup> emphasises rights, independence, choice and inclusion with citizenship as an implicit discourse, which was more overtly emphasised in the follow up paper

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<sup>7</sup> A subsequent paper, *Valuing People Now. A new three-year strategy for people with learning disabilities. 'Making it happen for everyone'* (DH 2009d) has been added to the *Valuing People* series with a re-focus on (amongst other priorities) the personalisation agenda for everyone with emphasis upon people with more complex learning difficulties and people from minority ethnic groups.

*Valuing People Now* (DH 2007a). The rhetoric expounded in the *Valuing People* vision papers puts the priorities for 2008 – 2011 as: personalisation, supporting the development of choice and control over support; What people do during the day, involving the development of community inclusion in leisure activities, evening activities as well as work; Better health, improving access to mainstream health services; access to housing, with an emphasis upon home ownership; and making sure change happens, with a focus upon improving the efficacy of the Valuing People Partnership Boards.

*Valuing People's* focus upon inclusion into the 'community', emphasis upon choice, through direct payments and work, are at once celebrated and controversial. *Valuing People Now* states that traditional day centres prevent people with learning difficulties from '...getting a job and education and a life'. (DH 2007a: 7), but goes further when saying:

[W]e know what people say is most important to them and what society expects for all other people – access to real, paid work. As well as providing income, paid work opens up other opportunities such as social networks. It is an achievable objective for almost everyone, including people with complex disabilities

(DH 2007a: 30).

These thoughts would not have been out of place in policy direction discussions in the 1980's with the publishing of *An Ordinary Life* (Kings Fund 1980) and *An Ordinary Working Life* (King's Fund 1984). However, the link between getting a job and 'getting a life' is more contentious and in spite of the assertion in *Valuing People Now* research has suggested 'work is not a panacea for loneliness, or a guarantee of companionship' (Rooney 2002: 93). Therefore, *Valuing People's* commitment to employment for people with learning difficulties appears to be attempting to fulfil some kind of normalisation ideal of 'normality'. This motivation simultaneously fits neatly within a general trend away from benefits towards work. This can be seen in the policy rhetoric around the reform



of incapacity benefit where even people with complex needs are being called to discuss the 'getting into work' advice.

It is these assumptions that are of interest. *Valuing People* (as a set of policy documents) draws uncritically upon some contentious ideas, as Stalker has argued:

At times, choice is used in a way which draws on a tradition of self-determination: at other times, it draws on the very different tradition of the market. . . . [t]hese two distinct strands are contained and indeed concealed within the one concept blurring different and potentially conflicting ethos within current policy initiatives. . . . fudging the concept appears to be more politically expedient than defining it

(1998 in Harris 2003a: 3).

As illustrated above, the terms, which sound appealing and unproblematic, become problematic. *Valuing People* forms the beginnings of the trend whereby the 'market discourse' has been placed upon the challenge made by the disability movement (Spandler 2004) and ideas of normalisation and human rights (JCHR 2008) creating a 'powerful hybridisation, but one riddled with tensions' (Scourfield 2005: 473).

Through this logic, users of social care are re-branded as 'powerful users of social care' (DH 2006a: 83). Powerful users making choices are central to this agenda and of critical importance not only in terms of the development of the local care markets, which have already and will continue to develop, but also the spinning of the policy. Choice is used and experienced in numerous ways, it is associated with; the development of markets (Clarke et al 2007); the individualisation of society (Needham 2003); but also with abilities and opportunity to make choices (Rabiee & Glendinning 2010; Arksey & Glendinning 2007; Arksey & Kemp 2008). The Public Administration Select Committee

report (2005: 42), *Choice and Voice in the Public Services* highlighted one of the many difficulties with choice – its limitations:

We believe that some of the problems with choice would be eased if there was more acknowledgement of its limitations. Rhetoric does not match the reality. Too often the 'choice' label is applied to schemes in which the most the consumer can hope for is second, third or even fourth choice. It should always be made clear to people what they can realistically expect from the choices they are offered.

Direct payments are sold on their ability to offer choice where before, the assumption is that there was none, however the era of responsabilisation becomes a key factor for users, parents and carers' in the attempt to maximise the benefits of direct payments. The *Valuing People Now* consultation (DH 2007c: 35) findings revealed this as an anxiety:

Some respondents, particularly family members, reported concerns about the levels of responsibility and work loads associated with managing individual budgets, and said that more support would be needed for people with learning disabilities and family members to take on these responsibilities.

Whilst the respondents call for more support to manage the individual budget, it is the nature of the offer of choice which creates the responsibility within individual budgets (or direct payments). However, as Dwyer (1998) argues an important element of citizenship, is the accepting of more responsibility for social care arrangements to avoid continued 'dependency' upon public services. It is critical here who is willing to take the responsibility and the implications of not taking that responsibility.

If the support can be effectively managed, 'choice' can make anything

seem possible, as advocated by 'Alan', a man who uses direct payments, in *Valuing People*:

[Y]es that's for me! I like the idea of employing my own personal assistants who I could ask to do what I wanted when I wanted.

(DH 2001: 49).

Throughout this discourse lies the assumption that anything can be bought, if there is money to pay. People like Alan can perform active citizenship and make 'good' choices to maximise their possibilities, but concerns remain for those who for whatever reason are not able to successfully negotiate the markets, as Clarke argues:

[C]hoice is framed by sets of injunctions about reasonable choices and responsible behaviour. Responsible citizens make reasonable choices – and therefore 'bad choices' result from the wilfulness of irresponsible people, rather than the structural distribution of resources, capacities and opportunities.

(Clarke 2005: 451).

Therefore, it is the individual's responsibility to negotiate the market and make good choices, irrespective of the options of a market that has had a questionable impact upon the experience and empowerment of social care users (Baldock 2003 in Scourfield 2007).

The implications of the market for some are positive, those who have always opted out with personal means to make choices, however crucially Gilbert (2002: 189 in Scourfield 2007: 117) highlights fears that 'policies devoted entirely to cultivating independence and private responsibility leave little ground for a life of honourable dependence'. Fears of inequity in experience as a result of direct payments has been a common area of concern. Scourfield (2007: 119) has highlighted that if personhood is formed and displayed through being entrepreneurial and taking risks this raises concerns about those who are 'insufficiently

enterprising'. The ability to be enterprising is not evenly distributed. *Valuing People* (DH 2001) and *Valuing People Now* (DH 2007a) speak of 'equality of opportunity' and 'equality of citizenship' respectively whilst there is no mention of equality in *Capable Communities Active Citizens* (DH 2010). Active citizens making positive choices may be the vision for social care. However, there are significant concerns about those who are not 'sufficiently enterprising' and for those people the principle of equality of opportunity fails. Where people with learning difficulties are involved and politicised through self-advocacy groups or where they have strong friend or family support direct payments and directly employing a personal assistant has been found to work well (Arksey & Kemp 2008), however in reverse many studies have found that both employers (Gramlich et al 2002; Flynn 2005) and personal assistants (Glendinning et al 2000; Gramlich et al 2002; Flynn 2005) lack effective and ongoing support to maximise the opportunity that cash payments may offer. In a time where collective provision of day support is being reduced through the re-provision of building based day support (initiated in *Valuing People* (DH 2001) where it is imagined that:

[P]eople [are] making choices about activities in pleasant neighbourhoods, with plentiful community resources. They are supported in this by their own staff, which they employ and who work to their specification. They are likely to be in work, and to have friendships and relationships, mostly with nondisabled people. Somewhere in all this there is the notion of independence. In many ways these utopias have been helpful. They have helped us see beyond the impairment, beyond individualising and disabling understandings of people, their identities and needs.

(Burton & Kagan 2006: 305).

But, choice is at once offered and withdrawn. Day centres are not 'good', choosing to go to a day centre (which is unlikely to be a possibility in

future<sup>8</sup>) would not constitute a responsible or entrepreneurial decision to make. Within this vision some choices are validated and structural inequalities are hidden (Spandler 2004; Leece & Leece 2006).

These utopias of friendship with nondisabled people, employing staff and plentiful communities are the world of personalisation. Julie Jones, as Chief Executive of Social Care Institute of Excellence described personalisation as, 'Personalisation means thinking about public services and social care in an entirely different way – starting with the person rather than the service' (Carr 2008: i). Some have characterised personalisation by its expedient ambiguity (Ferguson 2007), and there are few clear definitions. Leadbeater (2004: 19) defined personalisation in relation to privatisation as:

Privatisation was a simple idea: putting public assets into private ownership would create more powerful incentives for managers to deliver greater efficiency and innovation. Personalisation is just as simple: by putting users at the heart of services, enabling them to become participants in the design and delivery, services will be more effective by mobilising millions of people as co-producers of the public goods they value.

But personalisation is about much more than services, it places weight, responsibility and hope in 'community'. The history of people with learning difficulties could be argued to be a history of exclusion from the mainstream community, and the communities that existed, within institutions and day centres were and are not valued community networks, if we accept a normalisation perspective. Bauman (2001: 2), in his overture to an imagined community, emotes:

...in a community we can count on each other's good will. If we

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<sup>8</sup> Although the logic of the market, and Leadbeater's analysis of personalisation would suggest that demand will stimulate the market therefore through local care markets, if there is a demand, they may re-emerge.

stumble and fall, others will help us to stand on our feet again. No one will poke fun at us, no one will ridicule our clumsiness and rejoice in our misfortune ...[...]... when we fall on hard times and we are genuinely in need, people won't ask us for collateral before deciding to bail us out of trouble; they won't be asking us how and when will we repay, but what our needs are.

This is the imagined world in *Think Local, Act Personal* (PPFC 2011) where involvement in local communities will lead to a decreased reliance on paid support. Ferguson (2007) warns that it is this imagery of community which the personalisation agenda appears to depend upon, that is becoming the new 'warmly persuasive words' which we want to believe are true, but words which also disguise the potentially negative implications of this illusion. These warm words may offer a vision for increased opportunities for social inclusion for people with learning difficulties and opportunities for true co-production, rather than tokenistic participation, which is positioned as vital to improving the lives of people with learning difficulties (Leadbeater et al 2008). However, critics of personalisation – not in terms of the self-determination aspect of the agenda – have observed the potential contradictions and dangers in the policy. Where some form of 'community' can be created around us as individuals in society, the opportunity is not evenly distributed. Fyson (2009: 20), within the context of difficult economic times and service retrenchment, has concerns of inequality of outcome for people with learning difficulties suggesting that, where informal networks become of primary importance in the offering of support, 'social capital will increasingly predict welfare outcomes'. In turn Fyson suggests that risk of abuse will increase and people with learning difficulties rather than being visible in their communities, may in fact become further hidden. The individualism at the heart of Fyson's concerns has also precipitated concerns about the lack of opportunities to act collectively. The civil and social rights upon which direct payments are founded were won as part of a movement, however through the atomization of individuals within personalisation and individualised funding, spaces of collectivity may be

lost (Ferguson 2007).

These critiques of personalisation raise very real concerns for people with learning difficulties as of course the imagined community outlined by Bauman's image, if it were to exist, is tainted by the juxtaposition of freedom and security; 'the price is paid in the currency of freedom, variously called 'autonomy', 'right to self-assertion', 'right to be yourself'. Whatever you choose, you gain some and lose some' (Bauman 2001: 4). Nevertheless these new relations of support through direct payments were firmly situated within New Labour's personalisation agenda which sought to further embed the discourses of rights and responsibilities which are being maintained and extended through the current Government's commitment to 'The Big Society':

You can call it liberalism. You can call it empowerment. You can call it freedom. You can call it responsibility. I call it the Big Society  
(Cameron 2010).

For David Cameron the big society can interchangeably be empowerment, freedom and responsibility, at once calling upon 'community' and 'freedom' unproblematically. Direct payments suit the big society which equally draws out long standing concerns about 'DIY welfare' (Carey 2009: 183), inequalities inherent in the active citizen-consumer (Clarke et al 2007) and responsabilisation of the individual (Peters 2001). It is within this context that both the employer and the personal assistant, on a daily basis, as well as at the policy level, experience and negotiate these new relationships, which act as 'technologies of citizenship' (Cruikshank 1999) thus simultaneously offering prospects of freedom and choice whilst creating new methods of control.

## *Direct payments as a 'technology of citizenship'*

Beyond the rhetoric, direct payments represent a broader agenda; the development of 'social rights based on a principle of mutual responsibility rather than agreed definitions of need' (Dwyer 2002: 275). As such the extension of the development of 'local care markets' (Pearson 2000) and social care organised in the form of direct payments represents 'a complex confluence of new right, New Labour and welfare user ideologies and demands' (Spandler 2004: 190). The disability movement was not as concerned with who provided services, rather the focus was upon who controls the service, who the services are accountable to and the extent to which they challenge exclusion and discrimination of disabled people (Oliver 1996). In spite of the development of a 'quasi-market' which was assumed to confer some form of consumer power, Beresford (2005: 479) argued:

there are no clear indications that the market is any better at achieving the goals identified by such social movements, despite its consumerist rhetoric, than the state and the track record of state provision in these areas is heavily qualified. What is actually interesting is how similar the service systems are that have been developed by market and state. Both have shared a tendency to institutionalize, segregate, congregate, impoverish and marginalize people as long-term social policy service users.

Where private sector solutions have served to replicate the inadequacies of public provision, direct payments continue the logic of the NHSCCA but offer a more direct opening of markets and in theory consumer choice, with the intention of challenging the power differentials that were and are experienced by social care users. Whilst direct payments have acted as a tool through which to access these new social care markets, the discourse is also heavily imbued with an agenda of renewed



citizenship through which enhanced rights are contingent upon the idea of responsabilised citizenship.

In 1998 former Prime Minister Tony Blair shared his vision of citizenship when saying:

Duty is the cornerstone of a decent society. It recognises more than self. It defines the context in which rights are given. It is personal but it is also owed to society...It draws on a broader and therefore more accurate notion of human nature than one formulated on insular self-interest. The rights we receive should reflect the duties we owe. With the power should come responsibility.

(Blair, 1995: 5 in Dwyer 1998: 499).

It is within this context of duty and citizenship that the Labour government's modernisation agenda (Cabinet Office 1999) rested. The modernisation agenda is broad and eclectic without a single or coherent philosophy (Flynn 2002 in Scourfield 2007), however within social care the direction of the change is clear, what matters is 'what works' and that it is 'making sure that public service users, not providers, are the focus' (Cabinet Office 1999: 6).

*Modernising Government* (Cabinet Office 1999), states:

Too often in the past, the tendency in the public service has been to stick with the traditional. The world is changing too fast for that to be an effective approach. The best public bodies have shown an ability to innovate and improve

(Cabinet Office, 1999: 35).

The concern with making a break from the past and New Labour's modernisation agenda is conversely and at times problematically situated within the context of New Labour's analysis of new global realities (Cerny & Evans 2004) whereby '...[t]he requirements of globalization, enterprise

and flexibility are set against the problems of parochialism and bureaucratic inertia of unreformed welfare institutions...' (Scourfield 2006: 48). Therefore personalisation involves not only responses to social movements in improvement of quality of life for people who use social care services, but also a broader analysis of perceived economic interdependencies of national economies (Beresford 2005) which draws together analysis of the bureaucracy of state institutions, rights and evolving responsibilities of the state and the individual.

In 2001 *Valuing People* stated: 'People with learning disabilities are citizens too' (DH 2001: 22). But citizenship is contingent. Roche argues:

The politics of citizenship has for generations formulated its goals fought its battles and found its voice in the discourse of rights. In the late 20<sup>th</sup> century it also needs to be able to speak, to act and to understand itself in the language of citizens' personal responsibility and social obligation, in the discourse of duties as well as of rights.

(Roche, 1992: 246 in Dwyer 1998: 497).

Personal responsibility and obligation are critical discourses in the citizenship imagined in the development of the personalisation agenda. Whilst social care user groups have, in recent years, received unprecedented input into social care initiatives and have gained a 'voice' in the legislative process, governmental expectations have simultaneously changed. Scourfield (2007: 112) argues:

New Labour's perspective on citizenship appears to focus less on what the citizen can expect from the state in terms of social rights, and more on how the citizen *should be*—in this case, active, responsible and enterprising.

The birth of the citizen-consumer (Clarke et al 2007) has also given rise to unprecedented expectations upon citizens and in particular social care users to assume their citizenship. The basis for the development of the

citizen consumer has emerged from strands of academic thought; modernity, governmentality and the political economy.

In 1999 the white paper *Modern Markets: confident consumers* (DTI 1999) confirmed the commitment to consumer sovereignty and highlighted the necessity of recognising citizens as demanding consumers, creating what Needham (2003 in Peters 2004: 628) calls 'the consumerisation of citizenship', focusing upon the 'self-regarding individual'. For Giddens (1994: 4) the development of the citizen consumer is an inevitable part of 'reflexive modernity' whereby traditional arrangements are effectively challenged and nothing can exist unquestioned.

Within this climate of informed, questioning and reflexive citizens a key implication is a responsibility for choices and life decisions (Taylor-Gooby 2000). Foucault's discourse of 'governmentality' is useful as Rose (1999 in Clarke et al 2007: 18) argues society has been re-defined as a 'community of communities' with self-regulating, self-governing and self-regarding relations and it is through these evolving relations that risks, which were once collectively managed, can become individualised (Scourfield 2007: 112). Therefore in terms of the modernisation and personalisation agenda within social care we see:

The welding together of user-centredness with themes of independence, quality, achievement and self-regulation suggests that another transformation is under way. This transformation is not simply about the reconstruction of citizens as consumers but the transformation of citizens into both managers and entrepreneurs.

(Scourfield 2007: 112).

It is here that the reflexive, self-regulating citizen becomes at once consumer and entrepreneur.

The release of *Independence, Wellbeing and Choice* (DH 2005a) and *Our*

*Health, Our Care, Our Say* (DH 2006a) marked the continuation of this 'powerful hybridisation' (Scourfield 2005). Amongst the plethora of visions within these White Papers sits the role of the citizen, the development of direct payments and the implementation of personal budgets. In spite of the apparent commitment to change some commentators have argued that:

[T]he social care Green Paper, *Independence, Well-being and Choice* (DH,2005) that is, so it alleges, committed to breaking down paternalist forms of care and creating individual budgets and contexts for independent living. Yet, as some commentary suggests, it is not really seeking to change fundamentally 'symptom management' or the power of the medical professions, and as Glascott says, 'this isn't all new and innovative. Believe it or not we've heard lots of this before' (2005: 3).

(Edwards and Imrie 2008: 346).

In spite of *Independence, Wellbeing and Choice's* alleged unoriginality and minimal challenge to medical models, the development of and commitment to direct payments represent a further shift in the relationships between the individual and the state. The assumption behind the development of direct payments (through personal and individual budgets), beyond accusations of privatization by the back door (Hasler et al 1999: 7), is the emphasis upon the individual and the continuation of individual responsibility within social care. The emphasis upon 'well-being' is evidence of this and precedes an 'emptying out' of the public sphere, away from equality towards individual emotions (Edwards and Imrie 2008: 348) and individual responsibility.

Whilst the transfer of resources in the form of direct payments can be seen to signify the transfer of power from providers (Glasby & Littlechild 2002) including day centres or local authorities to 'users' of services (Leece 2010) and is expected to enable opportunities for choices to be freely made and whereby independence is created by appropriate

assistance, how these values or aims are experienced by people with learning difficulties remains unclear. Discussions of the social model of disability, its application to people with learning difficulties through an analysis of the social construction of impairment (Goodley 2001, 2011) and the influence of normalisation approaches to support for people with learning difficulties make apparent the places of tension when assistance working within these values also encounters the broader ideas of choice, control and independence. Implicit within the analysis of normalisation is a requirement for change and development. People with learning difficulties have been subjected to 'deficit thinking' (Goodley & Rapley 2001) and cast as 'perpetual learners' (Simpson 1995 in Williams et al 2009). This impetus has implications for how personal assistance is imagined to work in the context of choice and control.

Therefore independence, making choices and taking control exist within a context, a particular context related not only to New Labour and the current administration's analysis of the rights and obligations of citizens, but also inseparable from current constructions of 'learning difficulty' and normalisation led approaches to support. In 1995 Jack argued that 'empowerment of the user would involve having the money and deciding how it should be spent in pursuit of goals the user intended' (Jack 1995: 11), the implication being that the resources represent the point of 'power' and the wholesale transfer of which is a straightforward process. Early discussions of direct payments within the personalisation agenda in *Putting People First* (DH 2007b: 1) recognised 'that sustainable and meaningful change depends significantly on our capacity to empower people who use services'. Subsequent papers imagine a 'confident, empowered and diverse workforce with increasingly sophisticated skills' (DH 2009c: 6) to work in 'empowering' ways. It is here that we see a continuation of the empowerment rhetoric of community care. Direct payments have always been positioned as a means to control of support and intended to represent a direct challenge to the traditional relations of support. The view to 'empower' has been evident in successive

government social policies within which reactions against perceived 'welfare dependency' in terms of benefits have become inseparable from the construction of the 'socially excluded' (Lister 1998). Particular targeted groups, for instance the unemployed, and disabled people become subject to policies which connect personal responsibility and active citizenship through strategies of empowerment. Direct payments represent a clear example of what Dean (1999: 168) called 'technologies of agency' whereby:

...targeted populations ... are all subject to these technologies of agency, the object being to transform their status, to make them active citizens capable, as individuals and communities, of managing their own risk.

These strategies, as in the case of direct payments are positioned within a range of normalising strategies. For people with learning difficulties these normalising strategies are already well entrenched, as previously discussed, through the prominence of normalisation approaches to support. However, in line with its basis in governmentality these discourses are conducted upon, through and by those involved and therefore do not represent a disciplinary form of power, rather processes which are acted upon and at points resisted. Cruikshank (1999: 4) described policies similar to direct payments as 'technologies of citizenship', which she argues:

[d]o not cancel out the autonomy and independence of citizens but are modes of governance that work upon and through the capacities of citizens to act on their own ...[therefore]... are voluntary and coercive at the same time.

Therefore as *Valuing People* sets out independence, choice, rights and inclusion and the personalisation agenda pursues a community focus with emphasis upon development of informal networks with the intention of 'reducing people's reliance on paid support' (PPFC 2011: 3) these values

are shaped and constructed externally to the individual 'choosing' to take a direct payment. Internally, the intended transformation of support relationships through the offering of resources, are subsequently negotiated by the individuals involved.

How independence, choice, rights and inclusion are facilitated through personal assistance is an important question. The rejection of 'care' as descriptive of paid work through analysis of the separation of feeling and doing, 'caring for' and 'caring about' (Dalley 1988) and the power at play in relationships of inequality (in terms of traditional services) and dependency (in terms of both traditional services and where there exists an expectation of familial, informal care), enabled possibilities to re-think how support or assistance is experienced and critically how assistance is delivered and managed. The semantic importance of 'care' as akin to dependency led to new ways of defining this kind of work to express a shift of the power relations and intentions of social care provision. 'Care', 'help' (Shakespeare 2000), 'support' and 'assistance' have all either been explored and adopted, in preference to traditional 'home-helps' and 'support workers' but it is personal assistance that has been captured as the term which expresses the transformation of the roles and responsibilities at the foundation of self-directed support and direct funding.

### *Changing relations: from 'care' to 'assistance'*

Given the history of social care provision, the aims of the Independent Living Movement, in combination with constructions of and responses to the needs of people with learning difficulties, the social care workforce has been of increasing interest. At first there were vague mentions of personal assistants in *Valuing People* (2001), with more specific interest in *Working to Put People First* (DH 2009c) concerning recruitment and

retention and their role in supporting family carers, to the imagined creation of an 'empowered' workforce and querying the possible registration of personal assistants. Personal assistants will be discussed further later in the chapter, however it will be argued that drawing on discussions around 'care' and 'personal assistance' may have utility in attempting to understand the changing relations of support occurring in the direct payment employment relationship within a context which seeks user control, rights and 'empowerment' within the logic of the market (Pearson 2000).

The previous sections have argued that the personalisation agenda represents the most recent shift, from control in the early part of the 20<sup>th</sup> Century, to care with the newly developed paternalism of the welfare state to the new era of the individual and responsabilised citizenship. Within the context of the *active, empowered, responsabilised* or *abandoned* citizen (Clarke 2005) it is crucial to consider how the values of the personalisation agenda, *Valuing People and Independence, Wellbeing and Choice* (DH 2005a) and more recent contributions, *Capable Communities and Active Citizens* (DH 2010) are to be facilitated in the world of direct payments. *Independence, Well-being and Choice* imagines that services will be 'of high quality and delivered by a well-trained workforce or by informal and family carers who are themselves supported' (DH 2005a: 17) and subsequent government papers have emphasised the importance of a supported workforce (DH 2011). Direct payments have been in place since 1996, however, very little research has taken place to explore this 'highly qualified and well-trained workforce' (Flynn 2005; Scourfield 2005; Hastings 2010). It is here that interest turns from a citizen's relationship with the state to the micro level relationships that have emerged through the citizen-consumer directly employing their own support, emerging as an entrepreneur (Scourfield 2007) and it will be argued that it is through an analysis of this relationship that the broader discussions as to the direction of social care can more fruitfully take place. The assumption that purchasing upon the



open market leads to empowered social care users has been questioned, and this section seeks to further critique through a review of the current literature concerning the role and employment of the personal assistant.

In anticipation of the potential of individual budgets the Department of Health funded a large scale research project to evaluate their impact - the Evaluation of the Individual Budgets Pilot (IBSEN) (Glendinning et al 2008). Their findings suggested that individual budgets for people with learning difficulties, in comparison to people with physical and sensory impairments, who reported positive effects on all outcomes assessed, were more varied. It was tentatively suggested that people who are 'less disabled' may be better able to take advantage of the flexibility of individual budgets. However, what is of interest here is the link between the achievement of the greater flexibility of the individual budget and the act of recruiting a personal assistant. The report suggested that the people involved in the study showed some preference to being able to employ their own personal assistance, however the recruitment and retention of personal assistants was found to be a significant difficulty. Participants also reported fear that the relationship with personal assistants may break down forcing them to dismiss the personal assistant and experience repercussions through threats of legal action. Finally concerns were expressed that a 1:1 personal assistance relationship involving intimate care or regular contact may evolve to one more akin to friendship, which has implications, both positive and potentially negative, for both employers and personal assistants. In other studies concerns have been raised that direct payments have created personal assistant jobs which are non-unionised, with a lack of professional development and little protection from their employers (Leece 2006). As such the personalisation agenda has potential implications, which pass far beyond the outwardly emancipatory and empowering rhetoric.

The difficulty in recruiting care assistants and support workers has been a historic and current difficulty for social care providers, be they councils,

private or voluntary agencies and will, as documented (Carmichael and Brown 2002; Spandler 2004; Glendinning et al 2008) continue to be a difficulty for people who wish, through a direct payment, to employ their own support. Funding issues have been identified as potential difficulties in the recruitment of personal assistants (Glendinning et al 2000; Glendinning et al 2008) who work in a context, which Carey has argued to be:

...a depressingly low-paid and transient employment sector, that now employs over a million workers, limited organisational structures often remain in place to offer adequate monitoring or training of staff (*Community Care*, 2003; Scourfield, 2006, p. 13). Potential problems of exploitation and abuse will always remain as a common risk when employment rights are so low, and recruitment problems are so prevalent.

(Carey 2008: 923).

Here Carey highlights concerns about exploitation and abuse which were similarly raised in the IBSEN report (Glendinning et al 2008). However the opposite has also been found when choosing to be employed directly as a personal assistant, employees can find themselves in vulnerable positions and exploitative working relationships (Spandler 2004). Earlier research by Ungerson into personal assistant support relationships suggests that personal assistant work is:

‘unorganised and particular’ . . . There may be reasons why individuals seek out an occupation that is unorganised and particular. These may be to do with the job itself: because it is unmanaged, except directly by the employer, precisely because it allows for permeable boundaries between paid work and friendship, normally involves working for a few people, and can mean working for an employer over a long period of time in an intense and intimate fashion. It may also be the context of lack of organisation which attracts labour that wishes to work in a flexible, fragmented and possibly invisible way. Finally, there may be

labour market related reasons, to do with the availability of alternative low paid and uncredentialed work.

(Ungerson 1999: 598).

The altering of the formal relationship to that of friendship and confusion over the role is evident in similar research projects. Tidder (2006: 141) writes of her own role as a personal assistant:

...the role of a personal assistant is not just to be an assistant. It is also to be a friend and confidant, to give them support and respect.

Concerns have also been expressed that the role is largely unregulated and insecure, (Ungerson 1997a), that CRB checks are done at the discretion of the employer, and further that there are no formal training opportunities (Glendinning et al 2000) or possibilities for promotion. These, in combination, '...in the long run ...[...]... might generate hardship for the workers so employed' (Ungerson 1997a: 45). *Hard Work, Hidden Lives* (TUC 2008) highlights the Trade Union Congress' concerns about the limited support for employers and lack of employment rights for personal assistants. The workforce was not a primary concern in the development of direct payments.

The material conditions of the people employed as personal assistants have implications upon their ability to undertake their role effectively, but as Scourfield identifies this is a common conflict in the social care profession:

...paradoxically, the 'professionalising' effects of training [could] shift the balance of power away from employers, placing them more back in the role of care receiver than that of an independently living individual.

(Scourfield 2005: 483)

Nevertheless the development of direct payments, arguably initiated to

redress long standing inequalities and oppressions that have existed in more institutional forms of support, potentially shift the problem, for one person to be empowered does that necessitate the placing of another in a potentially vulnerable position? The difficulties of working as a personal assistant are hugely dependent upon the employer, however, until recently (DH 2011) have been rarely articulated in the personalisation agenda which is a significant area of concern and a primary interest of this project.

It is here where the earlier discussion of interpretations of 'care', 'dependency' and 'independence' once more becomes relevant. The new individualised and atomised workforce of personal assistants represent a re-branding and re-situating of former 'care workers' in community settings, to personal assistance. Clear boundaries have been drawn between those advocating and campaigning for disabled people's rights in which 'care' has been disowned in favour of tending (Parker 1981), support, helping (Shakespeare 2000) and most commonly used assistance (Shakespeare 2006). Language and the creation of meaning and reclaiming meaning have been essential in the shift between 'care' and assistance as symbolic of a re-arrangement of the social relations of support. Whilst attention has, necessarily been paid to the social relations of support through campaigning and activism, only implicit attention was paid to the people offering that 'care' or 'assistance', as the critical issue was who was in control of the support. 'Support' and 'assistance' has rarely been approached theoretically. Recent research into the role of the personal assistant has added specificity to Ungerson's (1999) 'unorganised and particular' workforce. Flynn (2005), through a Skills for Care funded project *Developing the role of personal assistants*, identified the varied roles personal assistants are required to perform. Some practical; personal care activities (requiring intimate contact) and household tasks (cooking, cleaning etc), other roles were less tangible and more personal; communication, empathy, trustworthiness and sharing interests and pastimes. Further to this list employers valued their personal

assistants for their 'personal qualities' and 'going the extra mile' (working beyond their paid hours). As such the role of a personal assistant has been aligned to 'informal' work (Leece 2006; Leadbeater et al 2008) due to, in many instances, the minimal hours involved per week, and as 'neither wholly professional nor wholly informal' due to the relationships that can emerge from working closely together (Flynn 2005: 42).

Whereas some disabled people have approached assistance as reminiscent of a tool or instrument to fulfil a practical task (Gibson et al 2009; Flynn 2005; Rivas 2003), others emphasise the importance of shared understanding and the building of relationships (Gramlich et al 2002; Flynn 2005; Williams et al 2009). Therefore, the personal assistant role appears to be able to transcend the practical and move into the realm of the emotional and personal (Kelly 2011). This blurring of the boundaries between the formal (more practical activity of care) and informal (relationship based) relationships (Ungerson 1990) raises the potential utility of Wærness' (1984) typology of care based on dispersal of power rather than location or prior relationships involved. Perhaps through a less polarised position and an exploration of the power, that has theoretically been transferred from the providers to the users of 'care' (Glasby & Littlechild 2002), may be useful in exposing the forces which shape working practices and identities in assistance relationships.

Kröger (2009: 398) calls for a re-look at 'care' as a useful concept to explore these new relationships suggesting that:

the relationship between disabled people and their personal assistants has much the same characteristics as the care relationship and requires a balancing of the needs and interests of the two parties.

Therefore to ignore 'care' and the significant analysis of the concept of 'care' may only serve to hamper our understanding. Rather Kröger advocates an engagement between disability and feminist studies which

may enable us to learn from one another. In this vein Kelly (2011) has suggested that it is important to keep 'care' at hand, using it as a 'complex tension' and so recognising that it has transformative potential in helping to explore and understand relationships involving employers and personal assistants.

Although the role of the personal assistant has been the subject of some increased interest, in the recent past the primary focus of governmental and academic research interest has been the experience of employers. Gramlich et al (2002) offered early insights in to the experiences of people with learning difficulties who use direct payments to employ their own personal assistants with the intention of offering a broad perspective of those involved. They emphasised the importance of direct payments for everyone which should be integrated into all areas of life; housing, employment and day services strategies. In order for direct payments to work supported decision-making needs to be available, be that in the form of circles of support, micro-boards (an individual not for profit agency for the individual), or Independent Living Trusts. This support was found to be critical to enable people to take control of their support. Similarly peer support was emphasised in line with engagement with wider disability organisations as well as appropriate supervision and on the job training for personal assistants. One of the direct payment supporters said 'The spirit of the social model of disability is about looking at the whole of society, not separating people' (Gramlich et al 2002: 96).

This is an important comment not only in relation to how 'learning disability' has been experienced and pathologised (Yates et al 2008), but the potential dangers of the individualising practices at play in the development of individualised support. Some people with learning difficulties have strong families who support in the management of their budget and management of support, others are involved with the self-advocacy movement which offers the experience and peer support to

help in managing their support (Gramlich et al 2002; JRF 2004), others have neither. Local authorities have a responsibility to offer 'appropriate' support to direct payment users. Direct Choices (DH 2004b: iv) states in the preface '[d]irect payments, managed properly and with appropriate support, will help make this happen'. Appropriate support is difficult to define, and is frequently cited in the direct payments literature largely undefined. The support can be understood as short-term intensive interaction around recruitment and employment contracts and legalities of employing a personal assistant and ongoing payroll support (DH 2004b). The transfer of resources therefore are not in and of themselves 'empowering'. Context is critical to understanding how these new relations of support are experienced.

Direct payments are a tool of the personalisation agenda. The personalisation agenda is broad in which direct payments represent a small, but important part. A Putting People First paper, *Working to Put People First* (DH 2009c: 17) which focuses on the workforce offers a vision for the new relationships which are forming beyond the micro level of support and imagines a workforce:

... which supports the cultural shift from:

- clients to citizens
- welfare to well being
- expert to enabling
- transactional change to transformational change
- "freedom from" to "freedom to"
- safety net to spring board.

This cultural shift not only seeks to challenge exclusion from and promote inclusion into a wider society which emphasises the role of all, beyond specific social care organisations. Inclusion has been posited as the primary aim. However, the individualism inherent in the rhetoric and the ideologies of New Labour and continued through *Capable Communities Active Citizens'* (DH 2010) vision for the social care agenda raise

questions as to the ability of direct payments to facilitate the aspirations of the agenda. It is within the context of the individual, reflexive citizen that more collective definitions and analysis will be explored. Jordan (2005: 159) argues that:

Individualism and the choice agenda have left a vacuum in social policy around the collective context, and the basis for membership, participation and belonging.

As such without consideration of the holistic view of a direct payment employment relationship these tensions will remain with little to mediate between the needs of all involved. The individual social context of those involved becomes crucial. Beresford (2005: 478) has argued in relation to current changes in social care that:

The heavily politicized debate about these matters engendered by the political new right largely ducked this issue. Consideration will need to be given to what counts as profit and what counts as loss and who or what it is that profits or loses. This has always been an issue, although the populist way in which arguments have typically been presented, means that it has tended to be ducked. For some people, anything that impinges on the individual's freedom to do what they want, represents a loss. To others, that freedom represents a cost if it is at the expense of other people.

A reconceptualisation of profit and loss may be a useful way to re-think policies which as Beresford suggests, are so tangled up in rhetoric and a presumption that the only way to achieve positive outcomes for individuals is to utilise the freedom of the markets. Beresford maintains that:

Any cost-benefit analysis of state and market needs to take account of the key concerns of the service user movements and include them centrally in its reckoning.

(Beresford 2005: 479).



In a reinterpretation of Beresford's call for user-movements to be central to any developments this research project seeks to engage both 'service users' in their new role as employer and personal assistants as direct employees, to explore the implications of direct payments in terms of their fundamental altering of the relations of support. Drawing upon the development of the citizen-consumer or entrepreneur and an assumption that interdependency is a characteristic of human relationships (Kittay 1999, 2002; Reindal 1999; Sevenhuijsen 1998; Burchardt 2004; Scourfield 2007) it is suggested that understanding the dynamic of these changing relations, which are reflective of our changing relationship with the state, will be a useful way to gain a greater insight into how and if social care practices can facilitate the values of independence, choice, rights and inclusion for *all* involved.

## Chapter 3

### Methodology

The literature review sought to capture the tensions in the development of direct payments and more recently the personalisation agenda and bring to the fore assumptions about consumer power, discourses of independence, choice, control and responsibility in combination with conceptions of 'care', support and 'assistance' in the facilitation of the values of *Valuing People* and the personalisation agenda.

#### *Research Interests*

Given what is potentially at stake in the development of the personalisation agenda, through the lens of direct employment relations, the scope of this research project was to consider how these new social relations of support are experienced by those involved. As such the research interests were:

- To explore our understandings of 'independence', 'choice' and 'control' in the context of the discourses of empowerment at play in the personalisation agenda in relation to people who have learning difficulties who are employers.
- To consider the power of the ideology of 'caring' or support and the rhetoric of 'independence' and 'choice' in personal assistants' ability to make sense of their role and their ability to service these values.
- To begin to reflect upon the implications of cash payments upon both the employer and the personal assistant.
- To consider if and in what ways direct employment using cash payments for people with learning difficulties place either the employer and/or the personal assistant in a vulnerable position.

To explore these areas of inquiry a small-scale qualitative research project was conducted which used unstructured interviews with 8 employers (7 who have direct payments and 1 who has a personal budget through a recent pilot project), their supporters, where a supporter was identified (6 employers identified a supporter, 3 were care managers and 3 were family members), and 7 personal assistants working with each of the employers (one personal assistant was unable to participate).

In addition to the employer – personal assistant – supporter relationships other people important to the development or ongoing support to people who have taken a direct payment have also been included. These are the local council's personalisation officer, the local Independent Living Service (who offer ongoing recruitment advice and support to manage the financial aspects of being an employer), and a self-advocacy supporter who has been involved in offering informal support to the self-advocates involved in the local Speaking Up group. This selection offers an overview of the experiences of people taking a direct payment and directly employing personal assistants in this area, as at the time of the research there was not an active Centre for Independent Living in the area. The small sample size offered the opportunity to engage and explore in depth into these people's experiences.

A qualitative approach lent itself to this project. A small but rich data set was intended to shed light upon these evolving social relations of support. Although the policy of direct payments has been legislated since 1997, as discussed in the previous chapter, there has been limited research which considers these support relationships in detail. Due to our lack of insight into these private relationships, yet performing effectively public functions, this project is explorative in nature and sought to ask broad questions to elicit a broad response from which to move forward. The qualitative approach suited this explorative project giving space for many stories to emerge rather than focusing upon predetermined ideas and

assumptions about what might be happening in these relationships. Therefore a quantitative approach was rejected as this would have depended upon working with a set of potentially problematic assumptions about what is an emerging area of enquiry.

The value of a qualitative approach equally lay in its accessibility. Hearing, valuing and using the words of people with learning difficulties was critical in the development of this project. The complexity of individual's lives and variety of experiences needed to be approached from the starting point of the person within their social context as well as the broader structural factors. The richness of the data and a process of effective triangulation, through an engagement with all sides of these relationships embedded within the policy and academic literature, enabled the possibility of a holistic view of support relationships which have commonly been approached separately.

This research agenda was identified without recourse to a research group, as an application for a PhD research project. In the development there was limited direct involvement, by either people with learning difficulties or personal assistants in the specific focus and process of the research or analysis. However, the vitality of co-production within inclusive research practices has been well documented (Barnes & Mercer 1997; Chappell 2000; Chapman & McNulty 2004; Oliver 1992; Rodgers 1999; Walmsley 2001, 2004) and this research project begins its research with these principles in mind.

### *Participants: Employers, personal assistants and supporters*

#### *Employers*

Recruitment of participants for this project revolved around the recruitment of the employer. This project sought people with learning

difficulties who have 'chosen' to take a direct payment and directly employ their own personal assistant. There is a significant body of research into labelling and there are well-acknowledged conflicts between the social services use of 'people with learning disabilities' (Goodley 1996; Koltz 2004) and a general preference in self-advocacy literature of 'people with learning difficulties' emphasising People First (Gillman et al. 1997). However, as this project is focused upon the experience of directly employing personal assistants the term 'employer' has been used to describe those involved who have taken a direct payment. The term 'employer' accurately describes their role, but also emphasises their agency in planning their lives and their support, in conjunction with the stream of responsibility that they accept when deciding to employ their own staff. The uptake of direct payments in this area is still relatively small and those who choose to directly employ their own supporters even smaller still, however as this project is interested in the relationships between the employer and their personal assistant it was decided that this project would focus upon people with 'mild learning difficulties' or people who are actively involved in the recruitment and ongoing management of their personal assistants. An 'accessible' pictorial leaflet with an audio version was created to explain the project to potential participants (see Appendix I pp. 261-68). In most cases there was an initial meeting over a cup of tea before they agreed to take part, which gave the employers an opportunity to talk about the project and ask any questions they may have. This gave them an opportunity to meet the researcher and assisted in the gaining of informed consent (discussed later p. 71).

The exclusion of people with more complex learning and communication needs does not imply a lack of interest in these particular relationships, but considers that where an individual's direct payment, or the employment aspect of an individual purchasing support is largely controlled and managed by a family member, supporter or care manager

that this would involve another important, but discreet piece of work due to the varying dynamics involved in those relationships.

Employers were recruited through the local Speaking Up group, a family support group and through the local council's Community Team for People with Learning Disabilities. The process of recruitment and involvement in the project was initially through the criteria that the employer was actively involved in the daily management and direction of their personal assistant. This did not mean that they individually managed the finances involved – all involved used the local Independent Living Service to manage payroll – rather as the project is interested in how daily support is managed and the experience of managing (and offering) support, the finances involved are of symbolic rather than practical importance. Even though direct payments and more recently personal budgets have been available since 1997<sup>9</sup> the uptake by people with learning difficulties has not been high (DH 2007a). In terms of personal support, direct payments can be used in different ways – people can choose to use a support agency or directly employ their own personal assistants. This project was only interested in people who directly employ their own personal assistants and as such the number of potential participants in this area was further restricted. A social services manager in this locality estimated (at the time, this has since increased) that only 13 people with learning difficulties who receive a direct payment have chosen to directly employ their own personal assistants. Of this pool of people this project interviewed 8 employers. Recruitment was approached through specific organisations as well as the Community Team for People with Learning Difficulties. These organisations, including the local speaking up group and a local carers organisation represent people who are interested and motivated by current developments in social care policy and who have been some of the first

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<sup>9</sup> Cash payments were previously made via the Independent Living Fund, however there was a tight eligibility criteria for this funding and it was not widely available to all people with learning difficulties. See p. 8.

people in this locality to take up the opportunity direct payments may offer. As such the sampling strategy was one of convenience sampling with the intention to draw upon the experiences of a group of people in one locality. Care Managers are commonly the gatekeepers controlling researcher access to people who use social care services, in other cases when exploring support, a support agency or charity may be a gatekeeper. In the case of direct payments the receivers of the direct payment are often disparate and difficult to reach without care management or social work involvement. This project approached care managers to recruit participants - one participant was recruited this way. Two people responded to an e-mail requesting participants sent to a carers organisation who have been working on person-centred working and the development of personal budgets. One participant became involved through word of mouth and the final four were recruited through the local speaking up group. These participants represent early adopters of direct payments and as such may not constitute a representative sample of social care users in this locality. However, the intention of this explorative project was to gain an insight into what is happening in these support relationships rather than a concern with creating any generalisable outcomes.

### *Personal assistants*

It was vital to the project that personal assistants were actively involved in the research. Due to the nature of the work of personal assistants they are disparate and fragmented and difficult to reach. All the personal assistants involved in this project were approached through their employer. It was agreed with their employer that they would discuss the project with their personal assistants in order for the personal assistants to have the opportunity to consider their potential involvement in the project. They were often difficult to approach and in many cases the

employer did not mention the project to their personal assistant. Therefore, contact was made with the personal assistants through the employers with phone calls to the employer's home and / or via e-mail. There were concerns that they may have felt compelled to participate due to their employer participating, however all the personal assistants who were contacted directly did take part and some commented that they had found the experience cathartic. An information leaflet was also developed for personal assistants to ensure they understood the project and to re-confirm their rights (see Appendix II p. 269). The practise of recruiting personal assistants through their employer offered great value in terms of understanding support relationships holistically, enabling an analysis from both angles of the relationship. However this also raised methodological questions and concerns. The employers, in research terms, are the gatekeepers of their personal assistants. Questions emerged around the ethical dilemmas of interviewing personal assistants about their work without the permission of their employer as this would have inevitably involved some breaching of confidentiality on the part of the personal assistant. However the opposite - recruiting through the employer - created other tensions whereby the personal assistants were nominated by their employer. This process in itself raises questions about which personal assistant the employer chose to nominate and why. In some cases (two employers) only one personal assistant is employed and as such it was the sole personal assistant who was interviewed. In all other cases (except in the case of the participant where the personal assistant was unable to be interviewed due to personal circumstances) the employers self-selected a personal assistant to be involved in the project. Personal assistants were reported to have been chosen due to the length of time they had worked with the employer (the more experienced personal assistant - this was reported by two employers) or where a follow up phone call was made to approach a personal assistant, the personal assistant who was working on that day was nominated and recruited (as was the case for the remaining three personal assistants). The impact of this self-selection could be significant in terms of the



employer choosing a personal assistant who may reflect well on themselves as an employer, or critically for this project, a personal assistant with whom they have a good relationship. These concerns needed to be reflected upon in the analysis of the interviews and validity of the findings of this project and may have been ameliorated should all current personal assistants of each employer been interviewed. In practice this would have created an uneven sample with some employers employing four or five personal assistants and others just one. Other strategies of recruitment of personal assistants would have removed the opportunity to gain a holistic perspective of the employment relationship. Due to the nature of their work and as a disparate and largely non-unionised workforce an alternative recruitment strategy could have been to recruit personal assistants through the local Independent Living Service via a letter drop. This may have gained some participants, however would have encountered similar sampling concerns due to the self-selection of the sample without the research benefits of the relationship with their employer. The complex ethical issues concerning personal assistant involvement is further discussed in the ethics section (see pp. 61-81).

#### *Family / supporters*

Family members or the employer's supporters have also been included in this research project due to their role in the taking up and managing the direct payment. The IBSEN report, *Impacts and Outcomes for Carers*, (Glendinning et al 2009), suggested that family carers of individual budget holders needed to spend time helping to maximise the benefits of the direct payment (or individual budget). As such the expectations of family carers or supporters of the benefits of direct payments and the role they play in making it work may be an interesting area of inquiry. Supporters also offer background detail to the experiences of the

employers. Similarly to personal assistants, family members or supporters were only approached after they were identified by their employer. An information leaflet was also written specifically for family / supporters (see Appendix III see p. 272).

### *Ethics and analysis*

The development of research governance frameworks (DH 2005b) have aimed to entrench informed consent procedures in all research projects. It is clear that gaining informed consent is more complicated than the one off completion of a form. Corrigan (2003) has highlighted the dangers of 'empty ethics', that the development of regulations around informed consent assumes the rationality of individuals and does not acknowledge the social context of decision-making. This is particularly complicated when gaining informed consent from people with learning difficulties.

The consent procedures for this project have attempted to offer ongoing opportunities to consent and object. Accessible leaflets were developed (with some input from self-advocates to improve the language and layout) for the employers and leaflets were also developed for the supporters and personal assistants. The leaflets included information about the researcher, why the project was being undertaken, what the project is about, what the interviews will involve, how long they were likely to take, and stating the participant's rights in terms of consent, withdrawal and retraction (See Appendices I, II, III, IV pp. 261-278). An accessible consent form was also created (See Appendix I pp. 261-71). This was included in the booklet explaining the project so each participant had a copy to keep. In most cases there was an initial meeting with the participants to discuss the project and answer any questions, before the interviews were arranged. Where there were concerns that the project was not clear, the supporter was asked to check that the employer

understood what the project was about and that they were happy to take part. At the interview the consent form was discussed again and it was completed. After the interview a copy of the CD recording, or transcript (whichever was preferred) of the interview was sent to each participant and each participant was offered the chance to retract anything that they would prefer not to be used in the final report. Audio versions of the leaflet and consent forms were also available to those who needed or preferred to listen rather than read. This process of ongoing consent offered the opportunity to withdraw and opportunities for the participants to clarify their contributions at several stages. This process and the project as a whole was approved by the University of York and the respective local authority's research governance procedures.

During the development of this project a major concern was *how* people were involved in terms of participation and outcomes. Similarly and in respect of the research relations the above steps were taken to ensure that the research did not impose upon or have too high expectations of the participants. As Stalker (1998: 17) argues:

A balance needs to be struck which ensures that the researcher neither intrudes unwanted in peoples' lives, nor becomes so immersed in 'the cause' that she loses sight of the academic agenda. Between these two extremes there lies potential for many positive initiatives in terms of drawing in individuals' particular areas of expertise or specialist knowledge. People should be invited to set out their terms and conditions and, as far as possible given the power differentials involved, a genuine process of negotiation needs to take place about the implications of involvement on both sides. Where respondents are not directly involved in the design and execution of research, accountability should remain a guiding principle.

Stalker clearly identifies some of the anxieties about doing this type of

project and also the importance of accountability to the 'researched' throughout the process from recruitment and consent to the act of the interview and analysis. Goodley and Moore (2000) have emphasised the importance of adaptive and flexible interviewing to ensure all can be involved on their own terms.

### *Interviews*

The word interview has been problematic throughout this process, the formality of the word and the associations it carries meant that it was avoided, whenever possible preferring 'meeting' or 'chat'. Nevertheless the 'meeting' was effectively an interview with a digital recorder. Each meeting was very different. Some people were happy to talk, needed very little prompting and had clearly well rehearsed stories about their experiences whilst others required more input from the researcher. This was a concern in some of the meetings with employers as well as supporters and personal assistants where the researcher had known them previously. They assumed and referred in the interviews to knowledge that the researcher had, but that she would not use unless disclosed as part of the project. One employer who is a member of the Speaking Up group, who has regularly told the researcher about events in their life when at Speaking Up meetings, referred to stories that they had told in a different context without explaining them. At these points they were asked if they would mind telling the story again, but reassured that if they would prefer the story not to be used that it would not be included in the final analysis of the interviews.

The interviews were designed as unstructured interviews conducted around a topic guide for each group of participants. The topic guide offered the interviewer focus to support in the redirection of the interviews, however the intention was to enable, as far as possible, the

direction to be led by the participant (see Appendix V p. 277). The questions were not always asked in the same order and follow up questions were asked depending upon the story the participant was telling. Every participant was different and required different approaches. Some interviews were done jointly with family (in one interview), a personal assistant (in one interview) and a care manager (in another). These interviews were done jointly to suit the needs of the employer and to ensure that they were comfortable with the process. Where supporters were involved in the interview with an employer they offered input when needed, such as re-phrasing a question, but did not speak for the employer, only themselves. Joint interviewing posed potential problems. The ideal interview set up was the interviewer and a sole participant, however this was not possible in all cases and where joint interviews were chosen it was because of the needs of the employer. In many cases the interviewer was unknown to the employer prior to the research process. Joint interviews occurred in 2 interviews - with Daniela (employer) and Diana (care manager) and Harry (employer) and his parents<sup>10</sup>. A third interview was done with Freddie (employer) and one of his personal assistants. This was not a joint interview but a personal assistant was there to support the flow of the interview rather than be interviewed herself. Daniela and Diana and Harry and his parents were interviewed together for similar reasons - to ease the flow of the interview, to gain a rich description of their experiences and to minimise anxiety on the part of the employer. This process may have implications over the data collected. In Harry's interview there were times when Harry and his parents disagreed and when his parents corrected him, Harry acquiesced. The involvement of Harry's parents certainly affected the content of Harry's involvement and ideally the interview process would have been done separately. In combination with concerns about reducing anxiety caused to the participants, time restraints of both the participants and researcher restricted this possibility. In the case of Daniela (employer) and Diana (care manager) a joint interview was

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<sup>10</sup> See p. 81 for introductions to the participants.

necessary to reduce anxiety of Daniela. Diana's role in the interview was one of support and also at times clarification. Diana, on making a contribution which might be seen to be clarifying Daniela's previous statement would say sentences such as "would you agree" to help clarify the story and also seek the permission of Daniela to offer her perspective. Diana equally spoke openly about her role in supporting Daniela and it was apparent that - due to the longevity of their working relationship - that there was transparency in the way Diana works. Had the interview focus primarily been on the role of care management support for employers this joint interview would have limited validity due to fears that either participant were not speaking openly or honestly.

The interview process was purposely flexible to account for the needs of the participants, as discussed above, but also in the tools used to undertake the interviews. The unstructured style of the interviews was designed to enable a conversational style in the interview and as such all interviews were recorded to avoid the need for note taking. Participants could expand on a particular area of interest, but the topic guide helped the interviewer remain focused on the broad questions she wished to discuss. The interviews ranged from 30 minutes to around 1 hour 30 minutes, but were largely completed in around 1 hour. A camcorder was offered to employers who the researcher felt might like the opportunity to do a 'day in the life' story to use in the interview. None of the participants wanted to do this, however for one meeting an employer and one of his personal assistants had found some photos to help the employer talk about their life. The importance of this flexibility of methodology has been highlighted by Aldridge (2007: 3):

If researchers are not willing to step outside the boundaries of their conventional methodological fields there remains the real possibility that people with learning disabilities will continue to be overlooked or considered too 'difficult' to include in research studies that are conducted outside the field of disability research.

Without using varied methods some of the participants would have found the process much more stressful and maybe akin to a social services meeting which it was vital to avoid. Goodley (1996: 345) highlighted the complexity of bias when researching people with learning difficulties:

For people who are unable to present long and elaborate anecdotes, the researcher may be placed in the role of interpreter or biographer. Such roles run the risk of researchers imposing their own assumptions, understandings and ambitions upon the stories that emerge. In turn, if the life story is taken as the basis from which sociological understanding emerges, whose understandings are presented?

Given Goodley's observations and personal experiences working on this project and with people with learning difficulties in general, the role and awareness of the researcher is central to the research process.

The researcher's former role in any project, be they 'participative' or more traditional styles of research, is integral to ensuring participants feel able to share their experiences freely. Issues of trust (Wiles et al 2006) and developing rapport (Atkinson 2005) have been readily discussed. Within this project the researcher does not fit the role of the research practitioner, the dilemmas of which have been discussed at length (Coy 2006), however she has been associated with social services due to previous roles in the area as a care manager and community development worker. The researcher was no longer working for the local council by the time the research started due to the potential conflict of interest when talking about support in general and especially when the conversation turned to funding. The researcher's role as a care manager both helped and hindered the development of the project. For some, it may have offered the research project an element of the researcher having a sympathetic agenda committed to the rights of people with learning difficulties, however for others who have had difficult experiences with the council it may have had more negative connotations. Throughout the recruitment

and interviewing phases it was made clear to all the employers, personal assistants and their supporters that this project was not connected to or funded by the local council.

The local Speaking Up group was one of the primary places where employers were recruited. This recruitment strategy was necessary due to the low take up of direct payments by people with learning difficulties in the area, but equally the even smaller numbers of people who have decided to directly employ their own personal assistants. The local Speaking Up group became the group where the possibility of this research project was discussed and commented on by employers themselves. There was significant interest in the group and several agreed to take part. This group of self-advocates were not involved in the design or research process. Ideally there would have been more direct involvement of people with learning difficulties, and personal assistants in the design of the project, however it was conceived as part of an application for ESRC PhD funding without the involvement of anyone beyond the researcher. Consideration was given to creating a parallel project, which could have been more participative in nature. However, given the initial project was not participative in design it felt that adaption at such a late stage may be a tokenistic gesture to a more participative project. User-led and participative research strategies are complex and contentious and questions have been raised about projects that appear to be user-led, yet in practice the realignment of power and agenda setting is less clear:

Simons (1992) notes that one local People First group was becoming inundated with invitations to participate in various activities. The satisfaction of being 'in demand' was balanced by the risk of the group's own agenda becoming squeezed as it responded to the requests of others.

(Stalker 1998: 8)

Concerns about the co-option of People First or Speaking Up groups onto



research agendas which are not a priority to them has been reflected upon throughout this project. Although this project is not based in a self-advocacy group some of the self-advocates involved in the local Speaking Up group were involved in the project. They have also helped in the project through offering advice about accessible materials and the project has benefited from their encouragement. The involvement of participants, be they employers, personal assistants or supporters has been an ongoing focus throughout this project and one which has been reflected in the style of research as well as the analysis.

### *Analysis*

All of the interviews were transcribed by the researcher. The research data consists of transcripts of unstructured interviews about people's daily lives. This interest in the everyday and the complexities of the social world lent themselves to the grounded theory approach to research and analysis (Glaser & Strauss 1967; Corbin and Strauss 2008). This approach enabled the research to gain an insight into how the people involved situate their experiences and expectations within the governmental discourses of independence, choice, inclusion and market discourses prevalent within the current policy direction of direct payments. The grounded theory approach offered the opportunity to view the participants' responses within their context and values and appreciates the complexity of the social world:

...the world is very complex. There are no simple explanations for things. Rather events are often the result of multiple factors coming together and interacting in complex and often unanticipated ways ...[...]... we try to obtain multiple perspectives on events and build variation into our analytic schemes. We realize that, to understand experience, that experience must be

located within and can't be divorced from the larger events in a social, political, cultural racial, gender-related, informational, and technological framework and therefore these are essential aspects of our analysis

(Corbin & Strauss 2008: 8).

The area of interest, particularly with regard to personal assistants, is a developing field of research and as such this project is explorative in nature. The inductive possibilities of grounded theory and approaching the data through microanalysis of the interviews further commended this strategy. This enabled, through the analytic process, the development of concepts and categories and this approach proved fruitful to assist in identifying the relationships between the various concepts that emerged. Similarly Corbin and Strauss' (2008) 'constant and theoretical comparisons' offered a useful method to explore the varying experiences and current understandings of all involved. This was especially useful in a project which is specifically looking to explore the new relationships that are formed within these employment relationships, be they complimentary, or at times at odds with one another.

The themes which emerged are discussed in relation to the core concepts that became apparent; *Beginnings*, which explores motivations to take a direct payment encompassing 'choice' and 'control' for employers and their supporters and motivations to undertake the work of personal assisting; *Roles*, which is concerned with how the work of employing and working as a personal assistant is managed within the value based discourses of *Valuing People*; *Responsibilities*, which positions these roles and relationships in the context of policy discourses of empowerment and within the wider renegotiations of our relationships with the state and *Relationships*, which explores expectations and evolution of these new relations of support.

The process of analysis was ongoing throughout the research process.

Broad themes emerged, drawn out from the participant's analysis of their life, their work or the person they support. Key codes emerged, often echoing key concepts used in policy literature, such as 'independence', 'choices', 'community', 'risk', and 'support'. These were collected into large charts breaking down the varying participant's analysis and use of the concept. This process was reminiscent of a framework approach (Ritchie & Spencer 1994 in Barbour 2008) and offered a clear visual representation of the data. Participant's responses were coded within broader themes such as those highlighted above. Each related-set of participants (employer, their personal assistant and their supporters) were colour coded to enable identification of consistencies and inconsistencies within each sub-set. Equally the broader sub groups of participants (i.e. the employers, personal assistants, supporters and professionals) responses were similarly grouped together. These were further considered through the identification of patterns and exceptions to these patterns. As an example the development of Chapter 4, 'Roles', emerged from a further exploration of the broader themes of 'choice' and 'support'. Utilising the analytic tools of constant comparisons and theoretical comparisons (Corbin & Strauss 2008) enabled an exploration at a 'dimensional' level drawing in reflections upon the roles of support and the activity of choice making at a policy, literature and personal level, specifically exploring the different interpretations between the different actors in a direct payment relationship. The emerging roles within the employment relationships were highlighted through the participants' reflections upon 'good support' and 'bad support', which in turn exposed divisions between employers and personal assistants perceptions of 'good choices' and the role of personal assistant support. These inconsistencies were situated within a theoretical framework which sought to expose tensions not only within these relationships, but also within broader discourses of control and consumer choice. Each chapter was developed through a similar process of themes, coding, revisiting the coding and constant and theoretical comparisons.

Grounded Theory therefore offered a flexible, adaptive yet rigorous approach to understanding the experiences of the participants' within their own and broader contexts. This approach to analysis has been undertaken independently and as such needs to be considered within the context of the breadth of literature concerning 'doing disability research' (Barnes & Mercer 1997).

### *Ethical Considerations*

Oliver (1992, 1996) identifies the alienation of disabled people within the research process whereby the research process acts as a subjectification of their situation with little or no material benefits or outcomes. This holds relevance in terms of the broader disability research and remains important within the realm of research with people with learning difficulties, with added layers of complexity. Social model theorists have sought to question the research process which is well theorised with respect to disabled people, however remains less so in relation to people with other difficulties, leading French (1993 in Stalker 1998: 17) and others (Goodley & Rapley 2001) to question the neglect of the influence of some impairments, which are more difficult to be solved by 'social manipulation'. Participative research strategies have sought to re-align research relationships when researching the experiences of people with learning difficulties, emphasising the importance of active involvement in the research process, including agenda setting, interviewing, analysing and writing (Chappell 2000; Chapman & McNulty 2004; Rodgers 1999; Walmsley 2001, 2004).

Given the nature of this research project its design is drawn not only from the movement towards inclusive research methodologies, but simultaneously from feminist research perspectives which have

highlighted women's role in maintaining the 'spectrum of care', be that informal or formal care-giving (Ungerson 1990; Finch 1993). The voices of people with learning difficulties have been historically one step removed from the research process, so too have paid supporters within the majority of research into 'care' and support. As such the methods employed in this research project seek not only to take notice and practice ideas of participative research (Aspis 2000) and recognise the call for 'nothing about us without us' (Charlton 1998), whilst simultaneously recognising that this project is working with not only one but two groups of people who have been historically marginalised within research practices.

The research design included the employer, their supporter and their personal assistant. The approach of interviewing all three offers an opportunity to gain a holistic perspective of what it is like to employ a personal assistant, but also importantly to work as a personal assistant. Interviewing people in a network posed ethical issues. Respect for the relationships involved was an ongoing concern during the interviewing process. In order to successfully carry out the interviews and write up without 'doing harm' all names have been anonymised as well as names of things, places and events where necessary.

The involvement of personal assistants has been largely minimised so far, rather the discussion has focused upon the involvement of employers. As raised above, personal assistants have been marginalised within the literature and equally in the government papers engineering the development of personalised funding and self-directed support (DH 2001; DH 2005a; DH 2007a; DH 2007b). *Independence, Wellbeing and Choice* (2005a: 17) envisaged services 'of high quality and delivered by a well-trained workforce or by informal and family carers who are themselves supported', however paid very little attention to the realities of these altered forms of employment. This project through its interest in both the employer and personal assistant seeks to redress this balance and

explore how these values of independence and choice are to be facilitated by this under-researched workforce.

The position of personal assistants as a potentially marginalised group was exposed in the development of this project. None of the participants in this project were paid for their time. Inclusive research practices highlight the importance of pay for co-researchers (Walmsley & Johnson 2003; Garbutt et al. 2009; Williams & Simons 2005) and the complexity that can accompany payment. In this project a potential conflict emerged. Although not working as co-researchers, some of the participants – the council’s personalisation officer, the independent living service officer and the self-advocacy supporter – were effectively paid for their time, in all cases doing the interview within their working hours. The majority of the personal assistants in the project gave up their free time to be interviewed about their work, which they would usually be paid to do. This raises issues of equality and highlights one of the reasons why it is important to interview personal assistants. However, questions arose regarding the possibility and feasibility of asking the employers to pay for that time. This was neither possible nor appropriate given the limited funds the employers have to purchase their support. The real concern here is that this project has perpetuated the very inequalities and high expectations that the project has sought to examine. This remained unresolved in this project and the personal assistants were not paid (by the project) for their time, however it is something that would require further consideration and discussion in future projects involving personal assistants.

Some of the difficulties in the design of the project have been highlighted above. Nevertheless the value of this approach lies in the holistic view of the employment relationship, which gives voice to all involved without privileging one or other in what is assumed to be an interdependent working relationship. It is within this context of researchers attempting to change the way research is undertaken that the following discussion of

the ethics of this research project takes place.

### *Rejecting research*

There is a long history of 'Rejecting Research'. For research to be person-led it has to be done by people themselves right from the beginning by using the words people want to use, putting together reports and papers that are understandable for them and others, and using the methods that make the most out of each person's skills. Then we have real ownership of the research. Person-led research is research started and controlled by people who have learning difficulties. Rejected research is where people with learning difficulties are not part of the research, when it is about them. Rejected research can also be when people are included in the research but not completely included. Where they are not completely included they are being rejected.

(Townson et al. 2004: 73).

It is apt to begin the discussion of research methodologies with a quote illustrating the turn towards a more emancipatory model of research within the learning disability research community. However the term emancipatory is not used unproblematically, as Stalker in a review of research methodologies identifies:

As Mitchell (1996) points out, the terms 'participatory' and 'emancipatory' are used inconsistently in the literature. At times, they appear to have the same meaning: for example, Cocks and Cockram's 'participatory' model is broadly equivalent to Oliver's 'emancipatory' one; elsewhere, 'participatory' is used to denote a transitional phase which is seen as a step towards 'emancipatory' work, (Zarb, 1992).

(Stalker 1998: 6).

This confusion has been recognised and researchers have sought to clarify positions from Oliver's pure emancipatory research - where the social model of disability, political situation and the social relations of research relations are fundamental to the process (Barnes & Mercer 1997) - to 'inclusive research' (Walmsley 2001) where people with learning difficulties are involved in varied ways in the research process. This 'inclusive research' can still be 'rejecting' with some expressing concerns about tokenistic involvement (Beresford 2002 in terms of service user research; Walmsley 1995 in Chappell 2000 and others emphasising everyone's value in different roles in the research process from setting the agenda to doing the interviews (Ham et al 2004).

Within this context participatory research can be considered a 'pragmatic compromise' (Chappell 2000: 40), given the difficult transition from the social model led emancipatory research which has consistently marginalised the specific dilemmas associated with doing person-led or inclusive research with people with learning difficulties (Chappell 1996 in Stalker 1998; Goodley 2001).

Given the difficulties and controversies involved in doing research with people with learning difficulties, be that as co-researchers (McClimens 2008; March et al 1997) or as participants, there is still a need for further analysis of where and how people are involved '...identifying where the process has been empowering and participatory and when it has not...' (McLaughlin 2010: 1604-5).

The obscurity of the term 'inclusive research' (Chappell 2000) has led researchers to call for openness and clarity about the research process, what has been done, by whom and why (Chapman & McNulty 2004). In the light of a call for openness this project began through personal experiences working as a care manager in a Community Team for People



with Learning Disabilities. During that time as a care manager people were beginning to request direct payments and it was the early stages of personal budgets pilot projects. As a care manager and later a community development worker, experiences and stories heard whilst visiting a local Speaking Up group offered much to the formation of this project. Many of the members of the Speaking Up group were using direct payments and experiences during this project echoed Williams & Simons (2005: 9) when they spoke of:

all business might stop for one person to come into the office and describe some problem he has had with a social worker, while another person is re-telling his or her experience of a successful training session.

The distraction from whatever our business was often turned to support and people's frustrations with their support, but also concerns for their personal assistants. These 'off topic' conversations highlighted the importance of the area to the self-advocacy group. Although not involved in the application, these conversations have been significant in shaping the thinking behind the research and understanding of the daily difficulties and successes of the group. This project is funded by an ESRC studentship. The application was made independently and has been written up independently. This project is however equally concerned with the roles and experiences of personal assistants who are integral to a person's experience of support. Many 'inclusive' projects have been undertaken to look at what is good support from the perspectives of those who use support (Gramlich et al 2002; Williams et al. 2009). However few have focused on the experience of offering paid support (Hastings 2010). The danger that non-participative research has lost its credibility by being associated with maintaining the status quo (Danieli & Woodhams 2005) has also been tempered with researchers':

struggle to resolve the tension that exists between research which is academically rigorous, acceptable to funding organisations and

publishable; and research which is of use to the people who are subject to it, which is relevant to their needs and can inform and promote social change

(Walmsley & Johnson (2003: 9).

This conflict between the academic and the inclusive has been the subject of ongoing tension during the development and enacting of the project. The process of interviewing attempted to add openness and the process of checking back the accuracy of the interviews has added transparency to a process that is often obscured in traditional research practices. It is within this vein of openness and transparency that the project seeks to be accountable to its participants.

### *Accountability*

Once the interviews were completed and transcribed, the transcriptions or recordings of the interview were sent to all the participants. This was done in order to extend the accountability and transparency of the project. Stories and narratives of people's lives and experiences are essential to the project and whilst gaining consent it was explained that quotes would be used in the final write up. Cordon and Sainsbury (2006) have researched participants' perceptions of the quality of research and how participants feel about the quotes used in research reports / publications. Their research suggested that the inclusion of verbatim adds interest to an article and their participants generally preferred versions of articles which included quotes, however what they found to be of importance was how the quotes were used by the researcher and how the quote was attributed to the participant involved. Cordon and Sainsbury's work has offered a perspective from which to reflect upon the use of quotes within the writing up process, but has also served to encourage critical reflection upon how quotes are used and crucially what the

impact (upon the participants) the choice and analysis of such quotes may have.

This is of particular interest and importance to this project which uses quotes to bring the participants' realities to life. Quotes of the employers, personal assistants and supporters are used throughout this project which accurately reflect the individual's words and speech patterns. The value of using extended stories offers an opportunity to gain insight into these people's lives. At times substantial quotes have been used. The value of an extended quote enables the voice of the person to be available to the reader, but also is vital to exposing the ambivalence, clarity, as well as tensions within these support relationships in the course of daily lives. To reduce that input to short snapshots would be to deny the complexity involved. In line with Cordon and Sainsbury's (2006) findings and good practice more generally in qualitative research this project has anonymised all participants. Pseudonyms were used for all the participants, who are introduced in Chapter 4, *Beginnings*. Pseudonyms were used to enable an appreciation of the relationships between the participants, however equally offered the opportunity to attribute the quote to a person rather than solely by a role e.g employer, personal assistant. In addition to further ensure anonymity where a story has been thought to be particularly sensitive no name has been used and locations disguised to ensure anonymity and protect the participants. Even where the quotes are not obviously sensitive attempts have been made throughout the thesis to obscure the participant's identity whilst using their words.

#### *Outcomes / dissemination*

This project attempts to explore the changing relationships which have developed within the employer / personal assistant support relationship.

It also seeks to contextualize these micro relationships within our changing relationship with the state in terms of the responsabilisation of the citizen (Peters 2001; Clarke et al 2007).

In spite of these aims and with a commitment to accountability within the research process this project also seeks to support outcomes of more immediate and practical benefit to those involved. Wiles et al (2006: 269) have suggested that:

Study participants in social research often choose to participate on the understanding or hope that their experiences will 'help' others in a similar situation. This is especially the case in research focusing on people in health and social care contexts or people who have experienced significant life events or transitions. Indeed, the aim of research is often 'sold' to potential participants on the basis that it will be used to contribute to the development of services, policy or knowledge in the area with the aim of helping others in the future.

This research was on some level 'sold' to the employers with the prospect of a more practical outcome for the people of the area. At the initiation of the project it was suggested at each meeting with the employers that there was a possibility of a local project as an outcome of this project if they were interested in getting involved. Many of the employers involved decided to be a part of this separate project. In discussions with some of the employers and later with the larger group of employers it was agreed what this group would do. There was a general consensus amongst the employers that there is not enough support for new employers or personal assistants. This ongoing project hopes to offer training, run by the employers group to other employers and their personal assistants using Williams et al (2009) personal assistant training pack. Furthermore the group felt it was important for there to be ongoing peer support for both employers and personal assistants in an attempt to address the isolation that both groups have identified.

This training group will seek to address the inequalities at the foundation of the project and the anxiety experienced during the research and transcribing process:

Questions of exploitation, or 'using' others tend to arise as you become immersed in research and begin to rejoice in the richness of what you are learning. You are thankful, but instead of simply appreciating the gift, you may feel guilty for how much you are receiving and how little you are giving in return.

(Dickson-Swift et al 2007: 343)

Other writers have reflected these feelings of guilt at the generosity of people to share their experiences:

This idea of feeling simultaneously excited and guilty by the data gathered has also been raised in the literature (Etherington, 1996; Finch, 1984; Lofland and Lofland, 1995; Oakley, 1981). Lofland and Lofland (1995: 28) refer to this feeling as an 'ethical hangover', which is a 'feeling of persistent guilt or unease over what is viewed as a betrayal of the people under study'. Similarly, Etherington (1996: 347) reports her unease: 'As I listened to some of these stories with my "researcher" ears, I became uncomfortable when I realized that I was thinking this is really good stuff!' For some researchers, this sense of excitement when they obtain data from people is often in stark contrast with their ethics about 'using' people for research purposes.

(Dickson-Swift et al 2007: 343)

The 'ethical hangover' of the research process, recruiting, interviewing, analysing in the anticipation of achieving a PhD carries a significant burden. However, on meeting the employers again for meetings to develop the training project all the concerns began to fade in the hope that this research project could hope to offer something near to a 'fair

exchange' (Daly 1992) and as Tregaskis and Goodley (2005: 372) acknowledge:

Yet in turning towards interdependence, we are reminded that our research activity is not only governed by such procedures, but is also resistant to it. Hence, our involvement with parents is not simply one of hearing their 'voices' but also of working with them in interdependent ways to, for example, explore social and political groupings which may offer them necessary emotional support outside the research process.

(Tregaskis & Goodley 2005: 372)

As such there are multiple outcomes of the project: the thesis, the training project and an accessible summary. In addition it is hoped that the training will lead to longer-term peer support for both the employers and personal assistants in the area adding to the fair exchange and accountability of the project as a whole.

### *Introducing the participants*

The following chapters in Part II are led by the words of the participants. Chapter 4: *Beginnings* introduces the participants through each of their stories about choosing to take a direct payment or work as a personal assistant. The lives and experiences of the participants are expanded on throughout the different chapters, however below is a short synopsis about each participant as a pre-introduction and useful reference point.

#### *Employers, personal assistants and supporters*

Ali: Ali is in his 40s living independently (with personal assistant support) as a tenant in his own flat. Ali lived for many years in

traditional residential care and fought to receive a direct payment in 2003. Ali employs 4 personal assistants and uses his personal assistants to help with everyday activities such as cooking, cleaning, managing his household and socialising.

Abbey - **Ali's personal assistant:** Abbey, Ali's personal assistant has worked for him for several years. They met through Ali's self-advocacy work when Ali asked if she would work with him. Abbey is in her 30s and has worked with people with learning difficulties in different capacities for many years.

Adele - **Ali's care manager:** Ali identified his care manager as the person who supported/s him with his direct payment. Adele is in her 50s and has worked as a Care Manager for around 10 years. Adele has worked with Ali for several years and helps Ali to manage his support.

Benji: Benji is in his 40's and was one of the first people in the area to get a direct payment for support in his home. Benji has his own tenancy and uses his support to help him with bills, cleaning and cooking and going out. Benji feels confident employing his own personal assistants and receives some help from the Independent Living organisation who help with the financial aspects of being an employer. Benji did not identify one particular person who helps him manage his direct payment.

Bev - **Benji's personal assistant:** Bev is a student in her early 20's at the local university. They met whilst she was on a voluntary placement related to her course and Benji asked her if she would like to apply for a job as his personal assistant. Bev works for on average 4 hours a week and has only been working for Benji for a few months.

Camille: Camille is in her mid 30's and has been employing her own personal assistants for approximately 5 years since she moved into her own rented flat. Camille uses her support in the evenings for help with meals at home and at the weekends to go out to the cinema and the theatre. Camille generally chooses to recruit students from a local college to work as her personal assistants. Camille did not identify a particular person who supports her to manage her personal assistant.

Cathy - **Camille's personal assistant:** Cathy is in her 20's and is a student at a local university in her early twenties and studying for a professional qualification in the social care area. Cathy has worked for Camille for over a year and appreciates the opportunity to gain experience working in social care.

Daniela: Daniela is in her 40s and lives in her own rented flat within a supported housing building. Daniela, with the support of her care manager (Diana) decided to take a direct payment and employ her own personal assistant when she was not happy with the quality of support she was getting from the 'care' agency she was previously using. Daniela asked Debbie, a support worker she met through one of the care agencies, to work directly for her as her personal assistant. Daniela uses her personal assistants to help her in the morning with personal care and throughout the week to help with shopping, meal planning and preparation, shopping and budgeting.

Debbie - **Daniela's personal assistant:** Debbie is in her 40's and first met Daniela when she was working for a local care agency as Daniela's support worker. Debbie kept in touch with Daniela after she left the care agency and agreed to become self-employed and work for Daniela as her personal assistant. Daniela has a close relationship with Debbie and Debbie often invites Daniela to join



her family for special occasions. Debbie is Daniela's primary personal assistant and has support from two other personal assistants whom Daniela also employs.

Diana - **Daniela's care manager**: Diana is a Care Manager in her 60's and has worked as a social worker in this area for many years. Diana has worked with Daniela for over 10 years and they both said that they have a very trusting relationship. Diana supports Daniela as and when needed with the managing of her personal assistants and also involves the local Independent Living Service to help with the financial aspects of Daniela employing own personal Assistant.

Ed: Ed is in his early 20's and at college. Ed decided to take a direct payment, with the support of his parents to employ a personal assistant in the holidays. During the holidays Ed lives with his parents and uses his support to go to work experience placements, go to the pub, cinema and see friends. Ed has employed several personal assistants since 2003 and looks for personal assistants who are his age and who have similar interests.

Emily - **Ed's Family**: Emily is Ed's mother and supports Ed to manage the financial aspects of Ed's direct payment as well as helping Ed to identify what he wants to do with his personal assistant.

Freddie: Freddie is in his 30's and lives in his own home with a housemate who offers him some support around the house. Freddie has a personal budget and employs different personal assistants according to his interests. Freddie loves music and has personal assistants who help him organise gigs, he also has a personal assistant who helps him maintain his allotment and another to help him run a small ethical business, who also helps him pursue his interests in human rights.

Freya - **Freddie's personal assistant:** Freya is in her 50's and has worked as a social worker with young people for many years. Freddie knew Freya before she became his personal assistant. Freya supports Freddie to run his business and also due to the number of personal assistants Freddie employs Freya also offers Freddie's other personal assistants individual and group supervision.

Faith - **Freddie's family:** Freddie's mother, Faith was keen for Freddie to take a personal budget due to difficulties in getting access to traditional support that worked for Freddie. Faith is very involved in helping Freddie to manage his employment role in terms of finances and personal assistants.

Georgia: Georgia is in her 40's and lives in her own rented flat. Georgia employs personal assistants to support her at home in the evenings and weekends with meals, shopping, socialising and general household tasks. Georgia employs 3 personal assistants and predominantly chooses to employ students from the local college.

Gemma - **Georgia's personal assistant:** Gemma is a student at the local college and is in her early 20's. Gemma is studying for a professional qualification within the health and social care area and wanted to work for Georgia to gain work experience. Gemma works generally less than 10 hours a week.

Gillian - **Georgia's care manager:** Georgia identified her care manager, Gillian, as the person who supports her to manage her direct payment and her personal assistants. Gillian is in her late 40's and works as a review manager and as such does not have much time to support Georgia with daily difficulties of employing personal assistants.

Harry: Harry is in his 40's and lives with his family. Harry decided to take a direct payment at a time when respite services were changing in the area and Harry did not like any of the options that were made available for him. The primary options were traditional respite out of the local area and family placement. Harry decided that he would like to stay at home with some support when he needs it – around meal times and general reassurance. Harry and his family choose to employ Harry's sister (who lives nearby) to work as his personal assistant when their parents are away.

Hetty - **Harry's personal assistant:** Hetty, also in her 40's, is Harry's sister and has supported Harry at home whilst their parents are away for over a year. Hetty supports Harry with meals and overnight contact to help him to continue to have a normal life whilst his parents are away.

Harry's parents – **Harry's supporters:** Harry lives in the family home with some support from his parents. Mr and Mrs Harry, both in their 60's support Harry to manage the financial aspects of employing his personal assistant – his sister.

*Other participants:*

Ivan - **Personalisation Officer:** Ivan works for the local council and is responsible for the development of self directed support and the personalisation agenda in the local area.

Joanne - **Independent Living Service:** Joanne works for the local Independent Living Scheme and supports people who take a direct payment through the process of recruitment and employment law. Joanne offers ongoing support to people who have direct payments around payments, holiday pay and PAYE. On occasion Joanne

will offer support to direct payment users when they are having difficulties with their personal assistants although this is done on a voluntary basis as it is not a service commissioned by the local authority.

**Katrina - Self-Advocacy supporter:** Katrina works with the local self-advocacy group. Katrina supports people who have taken a direct payment informally through the self-advocacy group. Many members of the group have decided to take a direct payment in preference to traditional support services and the group, with Katrina, offers members peer-to-peer support.

These people are at the centre of this project; people's lives and stories of their experiences form the basis of the following section; *Contingencies of empowerment – roles, responsibilities and relationships*. Chapter 4, *Beginnings* introduces the participants properly, in their own words and explores their reasons for employing their own personal assistants. It also seeks to explore the motivations of the personal assistants who work in this area of social care.

## Part II: Emerging themes: Contingencies of 'empowerment'

### Chapter 4

#### Beginnings

This chapter seeks to further introduce the employers, personal assistants and their supporters who shared their experiences of direct payments. Their trajectory from 'service user' or 'resident' in a residential home to employer can appear straightforward in much of the government literature, as it does with many of the stories of the employers, families and personal assistants in this chapter. However, it is suggested that the impact of the shift in power cannot be easily understood on a purely personal and practical level, but needs to be considered in the context of a political analysis of social care and that it is by viewing the personal and the ideological that the complexities of these new relationships emerge. It is these complexities and new relationships that are of interest.

*Capable Communities, Active Citizens* (DH 2010) offers a vision for social care based on the principles or values of freedom, fairness and responsibility. Direct payments through personal budgets sit comfortably within each of these principles:

The first value is Freedom. We want to see a real shift of power from the state to people and communities. We want people to have the freedom to choose the services that are right for them from a vibrant plural market. That is why this vision challenges councils to provide personal budgets, preferably as direct payments, to everyone eligible within the next two years

(DH 2010: 4)

Freedom here encompasses a power transfer specifically, looking towards the individual in their communities to take and use this power offered via direct payments. This commitment to and interpretation of the power of direct payments shifts the emphasis from a duty to offer the option for people to 'choose' to take a direct payment, to a prescribed preference for people 'choosing' to take a direct payment, which, by implication, confers the possibility to become an active citizen, a possibility which is assumed to be unavailable when 'choosing' not to take a direct payment.

This assumed shift of power from traditional service-led residential and day services to more person-led, personalised support, direct payments, be they in the form of the early direct payments, self assessed personal budgets (DH 2007b) or the piloted individual budgets (Glendinning et al. 2008), has been positioned as a central tool within the personalisation agenda (DH 2009a). The breadth of the personalisation agenda extends well beyond the narrow confines of direct support for daily living (DH 2008), however the nature and quality of the direct support work involved is critical to the agenda's success (DH 2006b; DH 2011).

This focus upon the communities in which we live as disabled and non-disabled people under New Labour culminated in the ongoing re-negotiation of our positions in relation to the state. The New Labour concern with responsible citizens where existing rights give way to responsibilities (Dwyer 1998) can only be developed, perhaps with different motivations, but similar effect within David Cameron's vision of the 'The Big Society' (Cameron 2010).

It is within the context of New Labour's rights and responsibilities discourse and the coalition government's new analysis of 'The Big Society' that the employers and personal assistants in this study, in combination with their supporters, live and work, in a small English city. Direct payments, within the context of the broader personalisation agenda, have offered a vision of life where choice and control can exist

unproblematically. In this locality there has been a strong commitment to the values of *Valuing People* and the personalisation agenda. This commitment was illustrated by the enthusiastic re-provision of traditional large day centres between 2003 and 2008. The re-provision, although not universally popular, was completed for all with the exception of a small building based 'service' for people with complex learning and physical disabilities. The new 'services' attempted to offer a more individualised service in community settings throughout the city in the anticipation that people visible in the community will, in time, become part of it. Therefore, it is within this context, that the people involved in this project have taken advantage of the new opportunities offered by taking a direct payment or working in the relatively new role of personal assistant.

The city council's commitment to personalisation led to affiliation to In Control's Total Transformation programme (Tyson 2008). This enthusiasm for the values behind direct payments, within the wider context of organisational change, is illustrated by the Council's personalisation officer, Ivan:

[I]t offers control because people can buy things that are not mainstream, not the traditional things that to us in our history of social work might seem a bit bizarre at times but actually make sense to people on a day to day basis so like flexibility to do things and change it in a more creative way ...[...]... I keep saying to people it's nice to think of things in terms of seasons now rather than weeks and years because people do different things in the summer and the winter and you might want to spend your money accordingly ...[...]... it's a bit more of the rhythm of life ...

Ivan emphasises the potential of direct payments whilst acknowledging the difficulties of entering a community that is not ready or may be unprepared to offer what the individual may want and need to live a fulfilled life. Ivan identifies in the 'rhythm of life' notably that the lives of

people with learning difficulties have been structured and inflexible, dependent on the needs of the supporting organisation, rather than the person. This resonates with Ali's experience.

Ali, as a result of receiving direct payments, now lives in his own flat with the assistance of a group of personal assistants who offer support at specific times of day with cooking, cleaning and managing his tenancy. Ali also uses his more flexible personal assistant support to go out and enjoy his life. Ali explains what his life used to be like and the change employing personal assistants has offered:

[In residential care] you had to go to bed at a certain time, meals were at a certain time umm basically it was quite regimented really it was quite institutionalised and it made me feel quite bitter really to be quite honest not being able to live my life how I'm living it now, going out and doing things which is, you know, when I first moved in here I was living life like an 18 year old student, doing all the things that ...[...]... you know here's me at 40 night clubbing and doing all the things that young people should be doing you know.

Ali reflected on the difference direct payments have made to his life. The opportunities offered through living in his own home with support that enables him to do the things he enjoys stand in sharp contrast to the regimentation of traditional services. Ali tells of his desire to live the youth that his traditional residential care home denied him and this is similarly illustrated in how he recruits his personal assistants. Abbey has worked for Ali for over 2 years and describes how she became Ali's personal assistant:

Katie: Why did you become a personal assistant?

Abbey: Ali asked me if I'd become a personal assistant.

Katie: How did you know him?

Abbey: Through [speaking up]. I think we'd all been out together



to a, it must have been (a restaurant) because we all ended up in (a club) ...[...]... and Ali said well I'm losing one of my staff if you are interested in some extra hours come and be one of my personal assistants so that's how I ended up being a personal assistant.

Katie: So had you done support work before?

Abbey: Yep well I worked as a learning and skills advisor at (a charity) for adults with learning difficulties.

Ali is clear in what he is looking for in a personal assistant and has often employed people who he has met through his self-advocacy work. This approach to recruiting was a common way for employers to find and recruit personal assistants. Ali identified his care manager, Adele as his supporter. Adele has been described as a very supportive care manager who has been able to re-define her role to enable Ali to make his own decisions (and mistakes), in spite of the traditional concerns of the care management process and potential difficulties. Adele explains:

[H]e has got one [PA<sup>11</sup>] who I think definitely does promote independence, again I think that he has a hand in that, he can make that difficult. Because I think sometimes he [will lack] the motivation to do the things they are trying to, that really would be an aim, I think it's easier all round for them to do the task and this is where reviews come into play cos we can gently remind people what is needed really. Although again it is difficult as you can't be there all the time to check up what is going on, even though the money does come from social services ...[...]... so that's a difficult one.

Here Adele highlights the tensions intrinsic in self-directed support and the changing nature of care management or social work practices; the support Ali wants from his personal assistants and the support that

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<sup>11</sup> The term personal assistant was abbreviated to PA by the majority of participants. Where PA was used in interviews it has been transcribed verbatim in all other places the full title has been used.

councils would previously have commissioned. The role of the personal assistant is here contested. Historically there has been an emphasis on a particular type of 'independence' focused on the development of independent living skills and 'independence' in the sense of appropriate support (Morris 2004), which sits more comfortably with the movement towards self-directed support. Adele similarly highlights the conflict that remains, her role is to assess and support self-assessment and fundamentally account for, through annual reviews, Ali's support funding. Therefore, Adele has found herself in between the role of advocate and the manager of resources or 'running the business' (Harris 2003b). It is this, at times conflicted relationship, that continues and is potentially heightened when negotiating self-directed support.

Benji, like Ali, now lives in his own home since he decided to take a direct payment in 2003. Benji uses his support to maintain his home, to have help with cooking main meals and to get out in the evenings and weekends. Benji was one of the first people with learning difficulties in the area to ask for a direct payment and had to convince his care manager that he would be able to manage. Benji describes how he discovered direct payments:

I went to a conference in 2003 with Katrina [self-advocacy supporter] ...[...]... I saw someone called [H] from [...] People First he moved out of residential and I said to myself I want to do that too. Katrina and I did a conference in 2003 with [the local Speaking Up group].

This conference was pivotal to those involved in the local Speaking Up group, and people with learning difficulties in general, in this area, learning and exploring the possibilities of direct payments for themselves. Benji was clear what he wanted and hoped to experience through taking a direct payment and employing his own personal assistants:

Katie: I am really interested in why you choose to employ

- your own personal assistant?
- Benji: It's really good to employ your own personal assistant you can have more choice to do things with your own personal assistants.
- Katie: Yeah so was it about choice?
- Benji: Yep.
- Katie: What was your experience of support like before?
- Benji: When I lived in residential it wasn't very good, I used to live with 9 people and I used to have 1:1 and I didn't have the chance to talk to the staff what I want..
- Katie: So you didn't have a chance to choose the staff who supported you
- Benji: No, yeah

Similarly to Ali, Benji has used direct payments to leave the inflexibility of residential care where he lacked choice and control over the people who offered him support. Benji also looks to employ people that he knows or has met through his work and other interests. Benji met Bev (one of his personal assistants) at a local music group where she was on a work placement during her music degree. Bev was keen to learn more about supporting people and started working with Benji with the intention of getting some work experience:

[I]t's what I want to do afterwards, music therapy, so I just want to get a bit of experience working with people with learning disabilities, I have a brother with mild autism, he has Aspergers so I have a little bit of experience but I just wanted to experience a bit more with other difficulties ...

The role of personal assistant, due to its limited hours and active nature, attracts students looking to learn about support work. Benji's motivation to move into his own home was inspiration for some of the other participants to take the leap from residential care to support in their own home. The aim of independent living is also evident in Camille's reason for choosing to take a direct payment:

[B]ecause I was living with my flatmate at the time and she was doing a lot of my support so a friend recommended that I take a direct payment, but I didn't have a care manager or anything at the time so I got a care manager and explained what I wanted a direct payment for they said 'oh no you don't need a direct payment for that why don't you get a cleaner?' ...[...]... I really had to fight for the direct payment ...[...]... you can have a cleaner for that and buy a microwave so I had to go ...[...]... we went to fight it because we knew it were wrong and then they eventually gave me direct payment, but it was a two and a half year battle.

Camille struggled to get the appropriate support to enable her to live in her own home independent of her friend, however she was not sure how it could or would work once her direct payment was agreed:

[T]o be honest I didn't have any thoughts as I wasn't sure how it works, I knew I didn't want to continue living in the situation I was where my friends was doing a lot of the supporting and helping me to live independently so I initially thought well I'm not sure how this is going to work so I'll look into it

Camille now has 15 hours of support each week to help her run her home, help with the cleaning and correspondence as well as assistance with evening meal preparations. Camille tends to recruit students as personal assistants and values her personal assistants' interests as well as the relationship that can come from working closely together. Cathy is currently one of Camille's personal assistants who is in the midst of a degree in Occupational Therapy. Cathy applied for the role through an advert on the local Independent Living Service and explains why she chose to pursue the role of personal assistant:

Cathy: I became a PA because I was at university and looking for work and I thought that it would help me find a bit of experience in the social care area which is related to

my degree of Occupational Therapy and so I thought it would be a fantastic experience. Primarily it was to earn a bit of money whilst I was doing my degree, but doing a job that was relevant was really important.

Katie: How did you come across the job?

Cathy: I came across the job on the (Independent Living Service) website, I had a look at the website, had a look at the people who were advertising, how many hours that they were looking for, where they were based ...[...]... I needed something I could get to easily that was near my house ...[...]... and so this job seemed to jump out at me, it's about 9 hours a week which is what I was looking for just to fit in with uni and so I didn't meet Camille until my interview ...[...]... but I knew her details and what she was looking for.

Ali, Benji and Camille all identified their aim to live independently and were critical of the traditional support (and lack of it in Camille's case) that they were offered.

Daniela, in contrast employed Debbie who she had met whilst Debbie was working for a private care agency, which the local authority had commissioned to support Daniela. Daniela was living in a flat in sheltered accommodation when she first considered taking direct payments with the support of Diana, her care manager. Together Daniela and Diana explain what Daniela's experience of support had been using a private care agency:

Katie: Did she come on time?

Daniela: I don't know she said about, came about 9.30 ish and left at 10.

Diana: I think how it felt for me, and I don't how it felt for you Daniela as if she was trying to be as efficient with her own time as possible so she would come into the building, she had other people to whom she gave a

service ...

Daniela: In the building, in this building

Diana: And she wanted the whole thing to be as efficient and get everybody done and her get away as soon as possible, so she came, Daniela would still be in bed, she rang Daniela's doorbell and said it's time to get up and start running your bath and then she went off and did somebody else ...

Daniela: She leaves me alone does somebody else and comes back here

Diana: and then there was your bath with [an agency support worker], did she stay with you all the time you had your bath

Daniela: I don't know I'm trying to think

Diana: It may come back to you Daniela because she got you to a certain stage in the bath and went off and did something else with somebody else here and then just kept coming back. It was like a time and motion thing, it's a bit like a dentist.

Diana in describing Daniela's support as 'a bit like a dentist' described a very impersonal experience of traditional home care agency working practices. Daniela is now supported at home by a team of 3 personal assistants coordinated largely by Debbie. The support agency mode of support was not working for Daniela, however it did not work for Debbie either:

I became a personal assistant because I worked for [a care agency] and then I left [the care agency] because it was not a good place to work and kept in touch with Daniela on a personal level for about 10 months, but in the 10 months that I wasn't caring for her she went down hill quite a lot so Diana told me about the [Independent Living Service] and I am already self employed so it's no big deal for me to do a tax return, so we discussed it with Daniela and agreed that she wanted to do that, she wanted me to

come back and look after her so that's what I did, but all in all it will be about 5 years at Christmas I've been going to her ...[...]... I had nearly a year out but kept in touch, I'd still come and see her on a Sunday and she'd come and have a sleep over at ours on a Saturday and watch X Factor, things like that so we did keep in touch, but she was not happy and we knew it was because of her morning care.

Debbie's pathway into becoming a personal assistant stemmed from her dislike of traditional home care work, but also an emotional connection to Daniela. Support relationships as has been suggested and reiterated in several of the government papers (DH 2010) are fundamental not only to the experience of support but also the experience of offering that support.

Relationships were also important to other participants. Ed was still at school when he with the support of his family and mother, Emily, decided to take a direct payment for support during the holidays. Initially Ed and his family chose to invite a friend to support Ed during the school holidays. Ed describes what he would do with his personal assistant (who was not able to participate in the project):

Katie: How did you start working with [your personal assistant]?

Ed: Really we just met together and cruising around in his car, meet all his friends and stuff like that, it was so much fun. We used to have a BBQ for his birthday and go to his garage and sort his car out, things like that, we used to get on well together. And there was another guy, [the personal assistant] who used to be my personal assistant at the YMCA at the outback we used to do things together like getting young people sorted ...[...]... it's just getting young people to do things so they are not bored ...[...]... it just went from there really.

Katie: What sort of things did you used to do?

Ed: We used to do activities, just go out together bowling um, go to football matches, get on together, have a laugh.

Ed's personal assistant offered Ed the opportunity to share in his friends and social and work life, offering Ed social support when not at school. Ed's use of direct payments to employ someone for this purpose is very much in evidence in *Valuing People* (DH 2001, DH 2007a). Emily, who works in the social care area identifies other reasons for the importance of taking a direct payment in the summer holidays, not only because of Emily and her partner's working patterns but also:

Because I think ...[...]... It was for during the summer holidays, Ed had started school and he had only been at school for just over a year ...[...]... and it was great he loved it at school, but once school finished ...[...]... weekends were busy, but that was ok cos we were doing our own thing and during the holidays it was like oh goodness he wasn't meeting up with any of his friends because they didn't do that, nobody seemed to meet up and it was also getting out to try new experiences so that was when we first ...[...]... well I knew about direct payments anyway but we explored it with the council's direct payments officer ...[...]... then looked at what we could do, what we could have, but we identified that it was really for his social needs to get out and about, [and] find out what was going on.

Emily identifies the importance of social contact and developing a variety of friendships inside and outside of school, but also the difficulty in maintaining friends outside of organised places or institutions, in Ed's case school. Emily also points to trying new experiences and the lack of opportunities for Ed to do this within traditional support. This they needed to develop for themselves.

Freddie and his family have worked hard to develop support that works for Freddie having had very negative experiences of supported living.



Faith, Freddie's mother highlighted the difficulties Freddie faced in supported living, which failed to break the institutionalising habits of more traditional forms of residential care:

At the time he was living in a group home, there were 3 people, 2 women with very different needs to Freddie and he was desperately unhappy and we were really worried about his mental health, he ended up just living in his room, ear phones on and head down ...[...]... he was desperately unhappy and so we had a review which we kind of led and made it a person centred review. Freddie has a circle of support<sup>12</sup> and one of his circle members ...[...]... is a trained person centred facilitator ...[...]... so she led the review and we had done a lot of research about person centred reviews and just knew that this had to be the way and it was fantastic because Freddie was very clear what was working well for him, but also that he desperately wanted to move out because he was desperately unhappy and it was great that he was able to verbalise that himself ...[...]... it had reached the stage where it was so obvious um that no-one was going to argue with him so to cut a long story short we decided that yes he had to move so we got together with him, we talked to the care manager and there was nothing else offered so we, really there was no alternative but to go down the personal budget route.

Freddie and his family's decision to go down the personal budget route stemmed largely from the inadequacy of traditional services to offer support that Freddie needed to live the life that he wants and needs. However, even for a powerful parent advocate Faith explains how the decision to transfer Freddie's support entirely to direct payments was not a straightforward or necessarily obvious decision to make:

I suppose if I think way back to the direct payments, it must be at

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<sup>12</sup> A circle of support in the context of support for people with learning difficulties refers to a group of people, largely or exclusively informal supporters who have a close relationship with the person and offer support, guidance and advocacy when needed.

least 6 years ago, I do remember going to a meeting about direct payments and thinking what has this got to do with me and what's this got to do with Freddie and it was only later on that the penny dropped really when Freddie's situation was such that he needed to be doing something that wasn't available in traditional services so again it was we don't have a choice here so I suppose the music and the food trading that was kind of dipping our toes into the water and at first I didn't like it particularly it was just something else to worry about really...

Freddie now has personal assistants to support him to pursue a wide variety of interests from music to his allotment to his food trading business. Freddie spoke about the variety of work and leisure activities he does with his personal assistants, here Freddie is talking about his food trading business:

Katie: What's it like to have a personal assistant?

Freddie: It's brilliant, it's brilliant, it's good.

Katie: What's good about it?

Freddie: Helping people to do lots of food-trade, and it's all different things, selling things, coffee, teabags, jewellery.

Freya works with Freddie, as his personal assistant. Freddie knew Freya before she became his personal assistant and Freya was interested in the role not only because they shared an interest in Freddie's trading, but also because the role offered a different and interesting way of working. Freya explains how she became Freddie's personal assistant:

I was working at the [children's charity] doing some sessional work there ...[...]... they had some funding to find ways of enabling young adults to volunteer and Freddie was then part of that I remember ...[...]... we were doing a bit of a role play ...[...]... I remember then I spent a bit of time with him ...[...]... so I suppose from there his mum had said to me that his personal assistant was

leaving and was I interested in doing that and because he was doing [food] trade and it seemed like a good combination, but I didn't intend to stay it was a sort of well I was thinking what next really ...[...]... I had some sort of caring responsibilities for my mum so I wasn't in full time work ...[...]... so I think that's what sort of continued, you know it's where I've had that autonomy, nobody is breathing down my neck, I don't have to finish after an hour, I don't have to necessarily write it up if I don't want to do it can be in the moment you know and I think that is a delight when you compare it to all the other work that we do, you know if I had gone into counselling you are still limited by time ...[...]... and it's active as well, it's that aspect of getting up and doing, not just talking about what you are going to do [a role] where together you can create your own arrangements and your own format and that delights me no end really because that is how I like to operate.

The relatively new role of personal assistant is as varied as the people employing them. Traditional services have frequently failed the people involved in this project, however equally they have disillusioned the workforce.

Dissatisfaction with traditional services, be that receiving or offering support from within their confines, has been highlighted by each of the participants introduced so far and it is equally true for Georgia. Here Georgia explains her expectations of getting direct payments and employing her own personal assistants:

Katie: Why did you decide to have one?

Georgia: To get more hours.

Katie: Have you ever used an agency?

Georgia: Nightmare.

Katie: What happened?

Georgia: Not enough hours.

Katie: What did they do for you?

Georgia: When they came I wanted them to stay a bit

longer.

- Katie: When they come what do they do?
- Georgia: They don't do anything they just sit there.
- Katie: This was before you got a direct payment?
- Georgia: Yes.
- Katie: Why did you choose to take a direct payment?
- Georgia: Because Ali and Benji have loads of hours.
- Katie: Did you think you would employ your own personal assistant?
- Georgia: Definitely.

Georgia uses her support to live independently in her own home. Georgia has support to manage her tenancy, money, shopping and food preparation and was hopeful that by taking a direct payment she would get the support hours she feels she needs. In order to manage her personal assistants Georgia has support from her care manager, Gillian and the Independent Living Service. Georgia likes to find personal assistants from the people she has met through her self-advocacy group and other interests. Gemma who is working as one of Georgia's personal assistants is a student who is keen to gain experience working with people:

- Katie: Why did you become a personal assistant?
- Gemma: It was basically to get more experience for part of my course cos I'm doing learning disability nursing ...[...]... so it's to get more hands on experience working with people with learning disabilities. The (personal assistant?) thing is really good as it's so person centred. The person I work with actually asked me if I would become a personal assistant so that's really good.

Gemma seems drawn to the work not only for experience working in support, but also in agreement with Freya and Debbie, the type of work and way of working she feels able to do within the personal assistant role.

Harry is the final employer who took part and his transition to taking a direct payment is more complex. Where other people experienced poor quality services be they in residential care or home care services and chose direct payments as a reaction to the service they were receiving, Harry's decision was arguably enforced more directly through policy changes. The process of day service re-provision, initiated through *Valuing People* (DH 2001) had consequences for other council run services; in Harry's case his respite service. Harry is in his 40s and lives at home with his parents and, prior to the re-provision of day centres in the city, had an allocation of respite at the council run respite centre. The re-provision prompted a change in eligibility to use the service and Harry and his family found themselves without the respite provision that Harry had enjoyed and his family valued. Harry and his parents explained the difficult search for a new service:

Harry's mother: You had a horrible experience, you want tell Katie about that?

Harry: Yes before when I was in...[Respite]... staff rang my mum and dad, not got any vacancies, moved me to [nearby town], no me know anyone.

Harry's mother: We didn't know where he'd gone, who he'd gone with or anything ...[...]... then there was an emergency he had to be in the emergency bed so they moved him out and unfortunately we were going away ...[...]... he didn't like it.

Harry: This lady got learning disability like myself ... no mum and dad, her live there permanently ... shop 2 miles away ... I only know little [this nearby town] for an hour or so.

Harry's mother: Then you went to [adult placement] and you weren't keen on that.

Harry: No I wasn't. Went to [adult placement] ...[...]... with [a support agency] ...[...]... this man a social worker [...].

Harry's mother: He didn't like it ...[...]... so everybody said about

this independent living so we looked into it and we've never looked back really.

Harry's negative experiences led him to think and talk about the options with his friends:

When [the day centre] closed down, high support needs moved to [Harry's original respite], people independent like me we move out I got loads of comments through Benji I've been in his house he explained to me if you want to stay at home when my mum go to the caravan, my sister make me my tea, dinner, I can stay here.

Harry and his parents approached his sister, Hetty to support him whilst his parents go away on holiday. This was a necessary decision for Harry's parents, not a choice, given the changing service situation:

Harry's father: Harry gets so frustrated about, with [his respite] closing, it seems as though people with learning difficulties get pushed backward and because they haven't got a voice like you or I they choke ...[...]... with People First where independent living with Harry came in, it was a decision that was made for him, that there's no respite care ...[...]... so we said what's going to happen ...[...]... but independent living is brilliant now for Harry because he lives in his own house, no disrespect I wouldn't want a student coming in here and it's far easier now that my daughter looks after him, because that to me is independent ...[...]... it gives Mrs Harry and myself that freedom now, if we want to go mid week, we say to Harry right that's your provision ...[...]... that provision is there, we are always just a phone call away, it give Mrs Harry and I that bit more freedom ...[...]... we used to have to book it a year in advance.

Harry's mother: We can say next week we'll go away, Harry you'll

be at home and that's it no problem.

Harry's father: We've no need to justify now when we want to go away ...[...]... to me 28 days isn't a long time, but 28 days is better than nothing.

Harry choosing to employ his sister was something which was not possible under initial direct payments legislation, Community Care (Direct Payments) Act (1996), however the rolling out has evolved to extend to relatives who do not live in the same home (DH 2003; Glasby & Littlechild 2009). For Hetty the decision to offer support to Harry was not difficult, and something that as a sister and part of a close family she had always and will always do, being paid was just a 'bonus':

He's the kind of person that he likes his own routine, he likes to know what he is doing umm so we sort of looked into it and he really was not happy going to other places taking him out of his routine so I said well I could look after him, you know well he could just come here and I mean and at that point I hadn't thought about getting paid or anything for it I just said for him to be happy I'd rather him be happy and come here, know where he's going, keep him in his own routine and then we enquired about it and it came up with the independent living that was one of the choices and obviously they have changed the guidelines on that they have moved the goal posts and said well family can now do it cos before family couldn't do it.

Each of the people who have taken part had their own motivations and expectations. The stories, particularly Ali's re-living of his denied youth, or Harry's sister helping Harry to stay in his home whilst his parents go on holiday or Camille being supported to live independently of her friends would not look out of place within *Valuing People* (DH 2001, 2007a), *Independence, Wellbeing and Choice* (DH 2005a) and certainly Freddie's entrepreneurial spirit in developing a food-trade business would sit neatly in *Capable Communities, Active Citizens* (DH 2010). However, these success stories cannot exist in isolation. In this area the council have funded a support service to assist with recruitment, employment law and

payroll. Joanne works for the Independent Living Service in the area and explains the support the service offers to prospective and current direct payments users:

We offer as much or as little support that people want ...[...]... we go and see people, give them advice on direct payments and we have to make them aware that they have responsibilities to be an employer ...[...]... right from the beginning in recruiting ...[...]... assisting with their job description ...[...]... and then we would advertise it for them ...[...]... so they would interview them, if they were appointed they would either ask us to help with references, with CRBs as well so we do all of that, that process of recruiting right through to doing the contracts of employment ...[...]... and then we also do the tax returns so we get all the personal assistant's details for them ...[...]... cos it's public money they have to do a direct payment return to the council every 3 months ...[...]... we can manage the money on their behalf, but we would still let them know about the money.

This is the type of support suggested as necessary in the recent Department of Health Guidance on direct payments (DH 2009a). The practical support with the contract, tax, Criminal Record Bureau checks (CRBs) may be vital to the rolling out of direct payments, but questions could be raised about the ability of these organisations to support other aspects of life when employing a personal assistant or managing a direct payment.

Katrina, who works as a supporter for the local Speaking Up group, highlights how employing their own personal assistants has contributed to valuable changes in the lives of some of the self-advocates she works with:

I think having their own staff and being flexible, they can say to their staff I'd like to go to [Brighton] today and there isn't anybody there saying we've got no staff



to do that ...[...]... they've had a lot more choices and can use their support workers in all sorts of different ways, like going on holiday ...[...]... most of them, the younger ones are prepared to support them with their friends, like going to the theatre, they can take their friend along as well...

The confidence Benji has developed as one of the first people in that area to take a direct payment and employ his own personal assistant has certainly inspired others in their self-advocacy group, and Katrina draws on the limitations of the formalised support of the Independent Living Service and the importance of other relationships in people's lives:

I think all of them have done incredibly well and should be proud of themselves ...[...]... the guys on direct payments have had to learn on their feet...[...]... I don't understand why people don't think that people with learning difficulties have the capacity to provide that support ...[...]... Ali gives far more support to Georgia than you could ...[...]... they are friends and they look out for each other and for me that's been one of the successes is of having a [Speaking Up group] and of being colleagues and learning to be friends ...[...]... it's been really good.

These stories highlight many of the aspirations and benefits of taking control of your own support through employing personal assistants. These people are the successful active citizens who are hailed in New Labour rhetoric as proactive and responsible citizens choosing to take control of their lives and refusing to be passive recipients of care, but what this masks is the complexity of human relationships and the processes involved. Personalisation through the tool of direct payments implies that people's decisions are equally valued and life choices are made free from the pressures and service-led structures of traditional services. However, the reality is more complex. Ali, Benji, Debbie and

Freddie revealed the inadequacies of traditional services as the motivation to switch to direct payments, however Harry's move was as a result of the modernisation of respite services, and although working well, perhaps better, was the result of changes in eligibility to receive residential respite services rather than an active choice. Adele revealed the developing of the care management role in direct payments, specifically how decisions are made and particular concerns about the care management role in the management of personal assistants. And the personal assistants Abbey and Bev talked about knowing their employer before becoming a personal assistant hinting about the potential implications of these new support relationships. It is through these relationships that the following chapters discuss the *responsibilities* and *relationships* of employers and personal assistants beginning with an exploration of the *roles* of employers and their personal assistants within the context of not only policy directions, but broader discourses of strategies of empowerment.

## Chapter 5

### Roles

The motivations of the employers and personal assistants in the previous chapter emphasise the variety of reasons why direct payments and crucially employing your own personal assistant was chosen. The lack of appropriate support, be that the unsuitability of traditional support for Freddie, or the changes in respite provision in line with the day service modernisation agenda for Harry or the aim of living independently for Camille, prompted the move to more individualised, personalised and self-directed support. Similarly the motivations of the personal assistants varied considerably with Harry's sister offering her assistance so that Harry could stay at home whilst his parents are away, to Bev and Cathy looking for work experience relevant to their university degrees and to Debbie resuming a role she previously played when she worked for a care agency. Each have now assumed a role which is at once theoretically controlled and directed by their employer but which is also situated within broader discourses and expectations of the personalisation agenda.

Direct payments have been a fundamental part of the development of the personalisation agenda and have been prominent in *Valuing People* (DH 2001; DH 2007a; DH 2009d) and more specifically within *Putting People First* (DH 2007b) and *Think Local, Act Personal* (Putting People First Consortium (PPFC) 2011). *Valuing People* has been described as 'an uneasy amalgam of the progressive and the neoliberal, the romantic and the practical' (Burton & Kagan 2006: 299) as such its essence is difficult to fully define. These romantic discourses offer visions of connected communities in which people with learning difficulties need to engage, and engagement in turn offers the potential for efficiency savings as *Think Local, Act Personal* (PPFC 2011: 4) suggests '[t]he most significant efficiencies are likely to come through reducing people's reliance on paid

support and changing the way that support is provided’.

These anticipated efficiency savings based within notions of community and community support link in with discourses of social exclusion/inclusion (Lister 1998), citizenship (Dwyer 2002) and the neo-liberal pre-occupation with productivity (Dowse 2009). *Think Local, Act Personal* (PPFC 2011:1), states that:

Personalisation and community are the key building blocks of a reform agenda, shaped around an individual’s own expertise and resources. When people need ongoing support, this should help them to retain or regain the benefits of community membership including living in their own homes, maintaining or gaining employment and making a positive contribution to the communities they live in.

Therefore personalisation - and by implication personal assistants - sit as the pivot in between the people they support and the ‘community’ in which their employers, and they themselves, *should* be engaged. *Independence, Wellbeing and Choice* (DH 2005a: 9) offers a vision whereby ‘services are of high quality and delivered by a well-trained workforce or by informal and family carers who are themselves supported’ yet there has been little or no provision to support personal assistants in their role. This is changing and the most recent contribution to the collection of social care papers, *Capable Communities, Active Citizens* (DH 2010: 34) reconfirms a commitment to personalised funding and acknowledges to a greater extent the importance of the roles of personal assistants when stating:

To deliver the vision the workforce will need to respond to the challenges of the principles at its core when delivering care. They will be crucial to delivering personalisation. ...[...]... The provision of personal budgets for all eligible people will mean personal assistants (PAs), directly employed by people who use care and

support services, working in new, creative and person-centred ways to play an increasingly important role in providing tailored support to meet individual needs.

This recognition of the 'new' and 'creative' and person-centred ways of working are inextricable from the independence and control of the Independent Living Movement (Morris 2004) and discourses of 'empowerment' through purchasing support, community and the market. It is through these discourses mixing consumerism, 'choice', 'voice' and 'exit' (D. Miliband in Public Administration Select Committee 2005) that people need to become agents of their own support, not just critical consumers, as O'Brien (2001: 12) wrote '[c]onsumers use things up; agents make things happen'. However, this analysis of active agents and 'tailored support' responding to the challenges of the principles of personalisation serve to mask the complexity of the role of personal assistant, which Ungerson (1999) described as 'unorganised and particular' and is subject to external as well as inter-relational forces. Dowse (2009: 575) observed:

The implied sense of the freedom of the consumer to use their purchasing power and exercise choice to determine the shape of their lives often in reality are closely related to new forms of self-regulation that are actively produced and conditioned by particular doctrines associated with neo-liberalism and intensified by globalisation.

This idea of self-regulation links strategies of empowerment to what Cruikshank (1999: 67) has termed 'technologies of citizenship' incorporated into Dean's 'technologies of agency' whereby targeted groups, such as people with learning difficulties, are:

required to agree to a range of normalizing, therapeutic and training measures designed to empower them, enhance their self-esteem, optimize their skills and entrepreneurship and so on

(Dean 1999: 168)

These technologies of agency act upon not only the employer in terms of how employers 'choose' to use their support, but also how personal assistants are expected to work. Disabled people have been subject to these 'normalizing, therapeutic and training measures', in different forms, but notably through medical and pathologising models of disability in a disabling society, which have in response prompted collective responses, one being the social model of disability (Oliver 1990). Goodley (2005: 334) explored 'resilience' in relation to people with learning difficulties and collective self-advocacy movements:

To assert that people labelled with learning difficulties have the potential for resilience troubles notions of naturalized, pathological and medicalized concepts of impairment. These concepts view people with learning difficulties as inherently passive, disordered and incompetent. Moreover, resilience adds some notion of collective agency – or resistance – to the clearly articulated structuralist views of the disablement offered by disability studies literature and the accounts of organizations of disabled people. Resilience refutes the view that disabled people are cultural dopes while challenging the commonly held view that people with learning difficulties are nothing more than their perceived impairments.

Resilience, therefore becomes something that we must recognise when exploring strategies, such as direct payments, which seek to 'empower' people with learning difficulties whilst harbouring tendencies which attempt to shape how the 'empowering' aspects of the freedom to employ and manage personal assistants are constrained. As such the 'unorganised and particular' personal assistant roles (Ungerson 1999) are subjected to and working through these 'technologies' which are sites of opportunity, resistance and negotiation.

Research has, perhaps unsurprisingly, focused on the role of personal

assistant from the perspective of disabled people (Meyer et al 2007; Stainton & Boyce 2004; Leece 2010) and older people (Clark 2006). Flynn's (2005) study quoted a disabled person's description of what they want and expect from their personal assistant:

It is the job of my PA to attend to me in all areas of personal and domestic need, and to act as a confidential escort and companion in my social and day to day activities...my PAs: have to undertake all that I am physically unable to do; need to follow my direction; need to be physically fit, preferably non-smokers; to use initiative, common sense and anticipate situations; PAs must have high personal standards in cleanliness, dress, discretion. I do not need: a nanny, a mother, a matron, a 'best friend'; nor psychological, menopausal or family problems ...[...]... personal qualities and attributes required of my PA include: accountability, reliability and trustworthiness; a willingness and ability to learn clean personal habits, including no smoking in my home; patience, intelligence, enthusiasm, initiative, a supportive, positive attitude and a sense of humour. Acknowledgement and respect of my lifestyle (including intellectual, sexual, cultural, educational and social aspects), my likes and dislikes, and two cats are important. It is also important to respect and not to overestimate my physical disability. My PA must always **ask** what my needs or wishes are, and **listen** to my requests and directions. All needs will vary from day to day and duties will alter accordingly, so my PA needs to be flexible with her time...[...]...Please remember a PA is always a guest in the disabled person's home.

(Flynn 2005: 30 emphasis in original).

This is a very bounded and rational description of the roles they wish their personal assistant to play and how they would like them to conduct themselves. It is undoubtedly broad, wide-ranging and personal qualities are clearly important. This task and character based description echoes

research into disabled employers which has suggested a preference for task-based support where personal assistants are 'taking the place of my hands' (Meyer et al 2007), and where, through the functional nature of their role, the personal assistant is rendered invisible in their work (Rivas 2003). Personal assistants, in this analysis, perform a silent and facilitative function offering their employer the practical support necessary for them to take their place as contributors to their communities (DH 2011).

Whereas for some disabled employers the role of the personal assistant may be silent and facilitative, research has suggested that the type of support relationship varies between individuals and more broadly between groups (Flynn 2005), where the personal assistant has a more visible, less practical role. As has been argued the value base of *Valuing People* owes much to normalisation (Johnson & Walmsley 2010) and although direct payments were initiated from a very different theoretical and analytical position, the role of employer offers people with learning difficulties the opportunity to assume a socially valued role. This socially valued role of the employer, acknowledged to be vitally important in the delivery of the aims of *Valuing People Now* (DH 2009d), has been given little thought in practice; specifically little critical thought has been given as to how *personal assistants* will work in practice. Government advice to current and prospective employers has been notably vague about the role of personal assistants stating that there needs to be '...a competent and well-trained workforce who are flexible, person centred and skilled in supporting people to be fully included in society...' (DH 2009d: 52). This competent, well-trained workforce is imagined outside the context of a vein of disability literature which is sceptical about the role of expert knowledge and professionalised support (Morris 2004), fulfilling roles which appear at once transparent and individual yet are products of notions of citizenship, (in)dependency, empowerment which places the role of personal assistant as a 'technology of citizenship' (Cruikshank 1999). As a technology of citizenship the personal assistant role is



subject to internal negotiations with the employer around how they wish to manage their support and broader forces which seek to position citizens as 'responsibilised' actors making 'good' choices (Clarke 2005). In the context of the personalisation of social care 'good' choices involve engaging with local communities creating informal networks and maximising independence and self reliance. It is at these points that the 'unorganised and particular' roles become the site of action and resilience by employers and their personal assistants.

This chapter, unlike the Department of Health's statement starts with the premise that people are complex (regardless of any label which has been ascribed) and support work is a subtle interplay of people, tasks, emotions and expectations. Even if we uncritically accept *Valuing People's* values of independence, choice, rights and inclusion within discourses of consumer citizenship (Clarke et al 2007), then enacting support, which facilitates these values, is problematic and requires more active and at times invasive potentially (dis)empowering 'support'. The experiences of the people in this chapter echo some of the findings from other studies in this area suggesting that as well as the ability to perform the practical tasks that would be expected from any kind of support work – shopping, cooking, cleaning, administration, bills – something else is needed. Specifically it is the *personal* in personal assistant which is prominent in what people think makes a good personal assistant. This chapter argues that these relationships need to be contextualised, not only within a history which has sought to 'empower' (and control) people with learning difficulties through pedagogic and normalising strategies, but that personal assistant roles also need to be considered within a broader context of 'technologies of citizenship' (Cruikshank 1999), which not only shape how choices are made and in turn expectations regarding how support should be offered. It is at these points where the contrast between expectations (in terms of how support is expected to be used) and choices (in terms of how employers wish to use their support) that tensions are exposed which can give rise to opportunities for employers

to resist the prevailing constructions of 'good choices' and 'responsibilised' (Clarke 2005) citizenship.

### *Personal assistant as practical*

The role of the personal assistant in the development of the personalisation agenda is something that has been largely overlooked and something to be specified by the individual employer, however it is also a role upon which discourses of empowerment are hinged. The Department of Health's 'easy read' guide to *Becoming an Employer using Direct Payments* (DH 2009b) describes the need for a job description which states what the personal assistant's work will involve and when they will be required to work, however it has been questioned how much this has been valued and applied in practice (Skills for Care 2008). Joanne, who works for the council funded Independent Living Service, explained the support they offer employers with their job descriptions:

[W]e support people, yes we do it together, they might use their care plan, but they might not, I mean it depends how they want to do it and we will type it up and write a list of all their duties, we don't do very complicated ...[...]... we just normally do a list of jobs ...[...]... they are very varied, we don't really do specs [personal specification] unless it's something very specific, it's normally families ...[...]... want more detail on them if they want something very specific, they need experience or ...[...]... its really up to individuals if they want it to be more [detailed] ...[...]... if they say they want it to be someone qualified we will put that in, they are very basic.

Joanne highlights the different value attributed to the job description by different types of employer, those who have family involvement and those without that support, suggesting essentially that a detailed job description

is not usually thought necessary. A list of jobs could imply a very task-centred approach to support. Gillian, Georgia's care manager highlights the lack of specificity in the personal assistant's role and how she has worked to clarify the work that needs to be done:

[T]here is a little bit of advice around personal care, not day to day things, but just overall managing certain aspects, keeping on top of her household, house work and things, she is quite good at that, shopping and budgeting around shopping, managing her finances and I have even put things in a bit more clearer cos it was a bit like you get 15 hours and that's your support off you go and do it you know so I felt that it needed to be a bit more structured for her than that really.

Although there is a lack of specificity, there are also collections of tasks which need to be completed. The vague responsibilities of personal assistants may enable the type of spontaneity missing from traditional services, but also may also offer space for further reaching expectations. Abbey experienced a similar generic description of her role as Ali's personal assistant:

It was a kind of clear description, but it was very generic, it was like help with household duties, personal care, social life, I mean it covered almost everything so you could expect everything and anything.

These experiences reflect recent research, where personal assistants have little or no job description (Flynn 2005; Skills for Care 2008). Cathy clarified the broad roles she undertakes to support Camille:

[O]n a regular basis I do the cleaning, support her to go shopping, we might go and pick up medication from the local pharmacy. I cook her meals for her, perhaps prepare sandwiches and breakfast in advance, go through e-mails and do a lot of admin, like bills, post and e-mails are particularly important cos she works from

home and although she can use a computer independently some e-mails and e-mail attachments are really complicated and they are written in very complex language so I do that and on a not so regular basis I go on day trips to the theatre, might go to a stately home, we've been to [Manchester] and [Newcastle] so when she has got the hours to do social things which are so important to her she asks me to go with her to those as well so it's a bit of a mixed bag really.

Cathy talks about 'do[ing] the cleaning', cooking meals, as well as 'supporting' work involving shopping, emails and bills. 'Empowering' working practices have been a matter of considerable discussion. Brechin (1998: 177-8) suggests that 'care work' has moved through a series of developments from the control of 'looking after' through the educational 'developmental model' to become a role of 'supporting self-advocacy' where 'the role is facilitative, enabling and as inconspicuous and normative as possible'. Cathy's 'doing' work is no longer ascribed a 'looking after' role, but one which fulfils a task necessary for the higher goal of maintaining a 'normal' life. Cathy's supporting work equally fulfils a function of supporting in her employer's work and enabling spaces for self-determination and 'self-advocacy'.

Daniela similarly describes the work her personal assistant undertakes in terms of tasks but also supporting more social activities, in terms of holidays and Daniela's personal responsibility for her home. Daniela lives in her own home and describes her support as being as varied from holidays to making the tea:

Katie: What do you like about Debbie?

Daniela: She's just nice you know, she takes me out, she takes me shopping, she takes me places that I've never been. Now I'm going on holiday very shortly with her again to Lille ... yes there are Christmas markets on ...[...]... Well Debbie does dress me, I can dress myself, but I

put the wrong clothes together ... what else does she do, um the bathrooms, the bedding, changes it. She makes my lunch, get it ready so I can have it, what else and then she told me to look after my house and keep it tidy so Diana (Care Manager) doesn't get angry with me (laughs)

Diana: I don't get angry with you

Daniela: Oh yes she gets my tea ready as well.

Daniela's support, like Camille, involves a collection of 'doing' lunches, washing and supporting, outside the home, with shopping and holidays. The 'doing' is valued by many employers. Georgia comments how hard working her personal assistants are:

I like [PA] and [PA] they do a lot of hours ...[...]... they are really good hard working...

Georgia's emphasis upon how hard working her personal assistants are implies the 'work' of the personal assistant in terms of practical tasks more akin to traditional support work.

Bev similarly highlights the practical support that Benji requires, but also finds that there are clear areas where she will offer 'to do' and 'support':

[W]ell it's just helping him out really ...[...]... I go up to his house, help him clean up a bit, I usually take him into town, get any shopping he needs, we may just wander about, I think it's a lot to do with a bit of company for him as well and a friendship as well and just somebody that he can go into town and wander about with, that he feels safe with as well then we would head back up to his house and prepare his dinner as well ...[...]... prepare lunches for the next day, whatever he needs basically, whatever he needs help with ...[...]... it's not like a service.

Not being a service is important to Bev, just offering that extra bit of help.

There is a sense of familiarity in the way Bev speaks about her role with Benji. The use of 'we wander' implies a relaxed working relationship in which support is offered or requested when needed. 'Help' is a term which has been explored in preference to 'care' or support' (Shakespeare 2000) as it offers a recognition of the breadth of support and the universality of our need of support, and as used by Bev starts to unravel the personal assistant role beyond a collection of practical, functional tasks. Each of these employers and personal assistants used 'doing', 'supporting' and 'help' to describe the more practical elements of their role. The personal assistance relationship as imagined by the Independent Living Movement and suggested by the disabled employer earlier in this chapter to be similar to a tool, practical and straightforward. However, where support is offered to people with learning difficulties not only are the roles less clear cut, often requiring assistance other than practical tasks (Reynolds & Walmsley 1998), but also potentially requiring more subtle skills of prompting, advice giving (Williams et al 2009) and companionship (Flynn 2005; Tidder 2006).

Emily and Ed further allude to these additional expectations. Ed looked for a personal assistant with whom he could go swimming, however the practicalities of the task impacted upon what they were looking for in a personal assistant. Emily said:

[W]e have had a few PAs, with some you had to be very specific about what we wanted, they didn't know Ed and we definitely wanted someone to go swimming with him, it was a fitness thing...[...]...he came and went swimming, that was a set day during the holidays, because he was a lifeguard so he used to come and do the swimming – that was it because he was very much a worker he was very much a support worker he was coming in to swim and Ed knew that, they got on but there wasn't any real relationship.

It is interesting how Emily refers to this particular personal assistant as

more similar to a support worker. The implication that a 'support worker' is task orientated and a 'personal assistant' is something else, something different or something intrinsically more personal.

### *Personal assistant as personal*

Emily positions 'support' work and personal assistance as qualitatively different. Whereas some personal assistant work has been characterised by its invisibility (Rivas 2003) where personal assistants' roles are task focused and silent, personal assistants as described by Emily are valued for their personal qualities, personality and become characterised by their visibility.

Recruiting a person who can work on a 1:1 basis can be a difficult task and recruitment and retention of appropriate personal assistants has often been highlighted as one of the difficulties associated with direct payments (Clark et al 2004; Glendinning et al 2008). Research into personal assistant work has described the role as fluid, involving personal care, domestic tasks as well as less tangible tasks such as offering empathy, knowing the person's 'biographical life and background', trustworthiness and shared interests (Flynn 2005: 6). The employers and personal assistants interviewed echoed many of the experiences and preferences highlighted in Flynn's study.

Camille does not recruit her personal assistants on the basis of their interests, however she suggests the possibility of a common connection, such as an interest in politics, as a positive:

I think that interests are [important] because you then get a feeling about the person ...[...]... it does help if you have got something in common with the person because then you have got something to

talk about I mean last night ...[...]... we were talking about ...[...]... I know its quite a difficult subject to talk about with people, politics because we are both quite interested but I don't think its really, really important its not one of the things I look for cos I think that comes out once you get to know the people.

Cathy, Camille's personal assistant reflects this when considering what she thinks is important to Camille:

...she was looking for someone who was reliable, somebody who was trustworthy, punctuality is very important as well ...[...]... Camille likes quite a routine, likes to know what is happening day by day which is fair enough ...[...]... and I think also she was looking for some people who were a bit younger cos she is in her 30s and didn't, I guess you can relate to somebody your age rather than somebody that isn't. She has also employed a lot of OT [occupational therapy] students before, she is really interested in our degrees and our work so she has an interest in us as well.

The prospect of getting to know someone better and finding common ground was often premised on having some similarities as Ed suggests when he talks about employing a student, as he is a student himself:

Katie: Did you interview [your PA]?

Ed: Yes I did.

Katie: What did you like about him?

Ed: It was just because I know he is a student yes and I now I'm a student so we get on well together and he doesn't mind, he likes doing all sorts and I was asking him, what do you like doing, and he said I like doing all sorts, not really it's a bit of a mixture really.

...[...]...

Katie: When you have a good PA like [a PA Ed thinks is good] what do you like about him, what makes a good PA?

Ed: To just have fun with him, just say lets go somewhere and



have fun, go for a meal and things like that, it's a shame that I can't do these things [here], but I can develop something similar possibly.

For Ed support is not about independent living, as he lives at home with his family therefore his support is used for socialising and leisure activities. The ability to have fun with his personal assistant is important to Ed as well as similarities in age. Simons (1992 in Reynolds & Walmsley 1998) found that people with learning difficulties, whose capacities have historically been underestimated, tend to emphasise their ability to care for others and the possibility of reciprocity. The opportunity to employ a personal assistant with whom they can have a good discussion (for Camille) or a laugh (for Ed) increases the two-way exchange possibilities in the personal assistant relationship.

Freddie is more specific about the interests of the personal assistants he recruits:

Katie: When you interviewed F [personal assistant] what did you like about her?

Freddie: She was nice, she likes music, different things, she likes Trumpets and different things though.

Katie: Is she a music student?

Freddie: Yes.

Katie: Is liking music important?

Freddie: Yes.

Katie: When you interviewed F what did you want to know about her?

Freddie: Have you got any pets and music yes she likes music yes.

.....

Katie: What other things did you like about her?

Freddie: She likes different things, cooking, ... I've got a hamster

...

Freya: That's why you asked the question about pets isn't it

Freddie because you wanted one, but you didn't have a hamster then.

Freddie looked for, not only an interest in music, but other things that are important to him at the time, at this point getting a hamster. Faith explains their recruitment process:

I suppose it depends upon what we are expecting them to do, so for example you know Freddie organises music gigs ...[...]... and when we are looking for a music PA we will always advertise in the music department at the university, we look for somebody who has a passion for music which they can share with Freddie and the same would apply to anything else, if we are looking for a cooking PA we would be looking for someone who is passionate about cooking ...[...]... but aside from that I mean I guess the really important things are about values and about the way that people relate to Freddie in the interview so I suppose the sorts of things that we are looking for are people who are very person-centred in their approach to people and in particular Freddie-centred, the interviews can be quite chaotic because Freddie comes and goes a bit so it is quite telling really the people who kind of engage with Freddie and then accept that that's Freddie coming and going its nothing personal about them and I suppose we look for people who are confident in themselves, people who know themselves and you know the usual sort of things like you know respect ... you know those are the sorts of things that we look for, we are looking for the right person, we are not looking for kind of traditional skills or qualifications in fact they might count against them.

Again the personal outweighs the formal. Faith expresses a common preference for personal assistants who are untrained or without experience, enabling the emphasis to be upon Freddie, rather than acquired ways of working that may or may not work for Freddie. Morris (1993a) suggested that professional skills and training can prove unhelpful

when recruiting personal assistants, suggesting that training brings values and experience which can shift the power back to the dependency of receiving 'care' (Scourfield 2005) rather than acting as an active agent of personal support (O'Brien 2001).

The personal relationship with personal assistants offers space for agency. As well as allowing a more teamwork approach which has been found to be important to employers (Williams et al 2009), Ali spoke of his relationship with his personal assistants as one of "respect" and a "two-way thing". Employing a personal assistant of a similar age and with common ground offers the employers the possibility of comfortable working relationships and these relationships can make a personal assistant visible whilst maintaining the employer / employee distinction. Camille draws attention to this visibility and distinction when talking about her personal assistants meeting her friends and neighbours:

I remember going out on a night I see people I introduce "oh this is my PA" but I think a lot of people see it as natural I mean I went up to see my neighbours to get some information ... but my PAs always just join in the conversation and they introduce me "oh this is the person that I'm working for" and if I think if you don't put any barriers in your way then it can be quite an easy...

Camille maintaining the distinction of employer / employee, whilst welcoming the personal assistant into the group of friends or conversations, challenges what some research has found to be silent and functional employment relationships (Rivas 2003). Camille expects her personal assistants to join in with conversations with friends whilst remaining an employee. It is this distinction, which is assumed to work as a lever of 'empowerment', the ability and opportunity to direct assistance, which is at play here and negotiated through the employment of people who can fit and adapt to their employers' lives, friends and neighbours. Rivas (2003: 79), exploring disabled people's personal assistance relationships in North America found that:

Some attendants do desire invisibility. Since their job is to confer independence, it makes sense that workers who want to do a good job will participate in making themselves invisible.

The conferring of 'independence' through invisibility and quiet and careful task fulfilment is not evident in the experiences of these employers and personal assistants. Brechin (1998) characterised the shifts of emphasis within social care as passing from control to skill development to supporting rights and choices. Positive working relationships in this section have been characterised through employer preferences and personal assistant characteristics rather than 'professionalised' or 'expert' support worker knowledge. However, the opportunities for employers to recruit their own support and become 'agents' rather than consumers (O'Brien 2001) does not remove all influences over how support is expected to be directed and offered. The shift between developmental models of support and support based on rights and choice making remains partial. The offer of rights and control over support is intended to act as a lever of empowerment, but one which is shaped by, not only a continuation of the developmental approach to support for people with learning difficulties, but also wider discourses surrounding what it means to be responsible and active citizens.

### *Personal assistant as a 'technology of citizenship'*

Support relationships, be they practical or personal (or as is most likely an interplay of the two) are situated within discourses of 'independence', 'choice', 'control' as simultaneously indicators and levers of the empowerment discourse embedded within the personalisation agenda. Jack (1995: 11) suggests that empowerment for 'users' would '...involve having the money and deciding how it should be spent in pursuit of goals

the user determined'. Once the money has been allocated, the market, in combination with the entrepreneurial spirit (Scourfield 2007) of the employer theoretically create the opportunity for the consumer to become an 'empowered' agent (O'Brien 2001) taking control of their own support. Direct payments are situated as a 'technology of citizenship' working upon personal assistants and their employers. Cruikshank (1999: 4) suggests that '[t]echnologies of citizenship do not cancel out the autonomy and independence of citizens but are modes of governance that work upon and through capacities of citizens to act on their own'. These technologies are often seen through participatory or democratic schemes which seek to 'correct deficiencies'. Personal assistants, in the discourse of direct payments and choice and control for employers are worked upon and are working through these discourses to 'empower', which are models of constituting and regulating individuals (Cruikshank 1999). Personal assistants therefore act as a pivot between the person, community *and* crucially the development of their citizenship.

In light of the personal assistant's role and *Independence, Wellbeing and Choice's* (DH 2005a) imagined high quality, well-trained workforce Camille recalls one of her first interviewing experiences:

[M]y first ever experience of interviewing someone ...[...]... cos I always have someone from the ILS [Independent Living Service] there who takes my notes and I think its best to have a second person there to observe as well I remember the first person ... I let her in the front door and she had not even got through the flat door and she said 'is this going to take a long time?' I said 'I've no idea' she goes 'I've got a job induction at TK Max ...[...]... I was like you go out the door, she said what have I done ...[...]... I introduce myself explain what it's about, my first question was have you ever worked with a person with a learning disability before? 'I've taken my granddad to the toilet does that count? I thought right I said sometimes I like to do things on a evening and she said 'I'm not doing that you can forget that we are not doing that' so a lot

depends upon the answers I get there's a lot I can tell by the way they present themselves I don't know you just get a feeling about somebody...

This candidate for the role of Camille's personal assistant reflects not only a misunderstanding of the role, but traditional task-based 'care work'. The employers and supporters in the previous section highlighted the importance of values when approaching this kind of support work. Values are embedded into all support work, but may be hidden through a task based job description, but also paradoxically exposed through invisibility in relation to facilitating 'independence' (Rivas 2003). The generality of the support roles discussed, in relation to the personal assistant as practical, implies a collection of tasks, but a collection which has a broader goal. Gemma reflects upon her understanding of her role in supporting Georgia:

...it's so wide what you can do with people it's not really specific you have to interpret it a little ...[...]... it's just maintaining independence, respecting the rights and dignity, confidentiality...

Gemma's interpretation of the role of the personal assistant fits with the influences of normalisation or Social Role Valorisation within Valuing People (DH 2001, 2007a, 2009d) in combination with the normalising tendencies of Dean's (1999) technologies of agency. The approach of *Putting People First* (DH 2007b; PPC 2011) advocating the individual and the community can be clearly seen in Ali's use of his first personal assistants soon after his move into his own home, from residential care:

Ali: [T]he first PA was fine, he was absolutely brilliant he did everything that... he was a really really good asset because he was one of my best friends when I was at [a residential home] so I knew him really well and it was him that actually got me out of the institutionalised ways, you know saying it is alright if I do this, is it alright if I do that? He used to say to

me “its your life Ali, you buy and get what you want to get”. So he was actually helping me get out of the institutionalised way of things.

Katie A good first PA...

Ali: Yep he was brilliant, absolutely brilliant ...[...]... it's a shame I've not had others like him ...[...]... I had another one ... and they were two of the best support workers I have ever had

Katie: What was [the other PA] like?

Ali: Lovely, absolutely brilliant oh we had some good laughs together we had some really good times together and we just got on and we went everywhere together. We went to the pub, the shops, it was [PA] who introduced me to all the staff in costcutters and that ...[...]... they know me really well and [off licence] know me as well they are really good ...[...]... the girl who works there used to go to the [] Church I used to know her family quite well.

Ali spoke of a personal assistant who helped him get out of his 'institutionalised ways' adopted whilst he lived in traditional residential care. Ali speaks of how personal assistants can use themselves to enable the person they support to start to make choices and get involved in a local community, which has been historically inaccessible to them. Ali was clear about what he wanted from living in his own home and becoming a part of the community in which he lives and the community of the Church. This development (as experienced by Ali) was led by Ali through a personal assistant who was able to support the areas of Ali's life Ali identified. A project, 'It's all about respect', which explored the roles and relationships of employers and their personal assistants has described the potential tensions in these relationships with regard to advice giving and skill development. The project concluded that:

It is hard to reconcile the idea of an adult-adult relationship with that of protecting the person from risks, giving advice on money matters, preventing debt, or giving advice on social or personal behaviour. To some extent, all these areas remind us that people

with learning difficulties are often still 'learning' about how to improve their skills. The PA's role, then, becomes quite like an educator or a personal tutor for the person, and the person with learning difficulties could become cast in the role of learner. This, again, provides a paradox; the teacher is often seen as the person who is in charge of the learning process, rather than the learner. Therefore, some of the skills for the PA will have to be around empowering and person-centred learning opportunities; these models do exist, particularly in adult and further education, and it is important that PA's are given the chance to explore how to facilitate learning.

(Ponting et al nd: 16-17)

The positioning of the personal assistant as an 'educator' and 'empowering' has been evident in supporting people with learning difficulties and is reflected in perceptions of the types of support which *should* be directed and offered.

Participative and 'empowering' support work strategies have been influential in services for people with learning difficulties. In this context the pedagogic history of learning difficulties support work stemming from Adult Training Centres (Henley 2001) and continued through the influence of normalisation (Wolfensberger & Tullman 1982), social role valorisation, O'Brien's five accomplishments (O'Brien 1987a in Thomas & Woods 2003), goal setting (Wigham et al 2008), person-centred planning (O'Brien & O'Brien 2000; DH 2001; DH 2009d) has been ongoing and is perpetuated through the discourses of independence and inclusion through the realising of socially normative practices. James and Wheeler (2006: 121) advocate participative support methods because 'it is a normal part of adult life' and emphasise that 'promoting participation in activity and developing independence ... is considered to be important both to one's physical and mental health' which in turn impacts upon the perception of self which in turn is positioned in terms of social roles. Their approach to support identifies teaching strategies,



some of which are fairly invasive and directive such as 'chaining' and the breaking down of tasks, and others more informal, specifically 'incidental teaching' where the person takes the lead with supporters offering prompts and general reinforcement. Hetty explains the differences she has seen in Harry's confidence since taking the direct payment and employing Hetty to support him, when needed, at home:

[O]h definitely, definitely 100% I would say he has changed he's a lot more comfortable ... he knows he's still in his routine he knows he can still do what he wants to do and I think really looking at him he does like time on his own he likes time out to be by himself you know and I suppose and I mean he still does bits at home you know like I've said to him when I've come in 'why haven't you washed the pots up?' you don't just leave them there you get them washed up umm and he said to me well that's what you're there for, no that is you being independent when mum's here you don't do that so you are not doing it now sort of thing. But certainly his confidence has really really grown.

As a sibling asking why the pots have not been washed is very different to a more formally employed personal assistant questioning their employer, however the 'incidental teaching' or more appropriately incidental learning has been an unintended and positive consequence of Harry having the opportunity to use and develop his skills.

Professional as well as disability studies analysis of 'independence' and 'empowerment' continue to influence expectations of support. Care managers maintain ultimate financial accountability over direct payments and offered their perspectives as to the intention of the support that they were expecting the employer to commission:

I think really it should be about increasing his skills, but there has not been a lot of that going on. Well it depends which support worker he is with really, the ones that have been

friends I think have tended not to be quite as, it's more task orientated than independence ...[...]... I think its easier all round for them to do the task and this is where reviews come into play cos we can gently remind people what is needed really. Although again it is difficult as you can't be there all the time to check up what is going on, even though the money does come from social services so that's a difficult one.

The challenge of direct payments within the personalisation agenda to the established relationships between commissioning and provision has placed in perspective the inherent values of the social work profession and *Valuing People*. The General Social Care Council (2010: 8) states that social workers and social care workers must work to professional values whereby '[a]s a social care worker, you must promote the independence of service users while protecting them as far as possible from danger or harm'. However, within this there are implicit judgements about what independence is and how a person *should* use their support. *Valuing People* urges independence to be presumed and confirms that independence 'does not mean doing everything unaided' (DH 2001: 23), whilst in a similar vein independence, it has been argued, 'is created by having assistance when and how one requires it' (Brisenden in Morris 1993a: 8). 'Independence' and the types of support, which offer the prospect of increasing independence, autonomy and self-determination have been internalised in the social work practices (Payne 2005). Where these skill development practices are seen as 'empowering', positioning people with learning difficulties as perpetual learners (Simpson 1995 in Williams et al 2009) empowerment through enablement and voice within services has been seen as a hijacking of the term, 'domesticating' it to serve the purposes of the status quo (Ward & Mullender 1992 in Jack 1995).

The 'domesticating' of empowerment practices may be seen and subverted through the process of working as a personal assistant.

Personal assistants are not blank canvasses and may have assumptions about what the support role involves. Cathy is training to be an occupational therapist (OT), which comes with its own set of values. At first glance the tasks Camille requires of her personal assistant appear straightforward, however for Cathy they caused some tension between what she had been taught and the role which she was being asked to perform:

...for me being an OT student, it's very different you kind of have to take your OT hat off and think this is enabling her to live independently although I am doing a lot of the stuff to enable her to live independently rather than facilitating her doing it, because that's what Camille chooses to do, how she chooses to use her hours, by perhaps us doing meal preparation and stuff so she has the energy and time to do other things, as an OT I would probably go in and say right lets make this meal together, but its not what I am employed to do, I am a support worker and that's the support that she wants and feels she needs so that was kind of a challenge at first, but I have got used to that now.

Cathy has reconciled her 'doing' with the goal of enabling Camille's choice to live independently. The inherent tension of a support worker's role, be they personal assistants or agency workers is, as the employer in Flynn's (2005: 30) study clearly stated '...to respect and not to overestimate my physical disability...'. A personal assistant's role therefore may be not to 'overestimate' or critically underestimate their employer's disability. This judgement creates a site of tension where the values attached to supporting people with learning difficulties include a tendency towards skill development – which by implication positions personal assistants as educators, (Ponting et al n.d). Essentially an implicit and at times explicit tension emerges between the 'doing' and 'supporting' aspects of a personal assistant role.

Employers in this project are subject to the general encouragement

towards skill development and independent living skills. This was highlighted by Georgia's care manager when she expressed confidence that personal assistants were not 'over care[ing]' for Georgia:

I think in Georgia's situation they don't tend to over care for Georgia I think she is quite assertive, she can be quite assertive at times so I don't think that there's a situation where Georgia is over cared for, but I suppose it can happen to other people where somebody takes it as I'm looking after you I can imagine that that can happen and there is nothing really there to stop it escalating.

Therefore there are negative assumptions associated with 'over car[ing]', which hark back to 'care' as control (Morris 1993a). Both of the care managers quoted (p. 132-3 & above) have implied that they have little influence over how support is delivered, however equally both suggested that developing skills or at least maintaining skills as being important and a part of the aim of the support. Neither Georgia, her care manager, nor her personal assistant mentioned a plan or clear vision for her support, however Georgia is clear about what she expects from her personal assistants:

Georgia: I found it very hard ... Employing people.

Katie: What's hard about it?

Georgia: Them not doing that much jobs.

Katie: How do you ask them to do what you want them to do?

Georgia: I just want them to wash up a bit more but they don't.

Katie: Why do they do that, do they give a reason?

Georgia: No.

Katie: Have you talked to anyone about this?

Georgia: I asked them to wash up at night-time when its quiet, but they won't do that.

Katie: Is that what they are employed to do?

Georgia: They get paid to do that.

Georgia identifies washing up, importantly her personal assistant *not* washing up, as a point of tension. It could therefore be assumed that Georgia's personal assistants are not listening to Georgia and not doing their job. Is it more important that the washing up is done? Or is it important who does it? Or how it is done? In this instance the personal assistant role is unclear. Georgia's personal assistant also identified washing up as a point of tension:

I do worry quite a lot of the time am I doing the best thing, should I be doing this, should I have said this, should I have made her be more involved, should I have just said, 'oh no you have a bath I will just do the washing up' its just like how much do I give her independence do I make her do everything its really like getting the balance.

Both Cathy and Georgia express the tensions they experience, not only because their roles are unclear, but furthermore their ongoing professional training (in nursing and occupational therapy) have encouraged them to think in specific ways about what 'good' support is. It is here where Georgia and Camille, through their choices about the role of their personal assistants, are offering resistance or resilience (Goodley 2005) to the image of the 'perpetual learner' in confirmation of their rights to independent living with appropriate support.

Daniela's experience of personal assistant support further illustrates elements of resilience. Daniela reflects on her experiences of traditional home care where, although not necessarily directed by Daniela, the support worker had clear ideas about what she should and should not be doing:

Daniela: She was knocking on door to let her in and said to me that I have to help, she never asked me to help her she said you can help me do some things, I think ironing and tidy your flat, and I can remember all of it but that's

what she said... she never did a thing.

Katie: What did you expect her to do?

Daniela: [I] Wanted her to help me to tidy up and she said to me can you keep it tidy and I said yes course I can.

Katie: So she was expecting you to do everything?

Daniela: Yes so she would just watch what I was doing, so she watches me first and then I said why don't you do something, she says no, its your flat, you've got to look after it, you've got to wash up and put the plates and things away which I am doing and clothes, to hang them up, to iron, she never did the ironing, no ... she didn't do what I asked her.

Again washing up is raised, and in Daniela's experience cleaning becomes the point of tension and potentially indicative of an approach to support work that focused on the development of independent living skills in line with the participative focus of James and Wheeler (2006). However, from Daniela's perspective this was not an 'empowering' experience. Debbie, Daniela's current personal assistant, spoke about offering what has been described as 'active support' (Stancliffe et al. 2008):

...we've tried it and it tends to frustrate her, she gets mad and grumpy...

Debbie, when describing her role, focuses on a very much task-based approach, but also begins to hint at some of the potential tensions implicit in the personal assistant support relationship:

Well it's personal care in the morning, help her arrange her money everyday, so she has an allowance everyday, she has done fantastic at saving ... shopping, diet, we are starting to deal with diet ... microwave meals ... so the biggest thing that we have don't have time to do is that she has to lose some more weight and she could do with some exercise everyday, we are doing our best she's

lost about a stone... with her being diabetic ... that's the biggest disability to me ... I said have you eaten them all, she said no, where are they then, in my tummy, then we had a laugh...[...]...Just make sure her feet are cared for, make sure her hair is always nice, make sure she is clean, she is tidy that she wears nice clothes, try and make sure she is in a good mood every morning, that she is organised, that she knows what she is doing, keep the flat tidy ... washing.

Whereas Daniela and Debbie have come to a compromise regarding skill development there are other interventions into Daniela's life through her diet. Dean (1999: 17) describes diets, in the context of Foucault's governmentality, as the 'ubiquitous exercise in self-government'. For Daniela this is not so much 'self-government' rather the 'conduct of conduct' (Foucault in Dean 1999) through the medical discourses surrounding the governance of our weight. Debbie talks about a holistic view of Daniela's life focusing on making change through diet, cleanliness to Daniela's mood in the morning. Talking about Daniela's diet and approaching the subject of healthy eating illustrates a clarity in what she feels her role is and a certain confidence in her responsibility to be firm and directive when it comes to Daniela's health. This element of direction, in line with 'best interests' decisions focus some of the tensions of the support relationship that need to, or aspire to offer 'independence', 'choice' and 'control'. From the perspectives of policy makers and professionals involved, 'enabling' needs to occur in specific ways around discourses that combine self-direction and quite prescriptive inflections about how one should accept support and the roles each should play.

## *Negotiated 'support', 'doing', 'independence' and 'resistance' in the 'community'*

The discourse of the citizen consumer within direct payments and the direct employment of personal assistants effectively commodifies the support relationship and is assumed to offer a lever for empowerment through possibilities of 'voice' and 'exit' in terms of the market and independence and control in terms of disability rights. This chapter has sought to position the confluence of market and rights agendas (Pearson 2000; Spandler 2004) in relation to how employers choose, direct and utilise their support within a society which has conceptions of 'responsible' choices and what constitutes an active citizen. Direct payments at once offer possibilities of active choices and control over support framed and shaped within discourses of the responsibilised citizen (Clarke et al 2007) and conventional understandings of 'learning disabilities' which position people with learning difficulties in the position of 'perpetual learners'. As such personal assistant roles in this chapter, have been conceptualised around their practical, personal and ideological faces, through their positioning as a 'technology of citizenship' (Cruikshank 1999).

The practical face of personal assistant work offers a task-based and uncomplicated view of the personal assistant role. Employers used support to assist with personal care, live independently and get out into their communities. At this point the commodity of 'support' is alluded to and it appears to be a straightforward transaction, the identification of support needs and the meeting of those needs, however the relationship is premised on more than the ability to perform tasks. The roles of the personal assistants, in most cases, were less clear-cut and amongst the practical was the personal, challenging the invisibility of 'care work' (Rivas 2003) with personal assistants' value lying in their very visibility. The roles that Ungerson (1999) described as 'unorganised and particular' remain so. The particular could involve the importance of the personal.



Employers sought personal assistants who would not only fulfil tasks, but contribute something of themselves to the employment relationship through their similarity to their employer or their shared interests. Employers emphasised the personal qualities of the potential personal assistants, their interests and potential for a personal connection.

However, the vagaries of the role created the potential for tensions in approaches to support work. The commodification of support relations sought to transform the relationships involved. The transformative or 'empowering' potential of direct payments and these new relations of support for the employers in this project offered the possibility of community involvement as for Ali and for Harry the development of skills and confidence. On occasion these employers' aims for their support chimed neatly with the personalisation agenda, for instance Ali's first personal assistant supporting him to get out of his 'institutionalised ways' learning how to make active choices and getting involved in local communities such as his Church. Ali's expressions of active citizenship in choosing to become not just a consumer, but an agent (O'Brien 2001) and controlling and developing his own support has enabled the creation of informal networks which *Think Local, Act Personal* (PPFC 2011) imagines will decrease his 'reliance' on formalised support.

It is here where those who have equally 'chosen' the 'active' role of the 'agent' (O'Brien 2001) or 'entrepreneur' (Scourfield 2007) are (as they have always been) subject to and working through wider discourses and tensions around what it means to be a responsible citizen, what does 'independence' look and feel like and where and how is power at play in the direct payments relationship. The view that empowerment for users would involve a transfer of finances and a change in the commissioning of support implies that 'power' lies purely in the commissioning process and that a wholesale transfer of the financial 'power' offers a total transformation of the relations of support. However this chapter has argued that the taking of the power (or the direct payment) and feeling of

'empowerment' is contingent upon more than a financial exchange. Utilising Dean (1999) and Cruikshank's (1999) Foucauldian analysis enables an analysis that not only recognises what impacts upon a feeling of 'empowerment', but also one which views power as something which is fluid, not finite, and something that transfers in and between these relationships between employers, personal assistants and care managers. 'Choice', 'control' and 'empowering' practices do not solely exist within a vacuum of the employer and the personal assistant, but are shaped through professional discourses of assessment (and review), conceptions of learning 'disability' and broader models of citizenship. Georgia talks about her role as 'the boss' and frustration at her personal assistants not working hard enough and specifically not doing the washing up and in a similar way Daniela has resisted support interventions aimed at developing skills and participative approaches to support. The identity of 'boss' or manager or 'entrepreneur' does not automatically offer control, however spaces were created for resilience and resistance.

Goodley's (2005) work on resilience is evident in these relationships and offers opportunities for an analysis of resistance and negotiation within these employer / employee relationships. Goodley suggests resilience is created in the spaces between individuals and groups, but is also hinged on the development of collective identities and places of challenge where people with learning disabilities have redefined themselves against essentialism associated with their impairment. The employers interviewed used their resilience to take the responsibility to live independently and direct their own support. For some, such as Ed and Ali, they used their support in ways which may be considered 'appropriate', within the perspective of normalisation approaches and the personalisation agenda, whereas others challenged the developmental and participative approaches to support. Goodley suggests that:

Self-advocacy groups have the potential to invite the development of a consciousness that is sensitized to disabling and enabling

conditions from which resilience grows. In this sense then resilience can reside in the space between structure and individuality. Resilience is not an individual attribute but a product of the contexts in which it can emerge.

(Goodley 2005: 334)

If 'empowerment' is contingent on the opportunity to control and resist then for direct payments to act as a lever of 'empowerment' there needs to be a broader conception of people with learning difficulties as part of autonomously organised groups – in the form of self-advocacy organisations – as well as the personalisation perspective which emphasises community over the collective.

As such it is the resilience to resist that offers one of the contingencies of the empowering possibilities of direct payments. In their discussions of personal assistant qualities the personal characteristics, personality and interests were prominent in successful and fulfilling support relationships. Emily clearly emphasised this when she said:

[H]e was very much a worker he was very much a support worker he was coming in to swim and Ed knew that, they got on but there wasn't any real relationship...

This statement, in combination with the comments of the employers, places the relationships between people and their personal assistants as qualitatively different from that of abstracted agency based support workers. 'Empowerment' of employers through a commercial model sought to fundamentally alter the social relations of support, but the personal in personal assistant equally offers a re-arrangement of the dynamics of the relationship. The following chapter draws on these interpretations of the roles of employers and personal assistants in an exploration, not only of the responsabilisation agenda at the root of personalisation, but also the specific, daily and nitty gritty realities of being an employer and managing support and working as a personal assistant.

## Chapter 6

### Responsibilities

In 1995 Dowson (1997: 106-7) in a discussion about empowerment, wrote:

Service agencies are almost always hierarchical organisations structured in the familiar form of a tree with downward-pointing branches. Direct care staff are positioned at the lowest level of the tree. However, decisions which users might want to make about their lives are also passed to care staff and thence upwards to the appropriate management level. By implication and – to judge from many conversations with staff and users – by common recognition, the users are also attached to the tree, as the lowest, least empowered tier of all ... [...] ... Workers in provider agencies are learning to live with the new reality that their employment is dependent on the policies of purchasers. To be hired and fired by service users would be another matter entirely.

The relationships between these employers and their personal assistants are *'another matter entirely'*. *'Service users'* have become *'employers'* following the presumption that cash and the direct (or indirect) employment of support fundamentally alter the social relations of support (Glasby and Littlechild 2002). In Dowson's tree support workers are the branches above service users, maybe not the most powerful, yet still influential. Although support workers may have limited influence over how things happen and making change, they are nevertheless assumed to be in a relatively empowered position to make daily and small decisions over the lives of their service users. How they use this influence, be it in an advocacy position (if this is possible within a large organisation), or more likely in the interests of their direct management, the role of direct support workers in large state, private and voluntary organisations has

been the subject of debate and criticism over 'empowerment' practices. As suggested by Glasby and Littlechild (2002) there has been an assumption that the transfer of power through direct payments has flowed directly from workers to service users, however (excluding the assessment and eligibility concerns of local authority social workers) Leece (2010) suggests that the power flow may more realistically be from social services to the direct employers. Workers have been largely neglected in the analysis of direct payments (Hastings 2010; Leece 2010).

A key lever of empowerment in the personalisation agenda has been the transfer of power through consumerist discourses and efforts to decentralise the activity of social care. *Capable Communities, Active Citizens* (DH 2010: 8) sets out a vision where:

The Government is committed to devolving power from central government to communities and individuals, and social care is no exception. Front-line workers and carers are fundamental to the delivery of personalisation – we want to give them the freedom and responsibility to improve care services and support people in new ways.

Here the offering of responsibility represents the opportunity for 'empowerment', directing and creating the future of support individually and locally. The previous chapter situated personal assistants as 'technologies of citizenship' (Cruikshank 1999) responding not only to the needs and wishes of the individuals they support, but also being acted upon, acting within and through broader discourses which seek to shape our behaviours in the formation of citizenship. The responsibility agenda of the coalition Government outlined above represents just one iteration of an ongoing project of responsabilisation and the transformation of citizen-consumers (Clarke et al 2007) into citizen entrepreneurs (Scourfield 2007). Responsibilisation within the personalisation agenda draws on notions of the community, the individual, and through our relations with the state, constructions of dependency. In an influential

Demos report, *Making it Personal* Leadbeater et al (2008: 79-80) argue that through the participation and co-production of previously collectivised public services:

[P]ublic service productivity should rise because highly participative services mobilise users as co-developers of services, multiplying the resources available. Participation allows solutions to be more effective because they are tailored more to individual needs and aspirations; people have to share responsibility for outcomes and devote some of their own inputs. Participation is the best antidote to dependency if people are equipped with tools so they can self-provide and self-manage rather than always rely on professional solutions.

Leadbeater et al (2008) draw on multiple discourses of efficiency, empowerment through responsibility, placing this in direct contrast to the 'dependency' created through traditional services which in turn has been propagated through the practice of expert and 'professional' knowledge. In the broader personalisation agenda new support and employment relations are positioned as one of the integral points of responsibility taking and transference of power. It is here that the social care workforce working in traditional services or as personal assistants are positioned as both 'empowered' and '(dis)empowered' in their working practices. The power to hire, fire and direct support are positioned as the key means through which control can be taken and choices can be made. In this context discourses of choice and control are linked unproblematically with responsibility in the seeking of 'better solutions' in terms of an individual's support (Scourfield 2005, 2007).

Making choices, taking control and responsibility as levers of empowerment have been articulated to work in conjunction with the development of the personalisation agenda and the idea of co-production. Leadbeater (2004: 20) argues that there are different types of personalisation which have very different implications:

This 'shallow' personalisation offers modest modification of mass-produced, standardized services to partially adapt them to user needs. 'Deep' personalisation would give users a far greater role – and also far greater responsibilities – for designing solutions from the ground up.

Leadbeater foresees the emergence of 'deep personalisation' as the 'harbinger of an entirely new organisational logic' (Leadbeater 2004: 20) which as we move through the process from 'shallow' to 'deep' personalisation:

...the implications become more radical and disruptive: dependent users become consumers and commissioners, and eventually co-producers and co-designers. Their participation, commitment, knowledge and responsibility increases. As the role of the user fills out, so the role of the professional must change in tandem.

Here Leadbeater equates users with dependency and hails the potential benefits of consumerism resting on a particular and often critiqued power of the market (Callinicos 2003; Ferguson 2007). Not only does Leadbeater's analysis hinge on a faith in the controlling power of market forces it is similarly situated within discourses of risk (Beck 1992) and reflexive modernity (Giddens 1994). This state of reflexive modernity where 'consumer culture features a populist and quasi-egalitarian impulse, asserting that everyone is entitled to consume and to consume what they want' (Clarke et al 2007: 10) offers the possibility of new rights and responsibilities. In terms of personalisation within social care, direct payments certainly reflect Leadbeater's conception of deep personalisation. It is here, where the logic of the consumer embedded within 'deep personalisation' that two competing discourses of empowerment, one emanating from the individualistic tendencies of the market and the other more collective vision of social movements, converge (Croft & Beresford 1995; Starkey 2003). Therefore, taking as an

assumption that power cannot be given, but must be taken (Evans 1992 in Jack 1995; Starkey 2003) and that power is not finite, but variable and fluid between people and groups of people at different times that this chapter seeks to explore how the personalisation agenda, through direct payments offers opportunities for empowerment through 'responsibilisation', in what ways, to whom and when. It is at this point that Leadbeater's analysis of dependency meets the self-reliance of the personalisation agenda (DH 2010; PPFC 2011).

Building on the different conceptions of personal assistant work, be it practical, personal or as a 'technology of citizenship' this chapter will explore how these responsibilities are manifested, arguing that the experience of direct payments and employing a personal assistant is significantly contingent upon access to support. This support although not readily available from the state (with the exception of support with the bureaucratic aspects of a direct payment) can come from family, friends and self-advocacy groups which themselves are highly contingent on the social capital of the family or individual involved (Fyson 2009). Similarly personal assistants are placed in a relationship of tension. Making choices, some 'good' and others potentially 'risky', is to be supported, enabled or facilitated through the personal assistant role. The personalisation agenda imagines 'an empowered workforce with increasingly sophisticated skills' (DH 2009c) to support people to take risks and live the lives of their choice. However, this is a workforce which is often - in common with their employers - isolated and unsupported. It is argued that personal assistants are equally subject to the responsibilisation agenda which through an emphasis upon resilience, independence and self-reliance places their role of personal assistant as simultaneously 'responsible to' yet ultimately 'responsible for' their employer, in a potentially vulnerable position. It is through this responsibilisation of both parties, within the context of limited support, that not only creates opportunities for inequity in quality of support, but also it is in the search for self-reliance (as a reaction against perceived



dependency on the state) that new and unstable dependencies can develop between the employer and their personal assistants.

### *Becoming a 'responsible' employer*

The decision about who to employ is only the first 'choice' employers need to make, once personal assistants are recruited the work begins. The government literature often refers to 'appropriate support' for employers (DH 2004b; DH 2010), this support is rarely clarified in detail, but is often in reference to payroll and the legalities of becoming an employer (DH 2009a) or 'social entrepreneur' (Prideaux et al 2009), and there is little reference to ongoing people management support (DH 2009a). The most recent guidance refers to the 'ups and downs' of being an employer and offers some advice about employer responsibilities (DH 2009a), but does not explicitly engage with the commonly expressed difficulties employers have found in the day-to-day realities of managing personal assistants (Morris 1993b; Glendinning et al 2000; Gramlich et al 2002).

Joanne who works for the Independent Living Service talked about the responsibilities of employers to ensure that they and their personal assistants are safe:

[W]e offer as much or as little support that people want ...[...]... we go and see people, give them advice on direct payments and we have to make them aware that they have responsibilities to be an employer ...[...]... so we say that we can offer advice and support ...[...]... right from the beginning in recruiting ...[...]... assisting with their job description, which may be from the care plan ...[...]... and then we would advertise it for them, however they want to do it ...[...]... we go right through the process of

application forms, we send the application forms on to the employer for them to look at they let us know if they want us to help with interviewing, they may do it themselves or they might ask us ...[...]. we send all the stuff on to them for them to make that decision who they want to employ [interview] from the application forms ...[...]. so they would interview them, if they were appointed they would either ask us to help with references, with CRBs as well so we do all of that, that process of recruiting right through to doing the contracts of employment ...[...]. and then we also do the tax returns so we get all the PA's details for them ...[...]. the majority do want the payroll ... [..] ...we can also do the direct payments returns ...[...]. cos it's public money they have to do a direct payments return to the council every 3 months ...[...]. we can manage the money on their behalf, but we would still let them know about the money.

The importance of this nitty gritty support around recruitment, interviewing, contracts and payroll commissioned by this local authority is not underestimated. The complexity of the recruitment process and financial side of becoming an employer is clearly addressed, however the ongoing responsibilities of being an employer are frequently underplayed. Here Joanne outlined the types of support the Independent Living Service can offer, not necessarily the ongoing support which people may need. Government guidance suggests that employers should treat their personal assistants fairly (see DH 2004a) and acknowledges that managing a personal assistant is more than managing the money (DH 2009a), however the focus remains on getting a personal assistant rather than *keeping* a personal assistant (DH 2004a; DH 2008). Employers in this project (in line with research from other studies, (Glendinning et al 2000)) were concerned about their personal assistants' welfare and anxious to fulfil their responsibilities as employers. These concerns ranged from health and safety to references to managing personal assistants' hours and personal requirements. Camille highlighted health and safety and concern for her personal assistant's wellbeing as a constant source of

anxiety:

Health and safety seems a real issue if a light bulb goes I have to wait for my dad to come or a member of my circle like a light bulb went in my bathroom which was really shit ...[...]. I felt really guilty my PA was here but I daren't ask her to get on the ladder cos it's a bit fiddly and my dad had been to drop the shopping off in the morning so I phoned him up, can you come back he said cant you ask your PA, I said I daren't because if they fall off the ladder they could sue you I mean they say in the ILS [Independent Living Service] when they first come your house has got to be ...[...]. there's nothing got to be dangerous in your house ...[...]. electrical sockets ...[...]. you'd feel guilty wouldn't you if anything happened, well I would ...[...]. one time we were defrosting my freezer and one personal assistant says we will use the hairdryer ...[...]. "you will not use a hairdryer whatever you do" ...[...]. she said "why not?", "because I'm not allowed to let you do that" I said "you might do it in your own house ...[...]. and I might do it, but you're not doing it" ...[...]. it's my responsibility.

The awareness of health and safety concerns were also evident when Ed said:

...just things like when you go out with me do you know how to handle the chair, tip the chair back ...[...]. cos I'm responsible for that, if I'm not doing something right it'll be my fault for obvious reasons it's one of those things.

There were also other employer responsibilities which are difficult to fulfil without support, but which are also confidential and sensitive to discuss with personal assistants:

Camille: I think one of the problems that I am having ...[...]. people are coming saying can I have a reference, well I can't ask one of my other PAs to do the reference so I have to rely on my

mum to help me to fill the form in or an advocate ...[...]... it would be nice if you could have someone specifically to help do the reference especially at this time I've had 3 or 4 come in and I can't ask anyone because they may be wanting a reference off me it is a bit awkward ...[...]... and another reason why I have 7 staff, I know it may seem a lot but you also have to think that someone might phone in sick.

Camille is very sensitive to the needs of her personal assistants and also her responsibilities as an employer, in this case a personal assistant's concerns about her hours:

[I]t bothers one particular person cos she likes to get her 40 hours in a month so I've got to be very careful ...[...]... With support I've learned to be quite creative sometimes this person works 52 hours so that means she works less the next month I think you've got to be a fair system, I mean quite difficult cos you don't want to be favouritising anybody ... [...]... I've had "which person's food do you prefer?" I ain't got a preference to anybody's.

Camille speaks of balancing hours and fairness. The delicate role of an employer is exemplified within the negotiating of different personal assistant's needs and wishes and balancing these with her own. There are many examples in the government literature; Alan, for example, in *Valuing People* (DH 2001: 49) said "...I like the idea of employing my own personal assistants who I could ask to do what I wanted when I wanted". Alan's idealistic ideas about what employing your own personal assistants might be like appear time and time again. Camille and Ed's concerns return us to the daily concerns of being an employer be that of personal assistants for your own support or a small business where personal relations and loyalties create complexity.

Camille and Ed highlighted the responsibilities they have to keep their personal assistants safe. Employers also have a legal responsibility to

offer basic training to their personal assistant, however this has not been widely or well funded (Flynn 2005). Emphasis has been placed on the social care workforce in general gaining qualifications, such as National Vocational Qualifications (NVQ) or the Learning Disability Qualification (LDF), however personal assistant work, due to the limited hours and often only working with a single employer does not offer the breadth of experience necessary to achieve the qualification (Skills for Care n.d.). Employers in this study expressed a desire to offer training to their personal assistants. Ali said:

...there isn't [any training for personal assistants] unfortunately and this is something that [Speaking Up group], this is something that we really want to do because I haven't been trained as an employer so basically I want to do things properly and get it right for other people as well.

This sentiment about being unprepared to be an employer was echoed by others in this study and the lack of training available for personal assistants was equally a common concern to both employers and personal assistants alike. Previous studies have found that employers may prefer to arrange training specific to themselves, emphasising, as Kelly (2010: 12) suggests, that personal assistants 'more accurately become specialists in certain individuals rather than in certain tasks or types of work'. The training and movement towards the semi-professionalising of personal assistance has been bound up at once with disability studies critiques of professional social services (Morris 1993b; Christensen 2010) and some commitment in government literature to create a 'well-trained' workforce (DH 2005a; DH 2011). Gramlich et al (2002: 134) sum up this dilemma: 'We think PAs should have supervision, training and support. **We will be in control of it**' [emphasis in original]. This contrast in approach, a concern with training perpetuating old 'care' relationships and expert knowledge may have resulted in an avoidance of the issue with respect to employers and their personal assistants. Some people in this study (for example Freddie) have identified specific training for their

personal assistants, and others have developed inductions and shadowing of, and supervision by, more experienced personal assistants, as on the job training, but these individual strategies have not always managed to make personal assistants feel comfortable in their work, as one personal assistant said:

I had learned the ropes but there was no formal induction from ILS [Independent Living Scheme] and that's one thing that I don't think is very good about the whole process because, like we have had no health and safety, no manual handling training, no training to know what to do if there was a problem.

This feeling of being unprepared for the job, and what to do when there is a problem was not only a concern for personal assistants. Research has suggested that support for families and employers has been inadequate (Flynn 2005) and employers and families of employers found similar experiences in this area. Faith talks about her feelings about taking on the personal budget through which Freddie employs his personal assistants:

I mean I think the difficulties were those of any group of families that, all the new partnership families starting out as pioneers if you like and being the first to do it so it's always more difficult. So I suppose it was about having to do all the research ourselves I mean because that's all, I was used to doing that it wasn't that I found that hard it was just another job to do really. I think we did feel that we were handed the money and told off you go and if all else fails well we do have a duty of care Freddie will be alright you know we will be able to find a place in a group home for him so I think it was that kind of rather negative ...[...]... I think that support wasn't around we felt very isolated and I mean I think there were some very difficult conversations we had about the budget...

Freddie's support is particularly complex, due to the number of hours and different personal assistants and as the only person in this study who has a full personal budget as opposed to a traditional direct payment (the set up

and development was a part of a pilot). However the feelings of isolation and responsibility run through other employers' experiences:

Camille: that is a real difficult one because you don't get the support to do that [manage PAs] I have a circle of support so we usually meet up every 6 to 8 weeks I usually talk to one of them or bring it to the circle of support.

Camille's circle of support offers a space away from social services and her personal life where she can speak openly about her personal assistants and concerns about how they are managed. Support being separate from the council would fit neatly within the personalisation agenda, and that separation was felt to be important as one family supporter said:

To be honest we didn't want to be involved with social services ...[...]... and I think that is probably because of [our] situation and the fact that when he came to live with us it was his and our choice we didn't want to think that we had to rely on the state to support us. We've chosen to do this and we will do it by hook or by crook.

Whether different participants appreciated involvement of the local authority or not, the lack of support in ongoing management is compounded as Ali (and others) stated above, "I haven't been trained as an employer".

Beyond tax and national insurance contributions the complexities of this particular practical and sensitive area of employment has been largely ignored in terms of support. Recent thought has sought to further understand these new relationships, which remain largely undefined, or problematised. Prideaux et al (2009: 566) suggest:

Disabled people who employ PAs under self-operated support schemes are employers in the same sense as any other. As such they

are operating as small businesses and are incorrectly stigmatized as 'benefits recipients'. Their labour fits squarely within the post-welfarist typology, since there is no pre-existent model which correctly and explicitly encapsulates this work.

This recognition of employing personal assistants as 'work' rings true for many of the employers in this project. This expression of 'work' is unrecognised, rather those who have chosen to take on the responsibility of becoming an employer have been reframed as active and responsible and entrepreneurial citizens (Scourfield 2007).

This active citizenship in the form of the 'work' of managing a direct payment and simultaneously the economic role of offering employment may enable a shift away from Leadbeater's construction of 'dependency', however the shift is not always the result of positive choices and 'empowered' decision making, rather it occurs through lack of choice and available options. Faith talks about her initial feelings about direct payments and subsequently switching to a personal budget:

I think probably when it came to having a personal budget I felt very anxious and thought there are so many risks here and we really didn't have any kind of support to say and if I and if this happens, well you know we can do x y and z. I remember lots of sleepless nights before Freddie, you know we were buying a house through shared ownership and starting to employ all these people and it did feel like a very big undertaking really, a big responsibility on top of everything else and it still is. I mean I am more used to it now and I can just rattle it off it's very easy, but it's not something you expect necessarily to do, having said that I mean I am much happier Freddie is a different person now than he was two and a half years ago and I wouldn't have it any other way so he paid a lot of costs in terms of is it going to work, and how, all sorts of worry about sorting out the budget umm but I wouldn't have it any other way because Freddie's life is so much more ordinary.



Freddie and Faith made the decision to take the responsibility of a direct payment in a reaction to the inadequacy of traditional services. Faith identifies several concerns about taking on a direct payment notably the risks and responsibilities involved.

Risks in the world of social care have been traditionally associated with the risk of harm. The weight of this risk has often been characterised by a critique of a risk averse social care workforce (Leadbeater 2004) and the juxtaposition of risk management and independence (or empowerment) (DH 2009c; Fyson & Kitson 2010). Direct payments shift these 'risks' to the broader context of risk in reflexive modernity and a culture, in which, Kemshall (2002: 8) argues '...failure to negotiate a risk adequately is rewritten as individual failure rather than understood as a result of social processes outside the individual's control'. This analysis of risk raises significant questions in the development of the individualisation or personalisation of social care. Freddie and Faith have moved from inadequate traditional services through to supported living with some personal assistant support to shared ownership of Freddie's own home which has made all the difference to his quality of life. Freddie and importantly his family were able and prepared to take the risk to leave the security (and inadequacy) of state commissioned services and commission and manage all of his support. Faith is now able to "rattle it off", but it is implied that that was a long and painful process. If risks are individualised and taking risks are increasingly the only way to achieve personalised support then this has significant implications for people without the necessary support network. The limited support offered by the Independent Living Scheme does not equate to the support that Faith can offer Freddie nor does it bear much relationship to the type of support offered by the care management process of assess, commission and review.

In the development of self-directed support, risks and risk management have been downplayed (Glasby & Littlechild 2009), redefined and re-

interpreted as 'risk enablement' (DH 2011; Tyson et al 2010; Glendinning et al 2008). *Independence, Wellbeing and Choice* (DH 2005a: 7) aimed to encourage debate around the ability to take 'risks', with the aim of:

Empowering the social care workforce to be more innovative and to take the risk of enabling people to make their own life choices, where it is appropriate to do so.

Personal assistants work at the bridge between the largely separate discourses of risk and empowerment (Manthorpe et al 2009), but are connected in terms of power and control and the regulation of self (Rose 2000 & Webb 2006 in Pollack 2010). The 'regulation of self' in combination with a presentation of 'true empowerment' as meaning '...that people might make decisions service providers disagree with' (DH 2010: 26) positions general and particular risks and risk-taking firmly within the responsibility of the individual (Ferguson 2007). Risk aversion has characterised the recent history of the welfare state and in particular the care management process and this aversion has served as a useful and compelling critique of traditional services (Morris 2004). Once again the convergence of the '...progressive and the neoliberal, the romantic and the practical...' (Burton & Kagan 2006: 299) is experienced or at least intended to be experienced as empowerment, but the taking of power and maintaining that control can be considered to be contingent upon making 'good choices'.

Ali typifies the new motivated 'citizen-entrepreneur', however any weakness within this position of 'citizen-entrepreneur' can be viewed as a failure (Scourfield 2007). Ali experienced a complicated situation where he felt his legitimacy as a capable employer was being brought into question which raised concerns (for the professionals involved), not only about Ali's capacity to be an employer and how and when personal assistants act 'unprofessionally', but it simultaneously raises questions over how different professionals' actions can serve to disempower.

Ali offered an example of a 'risky' situation where one of his personal assistants who had keys to his house, stayed overnight whilst Ali was on holiday:

Ali: Yep that was difficult because a PA came and stayed which all right, and if the person had just said, well, I would have dealt with it on my own but because it involved everybody of course I was non-existent.

Katie: What happened?

Ali: Well I was on holiday and I got a phone call from somebody from [a local charity that supports Ali with his finances] saying "well this isn't good and I'm going to have to speak to your care manager" and "blah blah blah" and of course I was like "oh" ...[...]... so of course it all happened and basically everybody and the whole world got involved and I was like "where's me I'm not here" ...[...]... well they had meetings without me and then they wanted my PAs to go to the [the charity] to have a meeting and I said "no!" the meeting is happening here, this is my gaff basically and I said that "you know this is where PAs work they don't work at [the charity] and they don't work anywhere else they work here with me" ...[...]... So we are having a meeting on Wednesday, hopefully things are going to be resolved and end of hopefully we will all be one big happy family

Katie: Is there anything that particularly frustrates you about this situation?

Ali: I think that it could have been dealt with when I got back from [holiday]. I would have liked to have been a little bit more involved and I would have liked to say my bit ...[...]... and then they got me an advocate who b a s i c a l l y t a l k e d l i k e t h a t t o m e oh and I'll never forget, I just think he is so patronising and I was sat there going I'm going to hit you ...[...]... I just felt like so horrible, not everything is fine.

This is clearly an example of misconduct on the part of the personal assistant. However what is interesting is how the empowerment principle at the foundation of the personalisation agenda is tested when safeguarding concerns are raised and things go wrong. The vagaries of the new roles of care managers and personal assistants are illuminated and actions questionable within the context of the direct employment relationship. Many things were at stake in this situation. Fundamentally Ali's legitimacy as employer has been overpowered through the involvement of an external organisation unsolicited by Ali himself. Additionally the arrangement of meetings without Ali being present and the introduction of an advocate who did not offer the advocacy support Ali might have required or work in a way that is acceptable to Ali. However, simultaneously it raises questions about the care management role in the support of employers and their personal assistants. Ali's care manager, who has been very supportive of Ali's choice to take a direct payment expresses her concerns and dilemmas as to her role when things are not going quite as planned:

Katie: When it was found that this person was acting unprofessionally what happened next?

Adele: Well it's really difficult really because Ali was employing this person and so ultimately it was up to him whether he employs or decides to discipline the worker and because he has got that friendship base with them, he often decides not to discipline them and I have often advised him to discipline them and ask for support from, he gets outside support from [a charity] and whenever I ask their advice they always say it's down to him, the employer, but it's a really difficult one because I'm not sure that he always gets the importance of disciplining them when something's gone not quite right.

Adele's position is delicate. Adele respects Ali's role as employer whilst raising some concerns about the choices Ali makes in terms of his relationships with his personal assistants and her capacity to get involved.

Adele implies that she takes a back seat and merely offers advice. Another care manager, in relation to a different situation, expressed similar concerns:

It's difficult because obviously I came in to review it so I am not the person who set it up so I'm reviewing something that has been going on for quite a while and things can have changed or maybe she is using the support for things, not prioritising what she really needs it for, but using it more socially, but then at the end of the day she is the employer so from my perspective I've got very little power over that since she is the employer so it can lead to difficulties for her.

Gillian highlights that "she is the employer" which prevents her from seriously questioning Georgia's decisions. Cambridge (2008) has suggested that care management within the direct payment relationship is ill defined and this raises scope for, as Fyson and Kitson (2010) fear, the pre-eminence of the values of choice leading to abandonment. Although they were referring to more serious recent examples of abuse, this challenge to the traditional care management role raises questions about how care managers will re-negotiate their role (Cambridge 2008).

Ali's experience exposes the spaces where empowerment is contingent upon successful performance of the role of employer. Equality of opportunity enshrined in equalities and anti-discrimination legislation enshrines rights, however, opportunities for empowerment and ability to take control and make use of those rights are not distributed equally. The move towards personalisation and self directed support have worked well for Freddie and his family, however the very 'empowerment', choice and control offered in the form of direct payments can serve to lead to an uneven distribution of the power that is at play. Fyson (2009: 20) argues that:

[S]elf-directed support and individual budgets appear designed to maximise inequality of outcome. This is because state-sanctioned

reliance on networks of family, friends and neighbours will mean that social capital will increasingly predict welfare outcomes. Some families may be better placed than others to provide support. Some may have better connections with individuals or community networks who can offer support in person or in kind. Families that include people with learning disabilities are known to, on average, have less social capital than other families (Widmer et al, 2008).

Fyson clearly situates self-directed support and individual budgets within a context of inequality and 'state-sanctioned' dependence on social capital. Whereas Freddie has a strong network of family support as well as a circle of support, others, specifically those employers who do not have a tight network of support, have no such support structures for either the employer or the personal assistant. Georgia explains how she has struggled with managing a personal assistant who is often late:

Katie: How long has she worked for you?

Georgia: A very long time [a year].

Katie: Has she always been like that?

Georgia: Always ...[...]... she won't turn up on time.

Katie: What do you say to her when she is late?

Georgia: I just want her to come on time.

Katie: And do you tell her that?

Georgia: I've told her plenty of times ...[...]... she keeps thinking that her kids come first.

Katie: Does she give excuses?

Georgia: She doesn't phone or anything.

Georgia speaks of the difficulties she has in getting her personal assistants to come on time. Georgia does not identify the type of support she might need to manage her personal assistant and care managers interviewed appear to identify this as a general support need, however do not appear to have the resources to meet this need. A care manager reflected upon similar difficulties with concerns that an employer is not able to handle the responsibility of being an employer:

I think she struggles really to handle responsibility and what's involved and give clear information to people ...[...]... so I think she does struggle, I think that she struggles with organising support and I think she struggles with what the support is there for getting that put in place.

As discussed in the previous chapter, with reference to personal assistant job descriptions, it is unsurprising that there may be a lack of consensus as to what the support is there for as the support planning integral to self directed support (Duffy et al 2010) and person-centred planning was not widely done in the early stages of direct payments. However, this is intended to be significantly altered with the development of self-assessment and support planning (Duffy et al 2010). Georgia identifies herself as the boss, but one who is not getting the 'service' she wants from her personal assistants and has been unable to negotiate and manage her personal assistant to come on time. Georgia's support needs related to her learning difficulty and the support she might need to help manage these relationships appears to have been removed from the equation. Joanne highlights the tight boundaries and critical gaps in support, within the work of the Independent Living Scheme:

I do feel they need more support to be employers. I feel, because we are not deemed to be the employer we can't get involved too much in that side of things. I feel it does need somebody who can do that little bit more for them who's quite neutral still about it, we do get involved probably as well, but not as much as we are not supposed to. Our remit is not to get involved as much...

Some employers felt more confident about their role as employer and all the responsibility that accompanies this. Ali speaks about his sense of responsibility to his personal assistants:

I think respect is the most important thing as well because it's a two-

way thing. I think it's very much a 1:1 thing because they are working with me and I'm their boss basically so if anything goes wrong they come to me to say look this isn't working or whatever and then if we can't solve it together then we involve the ILS [Independent Living Service].

Knowing where to go for help and working together to resolve problems is clearly a good approach for Ali to take when managing his personal assistants. Similarly, Benji's personal assistant talks of how Benji helps her to understand what he would like her to do:

[H]e will say yes ...[...]... he will just tell me, but he is very nice about the way, you know he will ask, he won't tell me to do stuff, he will say would you mind doing that, or is it ok if you do that because it is too heavy for me, it's not like you do that and I do this ...[...]... but he is very good, he will tell me exactly what he needs, he is not shy about asking for anything.

...

Benji is very easy to communicate with ...[...]... he can do a lot himself and it is easier if somebody can communicate as well, it would be a lot harder to know what they wanted or what they needed...

Being a skilled communicator is a skill that any manager needs and how an employer speaks to their personal assistant can be key to directing their own support and was important to Ed when working with his personal assistants:

Katie: When you get a new personal assistant how do you tell them what they need to do?

Ed: I just make sure they're comfortable as well as me, I'm alright but I've got to think about them as well.

Ed emphasises the importance of the feelings of the personal assistants as well as his own, which is similarly commented on by Camille:



Camille: I think some of the difficulties cos I'm not very, I don't like a bad atmosphere so some of the difficulties, if they do something wrong I find that quite hard to tell ...[...]... say please don't do that again it's like ...[...]... I also when I first started I found it hard to give them instruction and sometimes I'd say "oh do you mind doing this for me?" I found myself apologising cos I feel ah I feel awful for asking and they say "no we are here to do that it's our job" ...[...]... especially when I came to live in my own things changed an awful lot and like they helped me sort the flat ...[...]... we joke about it and maybe they shouldn't have done it for health and safety reasons, but they helped me move from one room to the next ...[...]... but stuff like that it's quite difficult to ask because you think well should you be asking that? Oh are you allowed to ask them to change a light bulb can they do that? ...[...]... they have to stand in a ladder ...

Katie: Would they say yes?

Camille: I think they would in that we've got such a good relationship ...

Employers spoke of how they handled a personal assistant who was not working in the way they would like:

Harry: your words against my words ...[...]... I maybe get someone in, expert, if that person is abusive towards me, no like I said earlier ...[...]... if abusive ...[...]... advocate, I tell them myself ...[...]... if you don't listen to me ...[...]... if they don't listen to my mum I get solicitor in ...[...]... no I got power.

Harry feels that he has the power in the employment relationship and has ideas about where he would go if there were a problem. Ali similarly reflects on the challenges of managing a group of people:

Katie: How do you find managing 4 people?

Ali: Urm it's quite difficult sometimes because everybody has got their own individual personality and ...[...]... I have to respect that really ...[...]... everyone is going to have differences of opinions or somebody doesn't like how things are being done do you know what I mean and when you've got 4 people it's really hard when someone is saying well this hasn't been done, that hasn't been done and with me not being able to see it sort of reflects on me in a way because it makes me feel a bit sort of oh well maybe I should have asked somebody to do that, you know what I mean.

People, like Ali are managing teams of people. Ali refers to the differing opinions of his personal assistants and also feelings that when things are not done or a personal assistant is not happy that it is his responsibility. The employers interviewed commonly expressed concern for and awareness of the needs of their personal assistants, and at many points the role of employer / manager was ascribed elements of 'work', expressing an acute sense of employer responsibility with limited support.

The stories of Ali, Ed, Georgia and Camille have illustrated different experiences of taking a direct payment. Freddie's family support has enabled him to buy his own home, have 24 hour support at home and pursue his interests be that music or his food trading business. Alternately Camille and Ali consider their role as employer in terms of their responsibilities, fulfilled in Camille's case with limited input from her circle of support and by Ali with the support of his care manager. It is clear that access to support is uneven which is problematic when considering that positive outcomes have commonly been associated with the availability of a strong support network (Dawson 2000). Georgia talks of her position as 'the boss', but also her frustration with her personal assistant consistently being late, highlighting the support she needs – but is not receiving – to manage her personal assistants. Joanne at the Independent Living Service was clear about her limited role, but that they need to work beyond their remit to ensure that some employers without

wide circles of informal support have access to the help they need to be employers. The contingencies of empowerment within direct payments were illustrated through Ali's experience of an unprofessional personal assistant and the lack of support was highlighted as a concern by supporters and employers alike. Given the lack of support for employers, personal assistant roles may take on new aspects to roles which have been imagined as practical and directed by their employer. The following section moves on to explore personal assistant roles within the context of support relationships, where the personal assistant is simultaneously supporting in practical and emotional ways, being *responsible to* their employer for the quality of their work whilst equally negotiating aspects of their role where they may be considered 'responsible for' (Twigg & Atkin 1994) their employer.

### *Personal assistants in conflict: responsible 'to' and 'for'*

So far personal assistance support relationships have been positioned as practical as well as personal involving a complex interplay of internal and external pressures and subtle emotion (Lee-Treweek 1996) and body-work (Twigg 2000; Wolkowitz 2002) where the role is negotiated by both the employer and personal assistant. The personal assistant has also been positioned as a tool of empowerment, albeit contingent upon personal and broader social factors of the employer, but clearly situated within an emancipatory discourse, which sought to transform the power relations of support. Kelly (2011: 9) cites the Centre for Independent Living in Toronto (2010) who offer a definition of personal assistance:

Attendant services do NOT include: professional services such as nursing care, physiotherapy, occupational therapy, respite care, physician services, 'care' or taking responsibility for the person with a disability.

Similarly a Skills for Care (2010: 15) report, *Personalisation and*

*Partnership*, suggested '[t]he PAs job is not to protect their employer, but to understand what they want'<sup>13</sup> and *Working to Put People First* indicates a vision whereby:

**Workforce development** [emphasis in original] should aim to create a more confident, empowered and diverse workforce with increasingly sophisticated skills in order to secure the dignity, quality of services and quality of life of those people receiving social care.

(DH 2009c: 6 emphasis in original).

Therefore, theoretically, we have an 'empowered' employer and an 'empowered' workforce who are critically to take no responsibility for or protect their employer. Rather than the supported and well trained workforce imagined in *Working to Put People First* (DH 2009c) and *Independence, Wellbeing and Choice* (DH 2005a) or *Options for Excellence* (DH 2006b), employers, through direct payments, have welcomed the opportunity to employ untrained workers (Flynn 2005). This has arguably contributed to a continued perception of 'care work' as unskilled labour which can only command low pay (Hussein 2010) and remains low status work (Beresford 2008). The nature of this type of work which often lacks employment rights (Oxfam 2009) and where workers are rarely members of Trade Unions (Flynn 2005; TUC 2008), in combination with the often minimal hours associated, particularly with personal assistant work, have lent the role to be considered to be 'informal' (Leece 2006; Leadbeater et al 2008). These influences place the personal assistant workforce between an articulated highly trained workforce and the workforce which is commonly desired by employers – untrained, and critically not professionalised. Flynn's (2005: 42) study about personal assistants observed there to be occasions when the role can be considered to be '...neither wholly professional nor wholly informal'. Personal assistants (as highlighted in the previous chapter)

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<sup>13</sup> This research project involved a variety of people who use direct payments and was not specifically focused on people with learning difficulties. Rather people who described their impairment as '[a] physical impairment' formed the majority of the sample.

described their job descriptions as “vague” and “generic” which could mean “everything and anything”. The lack of attention to particular roles and emphasis upon the personal relationship lends itself to a common sense understanding that the role of personal assistant is by necessity ‘informal’. Ivan, the local council’s Personalisation Officer comments on employment relationships within direct payments:

It’s interesting because I think some individuals would be really happy with a very almost informal kind of arrangement, they get paid, yes that person employs them, they work it out on a week to week basis and it will all run swimmingly fine and I think probably a lot of people will employ people on that kind of basis other people ...[...]... who have got much more significant support needs and I think again for me it’s back to the plan about making sure how that is set up and that it is right in the first place and it needs to respect the workforce issues as well so any plan that is agreed needs to be incorporated as part of that, so what does this mean for the staff team that are working with you, what are the contingencies, what if they cant hack it that day, they are ill or something happens to them on a personal basis that they can’t be there, that’s the contingency bit.

Here Ivan also creates this image of informalised arrangements, but also highlights the more complex situations where workforce issues exist and contingencies need to be considered. Personal assistant roles for people with learning difficulties (for example within the Skills for Care report and by the Toronto Center for Independent Living above) are often considered as indistinguishable from assistance for people with other types of impairment and disabilities. In the past, when eligibility to receive direct payments was tighter Williams and Holman (2006) observed that people with a learning difficulty who managed to convince the local authority that they are ‘willing and able’ to take a direct payment may have inadvertently talked themselves out of eligibility to receive services. This irony has been removed, however the reality of taking on the responsibility to employ people to offer support raises significant

questions of equity of outcome and in some ways denies the very realities of having learning difficulties, as Reynolds and Walmsley (1998: 75) highlighted that:

...diffuse range of support roles can be delegated to an employee by someone whose very need for assistance is prompted, not by physical impairment, but mental impairment or mental distress.

As such in spite of the commitment in the *Valuing People* and personalisation agenda to choice, control and taking responsibility as levers of empowerment, working with people with learning difficulties to make choices, take control and assume responsibility is of a very different order to just responding to requests and often involves more active and value laden support. Ponting et al (n.d) through an inclusive research project, *It's all about Respect*, aimed to find out what makes good support for people with learning difficulties. The second phase of their project suggested that joint decision-making is 'perhaps one of the key defining features of empowering 1:1 support' (Ponting et al n.d: 15). This section explores personal assistants' *responsibilities to* and in some respects *for* their employer and how personal assistants have negotiated these joint decisions with limited external support.

Abbey talks about the responsibility she feels to support her employer to "be my employer":

[O]ne of Ali's PAs it seems like he phones [Ali's care Manager] all the time and that's not a situation I want to get into because I think really Ali has elected to be an employer so I'm going to make him be my employer. I don't feel that going to [the Care Manager] is part of the deal really and also it kicks up a stink for Ali, big time, because that's like bringing in the big guns. I mean I suppose if there was something that was really worrying me I think I would probably go first to the ILS cos that's less jumping in on your life I feel than people at [Social Services]. I mean Ali has a fabulous care manager,

Adele is super. Ideally situations should be resolved between Ali and the people who work with him and it should be done there in his household and that's what he agreed to do when he agreed to be an employer ...[...]. I feel that I just want him to be a better employer because I don't particularly want to work for Ali for forever and forever and forever but he needs, then I think well who should be supporting Ali to be a good employer I mean who helps them be good employers ... [...] ... I feel particularly for Ali he is at a disadvantage with him not being able to see that people like A [another employer] and A [another employer] don't have to find ways round of in a way.

Abbey expresses her feelings of *responsibility to* support Ali to be her employer and in the longer term an effective employer for his other personal assistants, but also *responsibility for* Ali in terms of avoiding excessive care management involvement. Ali and Abbey knew each other before which sets up the relationship as something different from the abstracted employer / employee relationship. Abbey evidently feels that Ali (at times) lacks the support he needs to be an employer, but equally that care management involvement is problematic when frequently used to try and address personal assistant issues.

When personal assistants talked about their role they talked about their responsibilities to their employers. One personal assistant said her role is "whatever he needs basically, whatever he needs help with". Another said:

Just make sure her feet are cared for, make sure her hair is always nice, make sure she is clean, she is tidy that she wears nice clothes, try and make sure she is in a good mood every morning, that she is organised, that she knows what she is doing, keep the flat tidy ...[...]. washing.

Even these instrumental, or practical aspects of the personal assistant role, as discussed in the previous chapter, are value laden in how they are

undertaken. How the work is done is reflective of the negotiation of roles complicated by a history of support which can be characterised by various constructions of 'learning difficulties'. This personal assistant begins to suggest the fine line between taking direction from her employer and feeling the need to be "a bit firmer":

...umm it was quite scary because the company that I work for isn't classed as a care support group they just basically do payroll, I didn't get any extra training it was just what I'd had at university so I was a bit unsure about what I was supposed to do and the person I worked for is quite not demanding, but she is like you need to do this, I have rights, you do this so it is very like ...[...]... so I did feel a little bit out of my depth then I soon kind of realised that I need to be a bit firmer and I needed to say to her look I'm here to support you not to do everything for you, you need to help and especially with cooking sometimes she will just wander off and ring people and get in the bath ...

This personal assistant refers to the Independent Living Scheme as the company she works for, highlighting the lack of support she feels she has in a role which has to be, in isolation, carefully negotiated with her employer. The lone working element of the job was a difficulty raised by several of the personal assistants as Cathy explains:

I think just with the lack of support from ILS [Independent living Service] I think that's a massive challenge, yes not having that support, not feeling as though, I know I could call them up if I needed to but it's not open communication.

Support from the Independent Living Scheme was never really intended for personal assistants as there was no expectation that personal assistants would require support in their role.

We have seen how personal assistants, such as Abbey, working in



unsupported environments make continuous decisions about what to say and when to tell – constantly contacting the care manager may not be part of the deal - but the deal seems to involve supporting someone to be an employer whilst simultaneously attempting to offer the support they want and need which is in turn judged from afar by the social services annual review. Personal assistants are placed somewhere in-between, at once responsible *to* and *for* their employer. Leadbeater's analysis of personalisation lends itself to the notion of the individual, the citizen-consumer and increasingly the entrepreneurial self (Clarke et al 2007; Scourfield 2007). This shift from the collective to the personal carries with it the development of uneven and disparate outcomes for people, as Scourfield warns:

...building a welfare system around the 'entrepreneurial individual' means that public services become both privatized and atomized. There is the danger that individuals will end up in competition with each other over limited resources, an obvious example being personal assistants, who are in scarce supply. With the public sector relieved of more of its responsibilities, how will we ensure social justice in those situations? There are likely to be problems when risk is managed individually rather than collectively, when ad hoc innovation takes the place of strategic planning, and when the quality of service someone receives is less to do with what needs they have and more to do with their entrepreneurial competence.

(Scourfield 2007: 119-120).

Scourfield's concerns are recognisable in the disparity of setup and support the employers in this study have received. The individualising of support may lead to uneven outcomes, however equally, as Scourfield (2007) suggests, the individualising of risk. Personal assistants can face difficulties when working in the 'grey areas' of risk, risk management and advice giving (Williams et al 2009). Personal assistants often, by the nature of their work, work alone with their employer. When things happen which are of concern and may previously have been managed by

a group of people as part of an organisation with broader support structures, now on a daily basis, can become of concern to a personal assistant, who may only work a few hours a week, as Gemma says here:

Katie: Have you ever had concerns about Georgia's safety?

Gemma: Yes there have been quite a few occasions. I've had a, there is a lady who supports Georgia with her financial side and she's rang me once saying that someone in the street was hurling abuse at her or something and she was concerned so I went to Georgia, rang her and she said she was a little bit upset so I went round, especially where she lives she has had quite a lot of problems with her neighbours so I've obviously gone to the agency [Independent Living Service] about it and they have contacted the Care Manager ...[...]... especially she gives everyone a key to her house and that obviously and money issues so yeah there is quite a lot of safety especially as she must only get about 2 hours a day of PA support and the rest of the time she is independent on her own.

The *responsibility for Georgia's welfare* being placed in Gemma's hands is difficult to reconcile with the role of the personal assistant role Gemma described in chapter 4, which theoretically revolved around support at home and leisure activities. In this circumstance the Independent Living Service involved the care manager, however Gemma has never met the care manager and would not consider them to be a point of call when difficulties arise. We see the expectations and responsibilities of the personal assistant 'for' their employer, further emphasised by the care manager's views of Georgia's personal assistants:

The difficulty is though that she has already picked these people and put them in place and maybe if I was recruiting some people I maybe wouldn't have picked certain people that Georgia has picked because there is a lack of, I don't know common sense with some people, not helping her directly with things, or not ignoring it but

leaving it and it has led to some problems for Georgia really.

Whereas Gemma, the personal assistant, is contactable in cases of emergency the care manager feels that Georgia's personal assistants lack common sense in terms of doing practical tasks and responding to events. Gillian, a care manager, continues:

[B]ut they refer back to her mum so they get mum involved and so mum's ringing me up and saying Gillian she's meant to be independent, but I'm getting Georgia and her PA's ringing up really frequently for all this advice and help isn't that their job ...[...]. which yes it is really. There was a particular instance of her fridge breaking down, it was just that the fuse needed changing and the PA was like I don't know how to do it, got mum on the phone saying can you come over and do it. You would hope really that you could employ somebody who's maybe got the skills to look after your home and do your repairs and things.

The personal assistant remit and skill base is expanding from skills working with people, supporting, enabling, helping, as well as the maintenance of a property. Other studies have also found that personal assistants are thought, by family and care managers, to lack 'common sense' (Flynn 2005). This lacking, or perceived lacking in 'common sense', previously identified, may arise less from the particular characteristics of people who work as personal assistants rather the circumstances in which personal assistants work. The perceived informality and flexibility of the role as discussed in chapters 4 and 5, in particular in relation to ill defined and shifting roles in relation to the relationship between employers and personal assistants, lends the work to be judged according to external criteria rather than a prescribed criteria – such as a job description. If a personal assistant is employed to support someone to cook dinner and maybe go out to do leisure activities, at what point are they then responsible for changing fuses and as Camille has raised the changing of light bulbs and the up keep of the building.

Not only was Gillian expressing concern about the personal assistants' role and how they are working but also the alteration of the care management role which necessarily is in a state of flux, attempting to adapt to new ways of working in the world of personalised budgets.

Adele, another care manager also indicated this stepping back when she said:

[W]ell it's really difficult really because Ali was employing this person and so ultimately it was up to him whether he employs or decides to discipline the worker...

Care managers may be responding to the criticisms of the care management process of controlling and being risk averse and embracing the rights of people to be employers and make their own decisions with regard to their support, an area where traditionally care managers have been heavily involved.

However liberating the retraction of care management involvement may be, in situations where a personal assistant's employer is their only point of contact, personal assistants can find themselves in difficult situations. One personal assistant describes an incident that happened when she first started working for her employer:

[T]here was a time, she used to live with a housemate ...[...]... and she was abused financially and verbally by this housemate, she had been living with her for a long time ...[...]... on one of my shifts she actually physically hurt [my employer] and I was there, I'd only just started working and I didn't see it happen, I went in to see [my employer] and she had bruises on her so she was obviously at a massive risk of domestic abuse in that situation and I wasn't sure what to do because there wasn't any policies or procedures about what I should do, the situation had calmed down and I was willing, offered to take [my employer] out of the situation, take her to her

parents, to call the police, do lots of different things although [my employer] didn't want any of that course of action to happen at the time, so I felt in a very awkward position so I left that shift knowing that I had left her in that house with that woman who had hit her and who knows what else ...[...]... it really shook me up and I didn't know if I had done the right thing, but [my employer] had chosen to not pursue it at the time and so it was really difficult at the time ... the next day she told somebody ...[...]... lots of stuff started happening ...[...]... but it was that overnight thing, I don't think I did the right thing, but then it's very difficult, you can't force somebody to do something.

This personal assistant experienced, early on, probably one of the most obvious points of potential conflict of interest for personal assistants and a situation about which, unlike local authority employees, they will have received no formal training. This personal assistant, had she acted against the wishes of her employer, would have lost the trust necessary to have an effective working relationship, but had the situation escalated and a serious assault had occurred it is likely that questions would have been asked as to her role as personal assistant and her responsibilities to and for her employer. It is here where the decision not to respond to the incident could be construed as bad practice or misconduct under adult safeguarding guidance (DH 2000). However, the critical importance of this personal assistant's experience is her lack of support structures and training to adequately respond to such an incident. Traditional 'care' agencies have structures in place to report such incidents, however in the case of direct payment employment relations, the employer is the employment agency, without such structures within which to report concerns. In this instance the personal assistant had received no training into adult safeguarding, had no contact with care management and in addition to concerns around losing her job was unaware of how to report such an incident to social services. Whilst this example represents an incident, which could be considered misconduct, it is precisely the management of these types of risks that exposes not only risks to

vulnerable adults, but also the risks attached to the creation of an unsupported and vulnerable workforce.

The vision of an empowered workforce emanating from the Department of Health does not imagine these types of instances whereby on a routine and unsupported basis personal assistants are making decisions about which risks they effectively facilitate and those which they do not. Either decision may effectively terminate their employment – through an irreparable breach of trust with their employer or allegations of misconduct though exposing their employer to risk of significant harm. Abbey experienced a similar, though less serious concern when her employer asked her to buy him more alcohol after a heavy drinking session:

Abbey: I tell you I was challenged last week. We went to the AGM and came back and Ali I'd say was already pissed I mean he'd had 6 pints or 7 or 8 and he's not a big bloke and then said to me he wanted me to go and buy him 16 cans of John Smiths and I really wanted to say no and so I said to him are you really sure you want to drink these you really seem like you have had enough, he was full of energy I mean he had had his review that morning and he had been really stressed about it coming up and I think it was like a release of the stress but at the same time I'm really not sure I should go and buy you 16 cans of beer.

Katie: Did you do it?

Abbey: I did and I put them in the fridge ...[...]... I feel, I don't feel, as much as I can advise him what I think is right and what I think is sensible it's his choice, it's his choice.

It is these types of situations that have encouraged support agencies and allayed their fears about losing, through 'poaching', to direct payments, direct employment. Baxter et al (2010) found that agencies were confident that support workers who had chosen to leave the agency in preference to become a personal assistant would return due to the high expectations of

employers.

It is not only the employers that have high expectations. Personal assistants interviewed spoke about the difficult decisions they have to make when their role is unclear, but also expectations of them to be available in case of emergency and to take initiative. The care manager's suggestion that some personal assistants lack common sense in their work is positioned against the extent to which personal assistants who take the 'responsibility for' and 'go the extra mile' (Flynn 2005: 20), are highly valued, as Diana says:

[C]an I just say ...[...]... like Debbie's bought this 3 piece suite for Daniela because you weren't happy with the settee and chair that you had before and it's just somebody again with that overview saying well wouldn't it be nice to do this and having the commitment to go to ...[...]... and choose and wait for it to be delivered and make sure the money is alright and all that and it's just having someone who is willing to take that overall responsibility.

'Going the extra mile' and taking that "overall responsibility" represent one of the key qualities valued in personal assistants and not going the extra mile or lacking common sense have been expressed by care managers in this study (and others Flynn 2005) as key weaknesses of some personal assistants. Where taking responsibility and going the extra mile have been subsumed into their work personal assistants become involved in the re-negotiation of boundaries. The personal nature of the personal assistant role means that employers often have the personal mobile number of their personal assistant which may be used more than the personal assistant feels able to cope with. Debbie described how she managed frequent phone calls from her employer:

Debbie: Um I sort of did it in a jokey way, I'd say right I've checked my phone this morning and I had 20 messages from you and I would kind of do it in that way saying oh

if it's an emergency, but then losing her wonder web is an emergency to Daniela that's what I mean, she'd ring, "Debbie I can't find my wonder web", "right is it in there" ...[...]... "is this an emergency Daniela?", "well yes it is", so again it is an emergency to her and because I know that I'm the only person who is going to pick that phone up, if something was wrong, if she had fallen and couldn't get to that or whatever I tend to answer it, sometimes I ignore it, if we were doing something, I think you are going to have to wait and I'll ring you back, but not as much as I used to, maybe one or two a week whereas before it was one or two a day at least, but I can't say don't ring me, she slips a bit then I have to remind her and she stops, it goes like that.

Debbie's work does not fit into the space or time allocated by Daniela's direct payment funding. Debbie points to the responsibility she feels to Daniela as the main point of contact in case of emergency, Debbie essentially feels responsible *for* Daniela. This expression of responsibility *for* Daniela and high expectations illustrate another tension in the personal assistants' roles – notably the distinction between work and private lives.

Debbie's experiences fall in line with Davies' (1990) work on women and time. Davies argues that women working in caring professions have a tendency to sacrifice their private life for the people who they care for. She identifies several implications of care work. The first consists of the impossibility of fitting work into an allotted segment of time as needs vary from day to day. Although she was referring to home help work, which often has increased time restrictions placed upon the work, it is still relevant to the experiences of personal assistants in this project. Another personal assistant talks about frequent phone calls outside of work time:

...in regards of phone calls yes, but the agency [Independent Living



Service] is very aware of these phone calls cos it was getting to the point where when I'm at my other job she sometimes calls me 20 times a day and it was just like, I have explained to her how I am at university, I have another job and life and I can't always answer her calls, and she does understand that but...

Davies (1990: 106) considered the implications of care work where the public and private spheres are not 'sharply delineated' enabling public and private time to flow into each other. She continues arguing that care involves meeting the physical needs of the 'cared for', but also involves putting their needs first. Rita Liljeström and Birgitta Jarup write:

...In many ways women's jobs, the similarity between what women do for free and what they do for a wage makes it difficult for them to distinguish between what belongs to their private life and what belongs to the job.

(Liljeström and Jarup, 1983: 20 cited in Davies 1990: 126).

Davies cites how caring and the demands it places on women's lives have traditionally taken whatever time they needed and has consequently:

...shaped women's relation to time [therefore] if women have difficulty in delineating their private lives from their jobs, it is linked to this temporal consciousness which does not neatly divide one area off from the other...

(Davies 1990: 126)

Debbie and Gemma have differing relationships with their employers. Gemma represents a perhaps more typical relationship where she works a few hours a week and attempts to draw boundaries around her work and personal life. When Debbie speaks of the responsibility she feels *for* Daniela she expresses, as Leece (2010: 202) has found, that close personal relationships and 'being part of the family' increased job satisfaction but with that satisfaction comes obligations, described by

Glendinning et al (2000) as 'boundless obligations'.

The implications of 'boundless obligations' and limited support requires the personal assistants in this project to look to their personal lives for support. Personal assistants in this project have no formal outlet where they can, without breaching confidentiality share their experiences and concerns. In response to personal assistants seeking support from within their personal lives, an employer, in a research project involving web-based discussions of disabled employers, who was seen to be representative of the contributors to this website, wrote:

I have a PA who thinks she has to discuss her work situation with her family when she has a rough day. I feel that respect for professional confidentiality is extremely important and I have absolutely no wish to be the subject of discussion during the assistant's family dinner.

(Anderberg 2007: 262-3).

Here a personal assistant, in common with the personal assistants in this study, is seeking some kind of, albeit informal, supervision. The importance of supervision within social work practices is considered fundamental, not only to ensure that workers are working in an appropriate manner, but also to reflect upon working practices and relationships with their 'clients' (Morrison 2001; HM Government 2009). Another personal assistant summarises the impact of a lack of support with what could be considered a breach of confidentiality:

[W]hen I get home with my very understanding partner. He is very understanding, he would love me not to work for [my employer] anymore ...[...]... I think you get an awful lot of people doing really demanding jobs that have nondescript titles in a way because you can end up being a really valuable part of someone's life and I think that's when it almost stops feeling like a job because you feel a level of responsibility towards them which is more than a job and it can

really bind you to something.

Where no formalised supervision procedures exist, (as has been found to be a common experience (Manthorpe & Hindes 2010)), confiding in friends and family as a form of informal supervision seems to be inevitable and perhaps necessary in order to continue with their role. Published, in the wake of Baby P., *The Protection of Children in England* (2009) report stated:

It is vitally important that social work is carried out in a supportive learning environment that actively encourages the continuous development of professional judgement and skills. Regular, high quality, organised supervision is critical.

(cited in Morrison & Wonnacott 2010).

The critical importance of supervision and reflexive practice in social work is being revived whilst new roles, at the front line and forefront of adult safeguarding are being created entirely unsupported. Personal assistants raised concerns about breaching confidentiality with friends and partners, which may be an inevitable feature of an ambiguous role in an unsupported environment. One personal assistant talks about how she vents after a difficult day at work:

[Y]es I actually have two friends that are PAs ...[...]... we talk to each other about issues, we moan together and laugh together, we all understand where we are coming from and we talk to each other about the boundaries that we need to set and talk professionally about what we should be doing, what shouldn't we. I also talk to my partner a lot about it so he hears a lot about it ...[...]... the girls who are doing similar work are really important to talk to, but if I didn't, if my friends weren't doing these jobs and I didn't have that network I would feel probably quite isolated by it all.

This personal assistant found talking to fellow personal assistants who are also friends useful, not only to talk through events but also to reflect upon

their practice. For this personal assistant this support network proves very important. This type of peer support has been found to be valuable for personal assistants, however may be rare due to the nature of personal assistant work, which requires that they usually work alone (Flynn 2005). Others feared breaching confidentiality by talking to people about their work:

Gemma: Maybe having more support to talk to cos obviously confidentiality it is very limited to who you can talk to about it so if there was like, she does have other PAs and there is a communication book, but I don't have much contact with them so if there is a problem I feel quite isolated and it's like who can I talk to about the problem if I ring [a person who knows her employer well], then it's, I have to ring her at home in her free time and it's not really her role and it's like who do I contact who I can speak to about ...[...]... it's quite difficult and then I am constantly worried about what if Georgia says something that like isn't quite the truth, she does ring Joanne quite a lot of times saying my PA hasn't turned up but it's when she has planned something and told her not to turn up so I'm very wary about, if Georgia was to say something and I have no support and no-one to back me up it's going to be my word against hers and that's kind of a big thing.

Here Gemma highlights a variety of critical difficulties facing personal assistants in their work. Drawing together internal conflicts of breaching confidentiality whilst looking for ways to protect herself and reflect upon her working practices for her employer. Ultimately Gemma suggests that she feels exposed, unsupported and vulnerable to the changing mood of her employer. These were common feelings expressed by the personal assistants in this study which have echoed previous work in this area (Ungerson 1997b; Spandler 2004; Flynn 2005; TUC 2008; Rabiee et al 2009).

The idea of taking the "overall responsibility", 'going the extra mile', changing a fuse, supporting the employer to be an employer, facing

dilemmas about reporting abuse and buying more alcohol for a 'drunk' employer are just a few of the 'boundless obligations' that personal assistants can face. The weight of the challenges involved in personal assistant work, in combination with low status and lack of support may serve to minimise the potential impact this new role may be able to offer. When considering the approach to risk within the personalisation agenda Glasby & Littlechild (2009: 162) recommended that '[a]lthough risk should not undermine direct payments, this is an issue that needs to be addressed (particularly if frontline staff and the general public are to feel comfortable with this way of working)'. The risks and risk management processes explored in this chapter are not necessarily specific to direct payments and direct employment relationships. Rather they can be seen to represent a re-appraisal of risk which offers space for more 'risks' to be taken (in a context of a history of risk averse practices in social care) for instance for Ali to go out drinking. The personalisation agenda through more personalised support with a focus upon choice and control has embraced this approach – seeing the opportunity to take risks as central to the empowerment agenda – which is to be celebrated. However the contexts in which choices are made (or risks are taken) are significant for the personal assistant and needs to be approached rather than avoided through the guise and oversimplification of the realities of making 'choices' and having 'control' and 'taking responsibility', to make visible where the different responsibilities of each lie.

### *Responsibilities: questions of empowerment*

This chapter has been situated within the context of the responsibilities of both employers and their personal assistants. The responsibility element, being 'responsible to' and 'responsible for' was evident from the personal assistants in the previous chapter, however not something that is recognisable from the perspectives of the employers and equally not a

discourse at play in the development of self-directed support. Statements about risk taking and taking responsibility are important in a context of a history in which those choices were systematically denied and are generally articulated through an interpretation of personal assistance as critically *not* protection and *not* responsibility for. However, to avoid and downplay the risks associated (Glasby & Littlechild 2009) with living and making choices denies the implicit and explicit conflict in personal assistance roles for people with learning difficulties. The isolation and process of individualising risks was directly spoken about or alluded to by the majority of participants in this study.

Personal assistants are 'responsible to' their employer, however they are also, in some situations responsible 'for' their employers. Employers have expectations about what personal assistants should be doing, however they also have the pressure of the expectations of care managers, as seen with Gillian suggesting that some personal assistants 'lack common sense' and as discussed in Chapter 5: *Roles, ways of working to develop skills*. Employers are also responsible *to* their personal assistants in terms of employment contract, job description, pay and training and responsible for their personal assistant in terms of wellbeing at work and health and safety. As Ali says "it's a two way thing". But very often it is a process where one, other or both feel isolated and unsupported, as one personal assistant said:

...what I've heard and what I have experienced it is working out really ...[...]... just working out who you are working for because sometimes I think is [my employer] really on board with that is it what she wants or is it what you want and it's who is the boss really and it's working that out for yourself and I think when it isn't so obvious, like in other families either they leave it entirely up to you or I think that is the way I understand [it] PAs flounder really with the person they are working with, it might be right up to them and maybe they don't have, maybe the ideas really ...[...]... you can either sit back with that and think oh all they wanted to do was such

and such so we did really and if they haven't got a strong family sort of lead really.

The 'empowerment' experienced is contingent upon the support offered. Employers were very sensitive to their responsibilities for and to their personal assistants. Camille and Ed's comments on their responsibilities to keep their personal assistants safe whilst at work, paying for taxis at night and ensuring that they understand how Ed's wheelchair works. Similarly personal assistants were aware of their responsibilities to their employers in terms of decision-making and risk taking as in the example of Ali. But what this also exposed is the vulnerability of empowerment. Ali making a mistake by employing the wrong person quickly initiated a traditional process of meetings without Ali's involvement. This kind of event exposes the levels of responsibility *to* and responsibility *for*, felt by different people at different times. In light of concerns about a lack of support for all involved, tensions between how direct employment of personal assistants is imagined to work and how it is experienced in practice are exposed. Employers, their supporters and personal assistants imply some of the tensions implicit in these new (yet reflecting old) forms of work. Tensions emerged around four key areas. Firstly decision making, or risk taking, where personal assistants are unsure of their role; secondly, training, where people prefer to employ people they can train themselves we maybe disempowering a workforce who we should be investing in; thirdly management of personal assistants and supervision; and fourthly the increasing importance of social capital in outcomes of social care as a result of limited support in the ongoing management and support of personal assistants. Leadbeater et al (2008) draw on constructions of the individual, the collective, dependency and empowerment through participation. In a pre-emptive argument against suggestions of inequity within the personalisation agenda they write:

Personal budgets create a much fairer, more transparent match between the money being spent and a person's need. Rather than the crude equity of the current system, which forces people to take

the same service regardless of their need, personal budgets allow people to use the same resources in different ways to suit their distinctive preferences. The overall framework is fairer and more transparent; the outcomes are more personalised.

(Leadbeater et al 2008: 48).

These claims that personalised outcomes are entirely possible are illustrated by some of the participants in this project, however arguments of fairness would require a more committed approach to the support of all involved and a more nuanced understanding of the needs of people with learning difficulties. Outcomes, as argued by Fyson (2009) will be increasingly determined by a person's family, their involvement in self-advocacy groups (in peril due to lack of funding (Pridmore & Rose 2010)) or their ability to create close support networks in their communities or directly with their personal assistants. Where some people struggled to successfully manage their personal assistants and exert their authority as "the boss" and employed personal assistants who were perceived to lack "common sense", others employed personal assistants who took that "overall responsibility" for their employer's support. Equity and fairness is not clear in this equation, rather in a reaction against the perceived dependency creation of traditional services and traditional social work practices, this chapter would suggest that it is the lack of support for employers and personal assistants which is creating opportunities for new dependencies to develop, between a responsibilised employer and their increasingly responsibilised personal assistants. These new dependencies are fragile, based on the development of expectations and in some circumstances 'boundless obligation' (Glendinning et al 2008) of commodified relationships that inspire responsibilities beyond the contractual relationship. These new dependencies will be further explored in the following chapter explicitly looking at how employers, supporters and personal assistants view what begin as contractual commodified relationships but can develop into less commodified exchanges, questioning whether it is the cash in the direct payment that alters the relations of support.



## Chapter 7

### Relationships

In August 2010 Brenda Cocker spent her 80<sup>th</sup> birthday alone after Milton Keynes Council decided that home care staff visiting out of working hours was 'inappropriate'. Brenda said "I think it is absolutely appalling. Care doesn't stop when you shut the front door and say goodbye". In response Milton Keynes council stated that they acted in compliance with the Care Quality Commission (CQC) guidance<sup>14</sup>, which states that home care staff must keep a "professional barrier' between themselves and their clients' (Daily Mail August 7<sup>th</sup> 2010).

Brenda's 'home care staff' appear to have developed feelings which have led them to 'care about' a person that they are paid to 'care for' (Dalley 1998) in spite of regulations which prescribe that home care workers are not paid to *really* 'care'. The relationships discussed in the previous chapters begin to hint at the complexity, not only of the role of personal assistant, but also the responsibilities and relationships that develop in a

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<sup>14</sup> The Daily Mail quoted Milton Keynes Council quoting CQC guidance. CQC guidance incorporates the General Social Care Council Code of Practice which states that social care workers should not '5.4: Form inappropriate personal relationships with service users' (GSCC 2010). This vague stipulation has begun to be clarified in case law in one particular case where boundaries had been crossed and an agency care worker had begun working beyond the care plan. The care worker had become friendly with her client and they had been on holiday together, she had bought (with her client's money) and cleaned carpets, gardened and paid money into a Christmas club (at the request of her client), but these tasks were outside of the care plan. The court ruled that there was misconduct by exposing her client to the risk of financial harm, but that the defendant was safe to continue to work with vulnerable adults (Mrs P v Secretary of State for Education and Skills cited in Mandelstam 2009: 86).

workforce that is scattered, isolated and, although theoretically aligned to the General Social Care Council Codes of Practice (2010) do not work within organisations that are bound by the same rigid rules of practice. Rather their practice, in terms of the practical, the activity and of importance to this chapter, the personal, is negotiated directly between the employers and their personal assistants.

Brenda brings together the 'caring for' in 'care work' and the 'caring about' roots of 'care', a distinction which has been fruitful in broader discussions of how and who maintains the 'spectrum of care' (Finch 1993) in society. The concept of 'care' is contentious and must always be used cautiously; nonetheless it is a critical analytic concept which is 'socially and politically loaded' (Watson et al. 2004: 335), but also one which enables an exploration into and beyond the personal. 'Support' has been positioned as problematic, particularly as a term which has been used to describe a multiplicity of activities from *practical* tasks such as cooking and cleaning to the more *personal* 'having a laugh'. Therefore, this chapter seeks to further explore, with an eye to the potential utility of the concept of care, what is hidden behind 'support' and 'personal assistance'. If direct payments offer a challenge to the social relations of support (Glasby & Littlechild 2002; Prideaux et al 2009; Leece 2010) then it is important to understand how these new social relations are viewed and negotiated in the context of the 'commodification of care' (Ungerson 1997b) through direct payments. Chapter 5, *Roles*, argued that personal assistance, at its inception, was imagined to be an uncomplicated facilitative and practical role, which through the process of commodification, has been assumed to act as a lever of empowerment for the employers. However, these imagined functional roles move beyond the practical and become visible through the negotiation of responsibilities and the, potentially in-formalised, *personal* relationships involved. The practical emphasises the emotionless fulfilment of the role, which helped enable a rejection of 'care' as a symbol of oppression. However, as will be argued in this chapter, to

'brush aside' 'care' (Kröger 2009) would also mean a reductive analysis of the *personal* in personal assistance for people with learning difficulties.

'Care' has been a ubiquitous term within social care, which through common usage of 'social care' and 'community care' has acquired new meanings. Williams (1999: 678) observes that '[c]are suggests duty, responsibility, obligation, power, control, oppression, conflict, altruism, love, solidarity and reciprocity'. The powerful combination of more and less altruistic motivations has positioned 'care' as a word of love, but also as Morris (1997: 54) argues:

Care – in the second half of the twentieth century – has come to mean not caring about someone but caring for in the sense of taking responsibility for. People who are said to need caring for are assumed to be unable to exert choice and control.

The Independent Living Movement and disability activists and theorists have offered an essential critique of the term; inferring, as Morris implies that reliance upon the concept of 'care' equates needing assistance with, at once, meaning *and* creating dependency. This in tandem and at times in conflict with feminists' critiques of the term have effectively separated meanings within the concept; the activity and the feeling with a view to understand women's roles and position in society (Graham 1983; 1991, Dalley 1988). If 'care' has come to be associated with dependency, then 'empowerment' has come to be a by-word for independence, choice and control. 'Independence', in disability as well as government literature has been defined as:

...not linked to the physical or intellectual capacity to care for oneself without assistance; independence is created by having assistance when and how one requires it

(Brisenden 1989: 9 in Morris 2004: 427-8).

Often this 'assistance' is defined and importantly defended as largely

practical, as described by a disabled employer in the *Roles* chapter:

It is the job of my PA to attend to me in all areas of personal and domestic need, and to act as a confidential escort and companion in my social and day to day activities.... [...] ... I do not need: a nanny, a mother, a matron, a 'best friend'; nor psychological, menopausal or family problems.

(Flynn 2005: 30).

In this case support is seen to be necessarily practical and objective, implying that there are obvious tasks to be fulfilled, which can be undertaken in a polite, yet task centred fashion. This separation has played an important role in reconceptualisations of 'care', as a disabled person who employs her own personal assistant has said:

I had a telephone interview the other day with a girl who had written a lovely letter of introduction. But when I spoke to her it was her feeling to be needed, to be supportive and helpful that was the thing for her. That this was NOT what I needed was very strange to her—she had difficulties understanding that it was 'me' on the other end of line. To help and to put up with us, despite 'the difficult physical and psychological demands' as one of the applicants wrote, really got to me when I was reading all the applications. I get so tired of how people look down on me, on us.

(an employer in Anderberg 2007: 263).

Not only have perceptions of 'care' contributed to disabled people being perceived as being in need and dependent, but also to the external perceptions of the role and endeavours of the 'caring' professions. Here the physical and psychological demands of the work are downplayed, but the employer emphasises the potential for the role of the personal assistant to be a catalyst for the self-esteem and emotional needs of the personal assistant rather than the employer. Skeggs (1997), in *Formations of Class and Gender* writes about the experiences and community expectations of women who undertake paid care work. She suggests that

there is a culture of caring whereby women are expected to devote their lives to 'caring' indicating that 'occupational caring becomes the means of finding meaning and dignity assuming responsibility and respectability' (Skeggs 1997: 63).

Skeggs draws on feminist and Foucauldian analysis which sought to question the inevitability and 'natural' equation of gender and the capacity to offer 'care'. Skeggs contextualises 'care work' within wider societal social relations as offering women opportunities to assume 'respectability'. This analysis points, not only to individuals finding a role in society, but specifically to a role that has social value – albeit within the narrow frame of traditional gender roles. In conjunction with her analysis of responsibility and respectability Skeggs found that the education of young women undertaking health and social care courses sought to emphasise the personal responsibility element of 'care work':

Intuition is the ultimate caring disposition. This is defined on the courses as both instinctive and a result of experience. Experience, the disposition which develops the predispositions, is the key factor in generating intuitions which are naturally established. Caring becomes a feeling, and the women are assessed on their ability to feel. It is their affectual responses which they and others monitor. In this sense they are stripped down to their most intimate levels and measured, monitored and classified on the basis of 'natural' dispositions. All structural divisions and inequality are reduced to the ability to feel the 'right' things.

(Skeggs 1997: 69).

Skeggs found that the courses were intended to develop the individual's sense of responsibility and students came to value themselves in relation to the dependency of others. The power at play in any form of support relationships appears to have been fostered by these approaches to education which intends to internalise the 'caring personality' to an extent that they 'ultimately become a form of self-surveillance' (Skeggs

1997: 72) irrespective of their lives at work or at home. Skeggs' (1997: 62) students hinted at the emotions involved in their care work:

If I'm being honest it does make you feel good. I know it's awful, I've thought about it, it's their helplessness that ends up making you feel good.

The feelings in any kind of care work are instrumental in how that work is done and experienced, which have also been contextualised within discourses which have idealised the private sphere and family care (Meagher 2006). The controlling element that might be inferred from the quote above has been identified in subsequent work into the motivations to undertake work in social care. Emotions and managing those emotions are an essential part of working with people in whatever capacity. The complex feelings and emotions that motivate people to take support work, in whichever setting, can be critical to how they view their role. Hochschild's (1983) conception of 'emotional labour' has been used to further our understanding of how our emotions have been commercialised in post-industrial society. Hochschild in her discussion of 'emotional labor' uses flight attendants to illustrate the act of the labour. She says:

To show that the enjoyment takes effort is to do the job poorly. Similarly, part of the job is to disguise fatigue and irritation, for otherwise the labor would show in an unseemly way, and the product – passenger contentment – would be damaged. Because it is easier to disguise fatigue and irritation if they can be banished altogether, at least for brief periods, this feat calls for emotional labor.

(Hochschild 1983: 8).

Emotional labour clearly offers some relevance to the work of 'care assistants', 'support workers' and 'personal assistants', however where emotions were used and acted be they surface acting (where a person

displays feeling without necessarily feeling it) or deep acting ('exhorting' feeling) (Hochschild 1983: 37-48) the potential for 'emotive dissonance' may occur whereby 'maintaining a difference between feeling and feigning feeling over the long run can lead to strain' (Hochschild 1983: 90). Using the idea of feigned emotions *feels* conflicting when talking about health or social care work, be it nursing, medicine, social work or more prolonged and close direct 'care' work. Skeggs' (1997) experience of women's own emotions and identities being subsumed and in their place the vision of the selfless 'carer' can be recognised in emotional labour, however it has been argued that this may not adequately reflect the experience of workers in health and social care work. If emotional labour, in its most basic reading, constitutes the acting of an emotion, perhaps 'care' work is more adequately represented through the concept of 'emotion work' (Gattuso and Bevan 2000; Lee-Treweek 1996). Emotional labour allows the separation of the feeling element from the work conducted. However, emotion work enables descriptions of the complexity of felt, 'real' emotions and work undertaken. In a development of the concept of emotional labour, Lee-Treweek (1996) describes emotion work as a dynamic, which involves nurture and control: attending to the interests of the people as well as maintaining order, which bears resemblance to the personal assistants' experiences in the previous chapter with reference to personal assistants working as a 'technology of citizenship' (Cruikshank 1999) and Morris' (1993a) confluence of 'care' and 'control'.

These examples have offered some potential insights into the complexity of the 'feeling' and 'doing' aspects of 'care' or 'support' or personal assistant work and relationships. The separation of the feeling and the doing has been a useful analytic tool in the struggle against the paternalism and restrictions of traditional welfare provision and in the challenge to gendered social roles and 'care work', be it informal or formal (Baldwin and Twigg 1991). However, to assume that where contractual or financial arrangements exist that 'feeling' does not, but that

it is the 'activity' which is the commodified and the valued offering denies the experience of people who employ and work as personal assistants. The emotional labour aspect of personal assistant work therefore becomes a critical part of the 'commodification of care' (Ungerson 1997b). The strategy of direct payments assumes a direct and wholesale transfer of power, through the opportunity to purchase support, from the state to the individual (Leece 2010). This transfer, as discussed in previous chapters, does not acknowledge the inter-relational aspects of support which in turn impacts upon how the commodity is valued, and equally how the assumed transfer of power is played out.

Negotiating the 'power' that comes from a direct payment is managed in various ways. Having the 'power' to hire and fire does not always sit comfortably with all employers. The drive away from 'dependency' on collective welfare provision paves the way for new and less secure or predictable dependencies to develop in the personal aspects of personal assistance. This chapter draws on the experiences of employers and personal assistants negotiating the *practical* and *personal* in the support relationships further exploring the *personal*, focusing upon how and in what ways the *personal* is valued and negotiated within the discourses of choice and control. Discourses of power (Wærness 1984), identity, activity (Graham 1983; Skeggs 1997) and emotional labour (Hochschild 1983) enable the opportunity to start to explore within and between informal and formal 'support' settings illuminating the interconnections. As suggested at the beginning of this chapter, 'care' has been used cautiously and hopefully with appropriate attention to the assumptions and implications that lie behind it. However, the concept of 'care' has been widely theorised and as such it is thought to be a useful analytic concept to understand changing social roles and welfare states (Daly 2002; Yeates 2005; Kelly 2011). Support, may be a less globally significant term, has been much less considered within the theoretical literature, but accepted along with other used terms, personal assistance (Morris 1997) and 'help' (Shakespeare 2000). This chapter is situated



within the context of the commodification of support which is articulated in policy literature to act as a lever of empowerment through acts of financial control and exchange. However, it is argued that through the development of working relationships the anticipated 'empowerment' effects of financial control and exchange are shifted away from pure commodification towards a negotiated settlement through which elements of the relationship are (de)commodified. It is through this subtle process of (de)commodification that working relations are negotiated – sidelining the strict dichotomy of manager and employee – towards a relationship which has shifted the nature of the 'formal' and is valued for its (in)formality and potential for reciprocity.

### *'Working' relationships*

The personal assistant working relationship begins as family members, friends, acquaintances or strangers. The initial relationships have implications over how these relationships can develop. Katrina, the self-advocacy supporter, highlights how the shift from stranger to personal assistant can emerge:

Your personal assistant is your employee and not your friend ...[...]... you can be friendly but that little bit separate really and I think that happens for all of us, we are all good friends at [speaking up] but I still feel a little bit of distance or else I['m] not going to be of much use to them ...[...]... they are all their best friend ...[...]... I think that's the hardest part, there is someone who can help you with your money and do other things, but the emotional relationship side is really hard cos our guys haven't really been allowed to have friends, friends in the past, they often find that the hardest, like [so and so] thinking the woman downstairs is her best friend ...

The drifting between the activity and personal nature of personal assistance has been a common thread in the relationships of the employers and personal assistants in this project. The 'commodification of care' as discussed by Ungerson (1997b) sought to illuminate the transformation of previously informal relationships into a commodified relationship which carries contractual expectations. Ungerson used 'routed wages' to accentuate these contractual relationships which are in turn altered by prior relationships, be they strangers, friend or relative. Ungerson characterised these relationships as; "pure" – referring to a purely contractual relationship and – 'not "pure"' – referring to the prior relationships of friendship or kinship. The *Roles* chapter characterised personal assistants as a pivot between their employer and the 'community' acting within not only the demands of their employer, but also subject to external 'technologies of agency' (Dean 1999) through which the conduct of both the employer and personal assistant are shaped. In light of a current emphasis upon 'self-reliance' (PPFC 2011) and a commitment to community involvement stimulating informal relationships, the social isolation of people with learning difficulties has been a concern of self-advocacy groups, policy makers and researchers for some time. *Valuing People* (DH 2001, 2009d) emphasised the importance of a range of friendships and relationships in a fulfilling life. Therefore within this context a key role of any support for people with learning difficulties would be to support the development of connections in local communities. These community connections, friendships and relationships critically, it is firmly implied, need to be external to their paid support network, in essence complying with a normalisation perspective that encourages relationship with socially valued others, crucially people not labelled as having a learning difficulty and not 'staff' (Wolfensberger & Tullman 1982). In order to offer the potential for the development of these community connections good working relations with personal assistants and specifically, personal assistants who are well connected in their communities, becomes critical. The personal characteristics of personal assistants and the potential of a relationship

between the employer and the personal assistant have been highlighted as important in the Relationships chapter. Similarly Flynn's (2005) study of the personal assistant workforce highlighted the fine line between a working and a more friendly relationship. Katrina, in the opening quote, is clear that there should be transparent boundaries, however essentially suggests that this sharp delineation is not only difficult to achieve, but may not be what the employer wants and needs. There are many differing relationships between employers and personal assistants in this study. There were early policy concerns which led to restrictions concerning the employing of relatives and conversely raised concerns from other commentators that recruiting may be more difficult for people with limited social networks (Shakespeare 2006). However, recruitment difficulties were not a primary concern of this study as these difficulties have been extensively covered elsewhere (Glendinning et al 2008). Participants in this study at times alluded to some difficulties, however did not raise recruitment as a particular difficulty when asked general questions about difficulties they have faced. Nevertheless people have been advised not to look to recruit friends. Camille expresses concerns about employing friends and anticipates potential problems:

[N]o I think that would be very awkward I mean I find it quite difficult enough the first time I employed someone and I thought I don't like people just doing things for me I like to be asked ...[...]... it's like when we go shopping, it's just a little thing about fruit, to me it would have made sense to put the new fruit at the bottom and the old fruit on the top instead of the other way round it's just common sense about things my look at it is if you can be open about something with someone if something is going wrong because if you don't get on with them you are stuck.

Camille refers to potential problems with regards to asking her personal assistant to undertake certain jobs in certain ways which are important to her. Benji expressed similar concerns:

Katie: Have you ever employed anyone you know?

Benji: Not really no. I was going to interview one of my friends but they said it won't be good as I'd been friends with them a long time it would be difficult ...[...]... cause problems.

Both Camille and Benji express concerns about employing friends. Benji, less specifically, refers to potential problems, however Camille is more explicit about the difficulties she feels she would have managing a friend and the implications this might have. Firstly in terms of the type of support she will get and secondly potential conflict and getting stuck in a difficult situation. The intimacy of having support in your own home and working on a 1:1 basis has been widely acknowledged (Vernon & Qureshi 2000), as such employing friends, in spite of advice against, may appeal.

Regardless of a general resistance and concern about employing friends many did recruit acquaintances or students they had met through groups and societies to which they belong. Bev met Benji through a music group they both attended and talks about the shift from being a peer to an employee:

Katie: When you first started was it strange being paid to be with him?

Bev: Yeah it did a little bit I mean I had never really ...[...]... a couple of times I had been out with him, the [...] bingo thing and I think one time before that I'd been out and about with him, but it was with other people so it was a bit strange to think of him now as my employer, I had to fill out a time sheet, things like that, it was a bit like oh this is weird because it doesn't feel like work as well it just feels like I'm going to see my friends it is a bit strange, but I suppose it's something I will get used to.

Bev points to the time sheet suddenly formalising something which had

previously occurred fairly naturally through a shared interest in music. Benji successfully formed relationships with 'socially valued' others at a music group, but converted a part of that friendship into something different – a commodification of a friendly relationship.

For some, prior relationships have been a useful way of recruiting personal assistants. For others, a more detached approach to recruiting personal assistants avoids potential difficulties of employing friends or acquaintances. Camille is clear about avoiding potentially difficult situations involved in employing people she knows, however she does tend to recruit students from particular courses, for instance, occupational therapy students. Benji has recruited people he knows, but not necessarily people he would count as friends, as have Ed, Georgia, Freddie, Ali, Daniela and Harry has employed his sister. These prior relationships, be they close family as for Harry, or recent acquaintances for Benji or friends for Ali, have implications over how the relationship develops. As one personal assistant suggests:

[I]t is, I don't know I suppose because I knew [employer] before hand it was never going to be a situation of be just being an employee, but I think one of the reasons that I'm still working for him...

This personal assistant begins to hint at, not only the importance of the relationship, but also the implications of this. The emergence of a relationship that moves beyond the commissioned hours, fulfilling outwardly fairly straight forward tasks dissipates the 'formal' and paves the way for a less tangible working role and a relationship which does not resemble a knowable instrumental role, but one which involves more subtle personal skills to negotiate. Given the different starting points and variable methods of organising support within direct payments, the relationships between employers and personal assistants involved in this project have evolved in different ways. The following sections explore these emerging relationships from the different starting points of the employers and personal assistants beginning with a relationship which

most closely resembles traditional support work relations; 'friendly' relations.

### *'Friendly' relations*

Personal assistant roles exist outside of the restrictions of more traditional services, such as those experienced by Brenda at the beginning of this chapter. The role remains unregulated, has been described as 'informal' (Leece 2006; Leadbeater et al 2008) emphasising personal qualities (DH 2006b), but equally the role has been reflected upon in 'professional' terms advocating training and development opportunities and suggested plans for some form of voluntary regulation (DH 2011). In spite of the lack of formal regulations concerning personal assistants' work, and as illustrated by the Independent Living Service's advice not to employ friends, also identified in previous studies (Skills for Care 2010), concerns about the creation and negotiation of boundaries within the employment relationship were highlighted by employers, personal assistants and their supporters. Faith, Freddie's family supporter, comments:

Faith: Yeah I mean I think it's very difficult not to form friendships in that relationship and I think as long as you keep the boundaries tight then it's much the best way to be really, it depends how you define friends. I mean Freddie would regard everybody as his friend really, I don't think that there are any golden rules about, not in Freddie personal assistants' I think that the important thing is that Freddie remains in control that Freddie is in charge of what the relationship is and he has got some fantastic personal assistants at the moment, absolutely brilliant and they are all very friendly with Freddie, with Freddie it's difficult not to be and they are all very good at making sure that the boundaries aren't breached [laughs].

Katie: That's quite a skill

Faith: Well it is a skill, sometimes it is difficult with women personal assistants but again if somebody really is confident and sure about themselves then they won't have a problem saying that's not appropriate Freddie and I think that's been great really because he has got a number of women personal assistants who he's coping really well with that relationship.

Here Freddie's personal assistants have a delicate role to play offering a 'friendship' but within boundaries and on Freddie's terms. Freddie's definition and expectations of a friendship may differ from those of his personal assistants and it is the role of his personal assistants to manage and negotiate the relationship on Freddie's terms. Freddie's personal assistants tend to be recruited by advert according to the particular role the personal assistant may perform - supporting with gigs, the allotment or more leisure activities - so are generally unknown before they start working for him. They are working in an environment that has considered the role of the personal assistant and have clear guidance about how Freddie expects them to work. Freddie has a circle of support and his personal assistants have regular meetings with an experienced personal assistant offering group supervision and a space to express any concerns or training needs. This was an atypical way of organising personal assistants which may have helped to enable the personal assistants to be friendly within boundaries that offer protection to both Freddie and his personal assistant. Emily, Ed's family supporter, also emphasised the importance of boundaries:

[T]here was another guy E [a PA] who used to work with him ...[...] E was very active in YMCA and he used to take, even outside of his paid time, but he used to take Ed, he'd ring him and say there's a group going off to do something do you want to come and that was lovely ...[...] we need another [E] here really ...[...] Well it was in his work time, because he was a youth worker as well if there was anything he knew of he'd ask Ed if he wanted to come along so Ed would be part of the gang and that

was really nice and that worked well when we paid [E] ...[...]... [E]  
he was a paid worker but we had clear boundaries.

These working relations, which have been characterised as ‘friendly relations’, are positioned as akin to more traditional ways of organising support, with emphasis upon working roles and modes of supervision in terms of support for Freddie’s personal assistants and the importance of boundaries for Ed. Stone (2000: 90) argued when private (family or informal) care:

“goes public,” worlds clash. The values, feelings, and interactions that make up the relational essence of care in the private sphere are sometimes devalued, discouraged, and even forbidden in the public world.

Direct payments represent a continuation, within the personalisation agenda, of these discouraged personal feelings and interactions. One Care Manager interviewed expressed concern about feelings and personal interactions when saying “when does that professional bit end and the friendship start?”.

Personal assistants, however much the personal is valued, remain in the territory of the public sphere, whilst feeling and acting very much like the private. As suggested in the previous chapters and previous studies (Ungerson 1999; Manthorpe & Hinds 2010) the personal traits of personal assistants were important in the recruitment process (if they didn’t already know their personal assistant). However, terms of relationships are often difficult to negotiate. Emily describes the potential confusion and tensions between, what may have felt like a friendly act and what is part of the ‘commodified’ relationship, discussing the difficulties associated with buying ‘friendly’ support:

You can’t pay a friendship this is the crux of it you can’t pay for a friendship and that’s something that we have learnt or are



beginning to learn ...[...]... the way to do it maybe to get the support worker to come in, but the support workers role is to introduce him to other people to make those friendships ...[...]... to build up that true friendship ...[...]... Next time around we are going to have to be very very clear about what we want and how it's going to work.

This raises questions, not only of what a personal assistant should be, but also what they should be doing. The combination of friendliness and personal assistant work places personal assistants (as applies to the majority of personal assistants in this study) who do not have a support structure to make decisions about what is acceptable or 'professional' behaviour. It is here in the absence of direct policies and procedures that personal assistants are required to develop the boundaries of the role according to their perception of their contractual relationship. One personal assistant commented:

...I'm actually working for her on Saturday, taking her to a party ...[...]... One of her PAs who is not working for her now took her out for a pizza one Sunday and stuff like that. I don't do that because I don't know whether it would be overstepping that boundary. I am friendly with [my employer], but the boundaries might get a bit blurred I think, I don't know if that's me being hard hearted.

Cathy fears that she may appear to be hard hearted. Friendliness and friendship and work are at times difficult to negotiate and particularly difficult to re-negotiate. Through fear of being hard-hearted, she is arguably exposing the friendly 'surface acting' and 'emotive dissonance' (Hochschild 1983: 8) which she performs in order to do her job well.

In 'it's all about respect' (Ponting et al. n.d.) employers often talked about their personal assistant as their friend and enjoyed their company. In a recent Skills for Care (2010: 8) report into personal assistant roles and

responsibilities an employer said *"It is important that they are your friend, and understand your role"*. The report equally highlighted the importance of clearly setting out these boundaries between employees and employers. Many of the employers in this study felt similarly and at times this has required the personal assistants, rather than the employer to clearly set out *their* boundaries of the working relationship, as Gemma says:

Katie: How do you think she views you, does she view you as a personal assistant?

Gemma: No more of a friend, the other day she was talking about having a glass of wine, and I was like I can't have a glass of wine Georgia I'm at work and she said "no you're not" and I was like right and yes so especially with the phone calls she will ring me and just say "what are you doing" yeah so some things have been quite difficult but it is worth it at the end of the day, it is such a rewarding job.

Here personal assistants feel that they are hard hearted at exposing the limits of their professional role and the boundaries that they are unwilling to cross. Faith explained the relationship as 'on Freddie's terms', but equally that Freddie would probably consider his personal assistants to be his friend again draws attention to the subtle skills involved in managing these relationships. This section has attempted to draw out where different actors in these relationships have sought to maintain the formal in the personal assistant role, yet equally illustrated the negotiation involved in managing, negotiating and re-negotiating boundaries. The strict guidance which devalued Brenda's relationships with her home carers may be at play in these relationships, but the difference remains that personalisation has created an unregulated workforce, but one which is self-regulated by the employers and personal assistants themselves.

In contrast to Freddie, Ed, Cathy and Gemma's experience of personal assistants and working as a personal assistant, Harry has a theoretically simpler set up, employing just one person, his sister. However,

employing a relative may have implications for the sibling relationship by commodifying the family relationship (Ungerson 1997b) and formalising the informal.

*Formalising the informal – commodification of informal ‘care’*

Ungerson (1997b) described the payment of relatives through ‘routed wages’ as not a “pure” contractual relationship, but one which would be unlikely to be broken cleanly and one which offers a breakdown of boundaries between the ‘gift economy’ of informal care and the market economy. For Hetty, who acts as a personal assistant for her brother, Harry, having a sibling as an employer adds a different dimension to their relationship:

I enjoy having him, because I get to spend time that I necessarily spend with him umm I do things that I wouldn’t always do with him umm I don’t know if you were aware but he really does like fires, yeah he really likes fires does Harry and we have a fire pit so we have this thing where we get loads of wood and he’ll come and we’ll have a fire night and we will sit out there till 1 half 1 in the morning with the fire roaring and he just sits and piles wood onto it usually ...[...]... he has a Chinese, he likes a Chinese, so he’ll have his Chinese and he’ll probably have a bottle of wine ...[...]... and I just really enjoy the time that I can spend with him and I mean he has us in absolute tucks of laughter ...[...]... there are times when I have just sat and cried with laughter ...

Hetty describes how the ability to offer her time to Harry to assist him in staying at home instead of going to a respite centre has offered them valuable time together which they would not ordinarily have. However whilst cementing sibling relationships when the usual “banter” happens,

as Hetty is in role as a personal assistant, potentially different expectations arise. Hetty tells of a time when she overstepped the personal assistant line:

[W]hen say we like having a laugh and a joke there has been a couple of occasions where he has got quite, he's quite up tight about things umm and he has sort of turned round and said 'right I'm going to sack you' and I've said 'well just hang on a minute here' and it's making that difference between I'm not your personal assistant now I'm your sister and then we have had it the reverse way round where I'm your personal assistant you don't speak to me like that you know or I can walk out on you I don't have to take this abuse off you so that's been quite a juggling point when he's you know if he's gone off on one you know and I mean we have laughed about it afterwards but you know and I have said well we've just got to draw that line where I'm your sister at one point and I'm your PA at another point so that's been quite a line to sort of draw which has been quite interesting because as I say there has been occasions when he's turn and said well I'm going to sack you and when he's shouted at me I've said well hang on a minute I'm not taking that abuse off you I haven't come to work to do that don't forget I'm not your sister now I'm your PA I wouldn't expect you to treat anybody else like that so that's been quite a fine a juggling line which has caused some interest.

There is always a fine line where relationships move beyond a purely instrumental and practical support relationship. The move to allow family to be paid via direct payments sparked the potential for significant debate (Ungerson & Yeandle 2007b). The welfare state is founded upon the expectation of a certain amount of familial obligation and Ungerson and Yeandle (2007b: 196-7) suggest that '[p]olicy makers keen to avoid 'deadweight' expenditure may try to ensure, as in the UK, that public expenditure cannot be used to pay for care work that would be undertaken anyway, without any financial remuneration'. Earlier Hetty played down the financial aspect of her role as Harry's personal assistant

and happily offers her support for Harry and her parents when needed. Hetty comments on her dual role as a personal assistant and a sister at Harry's review:

... it gives me a chance to be with him, in a different environment to me seeing him at home, when he goes out as well it's seeing him get his independence you know that gives me a sense of satisfaction and it falls back onto mum and dad doing absolutely fantastic job with him ...[...]... even if he has had reviews or anything if mum and dad have been away I've attended all his reviews which I did in the capacity of his sister before anyway but I do it as his personal assistant now and I was invited to his, when he had his review at [Speaking Up], I got invited as his PA not his sister which was really nice as it was giving other people feedback as well on how well this is working for him and how things have changed and moved along for him ...[...]... so that was quite nice to be invited as his personal assistant rather than his sister but I have done it before in the capacity of his sister.

Crucially the opportunity to use direct payments formalised a role that she would have ordinarily played (willingly) through familial obligation, and as a result offering Harry the opportunity to develop his experience living more independently yet remaining in his own family home.

The relaxation of the rules relating to employing relatives using direct payments (DH 2003; Glasby & Littlechild 2009) enabled Harry to employ his sister to enable him to stay at home whilst his parents were away. The formalised change in Hetty's relationship with Harry is reminiscent, although more significant, than Benji and Bev's shift from friend or acquaintance to employer / employee. Hetty comments:

[W]ell to be honest I've never really thought cos I've always from him being young always looked after him you know if mum and dad wanted a break or they've gone on holiday I've always had him so it's never been an issue and then it sort of on the [] well you

can do it now and it's just a bonus that I get paid for it that it's not one of them things that I think about because regardless if I am getting paid for it or not I would still do it so really money doesn't really come into it it's not an issue because I would do it anyway.

Hetty underplays the monetary aspect of the relationship and defines it as just a "bonus". It is maybe awkward for Hetty to think of a financial aspect of the role that she would and has naturally played for her brother throughout their lives. Direct payments appear to have made it possible to think of this option without it feeling like an imposition. Hetty's love for her brother overrides the significance of the payment for what could and in the past would have been seen as natural support. Utilising Ungerson's (1997b) typology of payments for care describes 'symbolic payments', paid to kin, neighbours and friends. These symbolic payments, which do not have the formality of contractual arrangements indicated by 'routed wages', may be more applicable to Hetty's arrangement with Harry. Although the 'service' Hetty offers Harry will be reviewed and serves a prescribed purpose, rather than referring to a 'wage' Hetty refers to the money as a "bonus", an extra for 'work' that she would have ordinarily been happy to do, but one which had not been considered before the alteration of Harry's traditional respite centre. The minimal hours associated with personal assistant work may make them feel more like symbolic payments than wages, regardless of the prior relationship between the employer and personal assistant.

The difficulties alluded to by Ungerson with reference to the not "pure" contractual agreement has implications for other types of informal relationships. Ali explains the difficulties he has faced employing a friend:

Ali: So I employed somebody that I knew who was actually being made redundant from a shop he worked in and so I employed him first and he was with me till May and then I had another PA who I told you about at [speaking up] wasn't so good and I've had one or two like that who you

think are going to be really good and turn out not to be

Katie: You say the first person you employed was a friend of yours, do you do that often?

Ali: I try not to now, it was just that because they were making people redundant from the shop he worked in and I happened to just say oh would you like to come and work for me? Because basically he would have been out of a job and whatever.

Ali experienced the ability to help a friend out by offering them work, which did not work out well. The financial independence and possibilities of direct payments enabled him to offer help in the form of work in a way that potentially many small businesses do. This opportunity for Ali to offer help to his friend through employment is not one that would have previously been possible and potentially in Ali's situation the funding was not used to pay for support which was already naturally occurring and reminiscent of routed wages with reciprocity.

The limited hours available in personal assistant work have been highlighted as one of the difficulties in recruiting personal assistants (Glendinning et al 2008; Flynn 2005), however they are also the reason that employing a friend is sometimes an obvious choice. Emily explains what it was like when this personal assistant, who was a family friend, could no longer work for Ed:

It stopped ...[...]... [the PA] didn't want to do it anymore ...[...]... because he had started working at the garage (he had been a student at the time) he didn't want to be having two jobs because of tax and everything ...[...]... I remember because he felt so awkward with me ...[...]... he'd carry on as a friend but he didn't want to do it anymore because it was affecting his tax and it would be too much and we were like "oh not an issue" but that did change the relationship because then we didn't see him he is still classed as a friend but we didn't see him and I think sometimes even out of guilt that he comes round and says hello ...[...]... I

think for me it would have been better if we had just carried on that friendship ...[...]... just have been a friendship and let it go naturally and look to employ maybe someone else the boundary is so, so difficult to know because it is how close you want to get to somebody or how you want to keep it as a professional relationship and they come in and support and that's all.

There is current emphasis on 'natural supports' and community inclusion (DH 2001; 2009d) to develop networks of friends and acquaintances not only as vital social support but also as a potential pool of personal assistants (Shakespeare 2006). The risks in employing friends are clearly described by Emily, where once something was offered by the personal assistant in his capacity as neighbour and friend, the financial and contractual relationship at some point drove a wedge in previously relaxed relationships, the very relationships policy directives are encouraging.

Whereas Ali, Ed, Harry and Hetty have formalised an informal relationship, employing your own personal assistant lends itself to working in the opposite way; In-formalising the formal relationship.

### *In-formalising the formal*

Brenda, in the introduction to this chapter said, "care doesn't stop when you shut the front door and say goodbye". The formality of the paid role Brenda's home care workers play restricted their ability to offer Brenda a personal relationship beyond paid and working hours. The personal assistant role has so far been considered to be a 'formal' support role. The nature of the contractual, financial relationship implies that the role sits firmly within the formal world of work and as such the theoretical framework of the informal / formal care divide (Ungerson 1987) and the market as a commodified relationship (Ungerson 1997b). This divide has



been questioned with different conceptions of 'care' suggesting that the 'false dichotomy' created through the constructions of informal and formal care 'underestimates the extent to which the private and public avenues of 'care' interrelate and are interdependent' (Ungerson 1990: 10). Ungerson highlights the necessity for future research to create a 'language of care' which transcends public and private spheres and which does not maintain a divide between our conceptions of informal and formal care (Ungerson 1990). The relationships explored so far have begun to transcend this theoretical divide in small and different ways, however what is evident in most cases is the importance of the relationship. The emotional labour (Hochschild 1983) of a personal assistant in combination with the transcendence of the informal / formal care divide can place the personal assistant in a, at times, conflicted position, reminiscent of emotion dissonance (Hochschild 1983).

Debbie and Daniela's relationship began in a similar way to Brenda's although the significant difference for the quality of Daniela's life is that her relationship is no longer judged and restricted through council guidance. Debbie and Daniela have known each other for years. Their relationship began formally, when Debbie worked for a private care agency. Since then she was invited to work as Daniela's personal assistant as they stayed in touch in-between working for the agency and being directly employed by Daniela as her personal assistant. Debbie describes the 'work' she does beyond her remit and minimal hours as Daniela's personal assistant:

Katie: So you do a lot of work you are not paid for?

Debbie: Not as much, I don't do as much as I used to, I used to come in early every weekend, when X Factor was on, she would be lonely on a weekend, she would come and watch X Factor with my daughter and my partner, we'd have a Chinese and she would stay over and I would bring her back on Sunday ...[...]... but only while that was on and what I try to do is get as much done within the

hour in a morning and then bank it up, but it depends what time I've got, if I had more free time I would do more with her, but I just don't have the time. I do little things outside, but not a lot.

Debbie's work with Daniela is very much entwined in Debbie's family life, watching X-Factor and notably if Debbie cannot come Debbie's mother will come in her place. This type of relationship is one which is alluded to in discussions of the 'informality' or quasi informal relations of a personal assistant's work (Flynn 2005; Leadbeater et al 2008; Manthorpe & Hindes 2010).

These types of relationships have been described before in relation to community home-helpers in the *Kent Community Care Project* where home helps were interviewed about their relationships with the older people whom they supported (Qureshi 1990). The women and a few men involved with the study were excluded from the labour market for a variety of reasons and had no previous care experience or knowledge about their clients. At their first interview they were asked about their work. Many said that they saw their employment contract as adequately representing the entirety of their workload. However, by the second set of interviews the helpers had adjusted their views believing that their contract failed to represent the large amount of work they did. Although a few of the helpers referred to their clients as 'friends', this was rare, many saying that they had become 'attached' to their clients. Qureshi argued that this attachment did not reflect true friendship and their relationship, in spite of some more informal elements, could not be described as a significant movement away from their formal work status.

However, Qureshi (1990) identified several ways in which the relationships changed over the time period of the study. The helpers quickly began working outside their job descriptions: some were reluctant to lose the clients to whom they had become attached. This was due to the extent of personal responsibility many of the helpers felt towards their

clients, which led to a degree of informal contact where the families of the helpers became involved in their client's lives through, for example, invitations to dinner. The close relationships which many of the helpers developed, did not happen in every case, and those that did were positioned in 'no-man's land' and began to question if they were right to receive financial re-numeration for the work they did (Qureshi 1990: 75). Qureshi concludes that:

...informal, or quasi-informal, relationships can be generated from a formal basis, although such helpers have no wish to take on all the responsibilities of informal care, indeed the understanding that they will not have to do so underlies their commitment to continuing helping activity.

(Qureshi 1990: 77).

Therefore, Qureshi's analysis questions the conceptual divide between the nature of informal and formal care evident in much of the earlier research. Ungerson concludes from the findings in Qureshi's study that:

...schemes like the Kent Community Care scheme pose a false dichotomy between the 'formal' and the 'informal' spheres of care by assuming that the nature of the relationships that prevail in each of these spheres is totally different...in one...loving relationships prevail...and in the other monetary [and] contractual relationships prevail and love and spontaneity are absent.

(Ungerson 1990: 24).

It is these works of Qureshi (1990) and Ungerson (1990), and the blurring of the boundaries between 'informal' and 'formal' care, which is crucial in the course of this project paving the way for more inclusive conceptualisations of 'care', querying the informal and formal care theoretical divide, but also to add complexity to the use of 'support' work.

Returning to Debbie and Daniela, they have known each other for several

years and have spaces for each other in their lives. Here Daniela and Diana (Daniela's care manager) describe Debbie's work very informally:

Diana: Yes well I suppose from a care management point of view you can put on your care plan support Daniela to do this that and the other, but you cant think of everything, cos your care plan would be a couple of miles long.

Daniela: We even go out for lunch now and again, she takes me everywhere she can think of.

Diana: Including her own house for Christmas dinner.

Daniela: Yes Christmas dinner and the sister's birthday party.

Diana: It's almost like a residential service non residentially there is just about everything there would be in a residential service but it's from somebody who doesn't actually live with you .

....

Diana: Debbie helped with removing the bath and installing a shower and then redecorating it all, Debbie did all that as well, there's all that contacting plumbers and electricians and all that ...[...]... I suppose we are just so lucky that Debbie is such a nice person.

Debbie also speaks of her role very fluidly:

Debbie: She has asked me to go to the doctors with her today and I'll go, I wont get paid for it, but I will go with her cos she doesn't like going on her own and there is nowhere in the care plan to cover currently medical appointments, interviews, reviews, one time I put in and 12 hours I had lost cos I went to the psychiatrist with her, we had a couple of reviews because of the behaviour, 12 hours and I didn't get paid for it.

Katie: Do you do that in your own time?

Debbie: Yes, not as much as I used to, I mean I'm about to decorate her bedroom for her, which is going to be a big

job, I did the bathroom for her. If I'm going anywhere, TK Maxx or [the shopping centre], occasionally I will ring her. I'd like to spend more time with her, but I've got a young daughter and I've got my own business. I think we are going to go away with her again, last Christmas we went to Paris for 5 days, me my mum, my daughter and Daniela, had a fabulous time and I really shopped around so it didn't cost much money and then she has been nagging again so I've just last week been looking to go to Lille in France cos it's Eurostar...[...]...I think it's fair enough if she pays for travel, but not for attendance ...[...]... I don't know if that's good or bad, it works, it's working.

The difference here is whilst Brenda's 'care workers' and those in the Kent Community Care Project were encouraged or expected to work within local authority boundaries or agency expectations, here the "residential style" support has become vital and expected fitting neatly within what Wærness (1984) has described as 'spontaneous care-giving activity', expected activity and problematically state endorsed:

Diana: ... like Debbie's bought this 3 piece suite for Daniela because you weren't happy with the settee and chair that you had before and it's just somebody again with that overview saying well wouldn't it be nice to do this and having the commitment to go to ...[...]... and choose and wait for it to be delivered and make sure the money is alright and all that and it's just having someone who is willing to take that overall responsibility ...[...]... inherent in that flexibility and responsibility oversight and all the rest of it ...[...]... if you got someone who wasn't nice equally they could have just as much power to do bad things ...[...]... we are so lucky we have got a good and committed person.

'Flexible', 'responsible', 'nice' and 'lucky' are all words used by Diana and Daniela to describe Debbie and the support she offers to Daniela. Daniela is offered a level of support not generally recognisable outside of residential settings and represents a merging of the informal support

Debbie offered Daniela prior to becoming her personal assistant. The commodification of care and the development of direct payments more generally is situated (as discussed in the previous chapter) in relation to consumer driven support offering choice and control through the direct cash payment for a service, be that in the form of a personal assistant or another form of support. The relationships as discussed above illustrate the slippery or blurred boundaries (Manthorpe & Hinde 2010) between formal and more in-formalised aspects to the work.

These in-formalised aspects of the personal assistant role create the impression of a one way flow of in-formality, encouraged by the employer and either accepted and offered by the personal assistant or carefully negotiated through a combination of emotional labour and social skills of the personal assistant. However, the dynamics of the relationships, where in-formalised relationships have begun to form, offer spaces of reciprocity and it is through these spaces that the dynamics of commodification, largely assumed to be the 'value' of personal assistants are subtly challenged by both employers and their personal assistants.

### *Negotiated boundaries*

The earlier discussion of 'care' attempted to offer a multi directional perspective on the relationships that can form in 'support' relations, be they informal or formal in nature. The nature of 'friendship' is disputed and it is not for this project to judge the extent to which these relationships constitute 'friendship', however the blurring of the relationship from a purely economic exchange or commodified relationship (Ungerson 1997b) to something more akin to a personal connection is important. The breaking down of the commodified parts of personal assistance relationships through in-formalised aspects of the relationship creates possibilities for their 'value' to lie in the visibility of

the personal assistant as well as the tasks they undertake. It is here that the assumption that the empowerment effect of direct payments is the financial power to hire, fire and direct is subtly altered and subverted by the development of relationships. These relationships, characterised in this chapter by their 'friendliness' and the blurring of the formality and informality, rest on the management of the relationships involved. The importance of the possibility of having good relations with your personal assistant has been repeatedly emphasised (Cancian 1999; Stone 1999; Williams et al 2008), as have ways of managing those relationships (Gramlich et al 2002). The in-formalising of personal assistant relationships has been discussed in relation to Daniela and Debbie and their friendship as well as working relationship implies that is a one-way offering, that it is the personal assistant who, by offering more than they are employed to offer shifts the boundaries beyond the 'commissioned' support. This section draws upon these blurry relationships to explore the ways in which these essentially commodified relationships are negotiated through a discomfort on both sides of a relationship that starts and finishes with a contractual financial arrangement. These shifts have occurred in different ways, by different people, in different situations for different reasons. The following sections explore the ways in which the blurry boundaries are transgressed by different people, specifically in terms of; creating opportunities for exchange and redefining 'work' in 'but we don't feel like we're at work' and more direct exchange and (de)commodifying of the relationship through 'payment in kind'.

*"[B]ut we don't feel like we are at work"*

The characterisations of the different personal assistant relationships above have all involved the negotiating of the valued *personal* side of personal assistant work. Several of the employers talked about the affirming nature of their relationship with their personal assistant. When

talking about good relations with her personal assistants Camille said:

I think it's very important that you do, I mean I've kept in touch with one of them from last year, she was an OT and she has been back to see me, I think it's really important because I get quite emotional when they leave and one of them, after today she has only got 2 shifts left, you build up a relationship, the average of my PAs is staying about 2 years ...[...]... and because I'm so open ...[...]... we chat about all sorts and they'll say oh this has happened to me today ... I mean yesterday I had one of them text me 'do you know where the Abbey National is?' and like that's fine ...[...]... one of them came home the other day she said oh I just couldn't wait to tell you I've got some news she said 'I bought you a present back from Paris for your fridge she said I just want to tell you this ...[...]... she got engaged whilst she was there so I'm so pleased.

Camille talks about the close relationships that can develop and the time her personal assistant's asking her for advice about the location of the Abbey National Bank and spending time with her and her family. In a similar vein Ali describes what he particularly likes about employing his own personal assistants:

I think when, the best bits for me is when they say they enjoy what they do ...[...]... if we are going out people say 'oh are you his 'carer'' I mean I'd rather them say 'are you supporting Ali' ...[...]...so it's a bit sort of I say 'no they don't care for me they support me in the things I want to do' ...[...]... a lot of people, I think it's a real old fashioned word that people still use today, but no it's when the personal assistants say I really enjoyed that what we did today, I'm really glad you chose to do that and that really makes me really happy because I've done something for me, cos I've also involved them as well.

Here Ali not only delineates between 'care' and 'support', but also



indicates the duality of the experience of employing and doing things with his personal assistants. Some things, or leisure activities, are inherently more enjoyable when it is mutual rather than individual or alone. These two different examples illustrate the importance of reciprocity. Research into reciprocity is often all encompassing and refers to relationships that are not formed in a commercial exchange. The term reciprocity has been suggested to:

...rel[y] on a contractual form of agreement in which each party is expected to contribute to the relationship in measurably and definably equal ways. As Masschelein and Simons (2002, p. 597) explained, this is a model that demands that relationships be seen as:

calculable and calculating relations, as relations in which a transparent and reciprocal communication is central. Social relations understood in this way rest ideally on a contract or agreement and on negotiation between equal, autonomous and entrepreneurial subjects. (emphasis added)

(Fisher 2007: 292)

This definition seeks to define reciprocity in its broadest and political sense. Other work has explored reciprocity in terms of 'dependency work' (Kittay 1999), in informal 'care-giving' relationships (Fine & Glendinning 2005), in co-production work (Boyle et al 2006), research ethics (Oliver 1992; Barnes & Mercer 1997), within New Labour's conception of social justice (Ellison & Ellison 2006) including the developing conditionality of welfare (Whiteford 2010), and work involving time banking as a community development strategy (Seyfang 2004). Where work has been done in terms of formal support Beresford et al (2008) explored service users' experience of social workers in palliative care settings. Social workers were found to be valued when they offered 'informal' support and gave something of themselves, this giving was described by some as a 'friendship'. This raised questions of the professional nature of social work, the social work role, however also informs questions of the relationship and roles of personal assistants.

Personal assistants do not have any 'professional' role or code of practice through which to work.

When speaking about their work, it was the very personal nature of the work that attracted and kept personal assistants in their jobs, as Cathy says when she reflects on her work:

I have really enjoyed getting to know Camille, it's the most personal job that I have ever had, you can really get to know somebody, understand their ups, their downs, understand how she ticks as well, that's been really really good ...[...]... it's really nice that you have that consistency, in a lot of care jobs and support jobs you will be with different people everyday, every week, but that's fantastic about this job. I enjoy the variability of it, so when we do go out for day trips it's something different for me as much as it is for Camille, those days are really great. It's brilliant that she can live independently with support, it's really rewarding that she can and it does her mental health as well as physical health so much good, being able to do that is so important to her ...[...]... I think it's great that she enjoys the fact that we're of a similar age so I've got similar interests to Camille I can understand where she is coming from, music tastes, tv tastes and all sorts of things. I think she enjoys having PAs of a similar age too because she doesn't feel when we are out it looks as though she is with a carer perhaps, people might think she is with a friend, sister or whatever, there's not that distinction.

Cathy refers to the personal aspects of the work, but also the intention of the support Camille's personal assistants can offer. Gemma has found the time and self-management of work time (with regards to what their employer wishes to do) enables them to work in an effective way, which offers its own rewards:

Oh it's just so rewarding and you go swimming with them and take her to the pictures and you can just tell that she has really enjoyed

herself, like on Saturday she had such a good day and she was like thank-you and for someone to say thank-you just for taking them shopping it's just so nice and when things are going good it's quite a relaxed atmosphere like you can just go swimming, there's no rush, there's no, we don't have any time constraints cos she just pays me for whatever I do and because it's on a one to one basis I'm not distracted, I can give her my full attention whatever she wants within reason we do, so it's just yeah it's really good.

Both Gemma and Cathy express a satisfaction from their work, a satisfaction that comes from really getting to know their employer. It is the personal connection that appears to offer the opportunity of positive work experience. As in Ali's situation Dawson (2000: 55) found that employers were happy that they were able to directly add to their personal assistant's 'welfare and income...[...]...in exchange for their support in domiciliary tasks. One was not dependent on the other but rather there was an interdependence'. Opportunities for the relationship to have elements of mutuality and reciprocity further questions what has been assumed to be a 'one way flow' in 'care' relationships (Kröger 2009). Although this has often been thought in relation to informal care and in reaction to the 'burden' analysis of informal caring relationships (Tronto 1993) this also holds weight within more formalised 'support' relationships potentially calling into question the instrumental and practical conceptions of support work.

In a similar vein Freya talks about how she supports Freddie with his food trade business:

This is very much Freddie saying this is what I do, Freddie would rather that it's Freddie and Freya to give him that security, but it's Freddie's food trade business and I have PAs to help me to do that ...[...]... sometimes I feel like the role is shared, or may be it would be more authentic to say that it is that but then no, no, we are not doing it like a business ...[...]... if I say to him, you're the boss

Freddie, you tell me what you want to do or what you would like me [to do] and he finds that quite tricky still, scary and sometimes he wants to put my name on the form, emails and stuff because we do you know raising awareness through e-mails, but now we have substituted my name for [food] trader and that's sort of gets a bit of balance it's still shared a bit within the [food] trader title.

Freya talks about herself and Freddie negotiating their roles. Is the business run by Freddie with the support of Freya or is it something that Freddie and Freya could do together like the good day out described by Ali. The values of *Valuing People* and the personalisation agenda although not specifically defined encourage a certain notion of independence; that it should be exactly what Ali wants to do – even though it is more enjoyable when it is shared and it should be Freddie's business even though he (as many would) prefers the idea that it is a shared enterprise. Does having both names on an e-mail symbolically shift the power in the relationship?

These support relationships are necessarily complex and these small acts become symbolic of the wider discourses of empowerment. In this context of slippery boundaries between worker and 'friend' and negotiating responsibilities *to* and responsibilities *for* the employer, the commodification (Ungerson 1997b) of the support relationship is gradually being (de)commodified through the development of relationships and personal assistant understandings of their role, as illustrated by Camille when she talks about her responsibilities to her personal assistants when eating out:

I have quite an issue with this especially if we go out for a drink or something or a meal your PA says 'no I'll pay', but you've got to say, no you are at work so I've known people sit there with a glass of water 'you're not paying for a cup of tea for me ...[...]... "that's not right we're out" yep but what you've got to remember is you're at work "yes but we don't feel like we are at work", "yes but you

are enabling me to do something that I'm not use to being able to do".

Here Camille talks about re-drawing the boundaries which the personal assistants are challenging through their refusal to let Camille be the 'boss' or the 'manager' and take the responsibility to pay for her personal assistants whilst they are eating out. Here the personal assistant's refusal to 'normalise' the relationship stating that "it doesn't feel like work", implying a more social and personal relationship, whilst equally exposing the uneven relationship through not taking a cup of tea with their employer and choosing a free glass of water. Here it is the personal assistants, rather than Camille, as employer, who are renegotiating the commodification of the support they offer. This was raised by several personal assistants who expressed concern about taking advantage of their employers. Bev, Benji's personal assistant, when talking about Benji buying her lunch in particular, said:

I haven't [accepted lunch] yet, I might do, other PAs don't have a problem with it, I just I don't want him to ever feel that I am taking advantage of him so I'd just rather pay for my own ...[...]... I have so far, there was one day when he bought me a cup of tea and a doughnut and the next week I paid him back for it ...[...]... I just felt bad about it ...[...]... you know he is already paying for me to work for him, you know what I mean, I don't see why he should be, like if I am there over dinner time he will ask me to stay for dinner and things like that I don't mind because I am cooking a big meal anyway so just cook for the two of us, it's not a big expense on his part, but if we are out and about buying lunch and things like that it's just a bit too much to ask.

It begins (or becomes) a commodified relationship, however with Cathy and Bev they do not want it to feel, or become exposed as a commercial relationship. Drinking water whilst out with their employers exposes the roles of employer and employee. The personal assistants describe their

employers paying for food whilst out as potentially “taking advantage”. This could be an expression of their vulnerability, or respect for their employer whilst Bev describes a process of paying in rounds as a part of a mutual and reciprocal exchange. Perhaps inadvertently the personal assistants are subtly challenging the roles of employer / employee and the roles and responsibilities of each and it is at this point that formal ‘work’ and informal ‘company’ become exposed.

Eating and drinking out acts as a point where the relationship is exposed as one of employment and commodification that appears to place personal assistants (and employers when personal assistants resist) in an awkward position placed between their rights as employees and their relationship with their employer. The personal relationships discussed throughout this and the previous chapter effectively work to re-position the working relationship, although they remain primarily a commodified relationship with elements of in-formality.

### *Paying in kind*

Different people at different times have looked to subvert the purely contractual, commodified relationship within direct payments. Employers have become friends with their personal assistants, or recruited friends to work with them, care managers have applauded personal assistants who “take overall responsibility” and criticised personal assistants who do not use their “common sense” and personal assistants have become friends with their employer and created and challenged boundaries. It is through events such as these that the assumed empowerment effect of direct payments – as an effect of the transfer of funding – begins to weaken. Both employers and personal assistants in different ways reject the contractual relationship which sits uncomfortably with some. When first hearing about direct payments and becoming an employer, Faith said “...what has

this got to do with me and what's this got to do with Freddie and it was only later on that the penny dropped really..." and another family supporter, Emily said "...it's a sad state of affairs when you have got to employ someone yourself to work with your son". Their initial ambivalence at needing to become employers and their dissatisfaction that led them and their son to take direct payments and directly employ their own support has also led to Emily considering different ways in which this situation (which was not desirable in her terms) can be made more comfortable. Emily says:

Emily: I felt confident in dealing with them if we are paying them which in a way if we are doing by I don't know software for the computer if it's a student or something in kind or paying for driving lessons in kind it actually changes that slightly because that is more of a friendship, you are encouraging more of a friendship than an actual person to come in as a support worker so then the boundaries are more blurred and I think that that needs to be handled a bit more sensitively but I would rather that in a way I think

Katie: Have you ever paid people in kind?

Emily: No we haven't as yet but we are planning to I have suggested it to a person.

Katie: How do they respond?

Emily: They are quite keen on the idea, saying quite keen, a bit taken aback ...[...]... the guy who has just recently left, cos he was learning to drive...[...]... and he said "oh that would be great" because it would pay for his driving lessons ...[...]... it will be interesting to see because ...[...]... again it depends upon the person ...[...]... that comes on board that is why it is so complicated it is so difficult to know what to do ...[...]... do you go down the traditional line of employing someone, that's his PA this is what we expect you to do and that's what they are and they come and they go or we are trying to build up a relationship with the employee.

Here Emily is explicitly attempting to subvert the very 'thing' that was assumed to make direct payments and direct employment of personal assistants work and act as a lever of empowerment. This exchange or "in kind" payment offers the possibility of the breaking down of the commodified relationship using it as a way of effectively (de)commodifying the support relationship in an attempt to somehow informalise what is essentially a commodified relationship. The implications of the (de)commodifying of the relationship are many and various, but rest upon a perceived problematic starting point – that of a commercial relationship - that has expectations of the personal and in some cases the reconnecting of 'caring' for and 'caring' about.

### *Commodification and (de)commodification of support*

Brenda's denied friendships with her home care workers, some of whom she had known for 15 years, stands in stark contrast with the employment relationships highlighted in this chapter. Where important critiques of the paternalism of 'care' and analysis of independence has sought to separate the 'feeling' and the 'doing', in order to in turn re-negotiate the social relations of 'support', the experiences of these employers appear to represent a continual negotiation of relationships.

Disability researchers have, for many reasons, chosen to 'brush aside' the literature on care (Kröger 2009), and this chapter was explicitly located within the conflicting discourses of 'care' from feminist and disability researchers in an attempt to explore the realities of the relationships that can occur within a direct employment relationship. This was also a conscious effort to distinguish between disabled people who employ personal assistants and people with learning difficulties who employ their own personal assistants. Theoretical discussions about redistribution and transfer of power may have relevance to anyone who uses social care



support or employs their own personal assistants, however it is important to acknowledge the differences between different people's support needs in order to expose the difficulties (Flynn 2005) and work to resolve them rather than brush them aside.

The debates around 'care' can point to the idea of dependency (Morris 1993a) and in opposition independence. The director of the British Council of Disabled People argued:

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

(Wood in Shakespeare 2000: 63)

It is specifically because of this critique that the concept of 'care' is useful to enable a critical exploration of 'support', which in turn creates opportunities to respond to the critique of 'care' whilst not removing the *personal* in personal assisting work. One personal assistant clarifies the *personal* in personal assisting and the blending of Davis' (1990) 'temporal consciousness' at work:

I think as well there is that aspect of that people are, my partner would say you're over committed and that's the danger, you don't close a file or turn computer off you know it's a real live person all of that time and even if it's once a week you know it's like he is huge in your life really so I think that's another potential danger because then you can become very ...[...]... lose your objectivity...

What personal assistants do and how they 'feel' about their role allows and encourages the blending of work life and personal life. The emphasis upon independence and control as a vital foundation of support or assistance can create tensions between the expectations and working

experience of personal assistants. However, independence, be it physical or emotional, has been suggested to be a fiction (Kittay 2002: 268) with others including Shakespeare (2006) reflecting that dependency is inextricable from human existence. The employers, supporters and personal assistants emphasised the importance of reciprocity in the support relationships. Employers talked about good days as those where the personal assistant had said that they had enjoyed the day out and when personal assistants were reflecting on their role it was the personal contact and the process of getting to know their employer that they highlighted as the qualities of their work.

Personal assistant work almost begins with the in-formal. Current personal assistants in all but one of the employers interviewed were invited to interview for their job after meeting previously. Government literature proposes the importance of a skilled workforce and the GSCC through the Codes of Practice have sought to formalise and define the responsibilities of the roles of care workers. What is valued within the personal assistant role becomes important. The people in this project suggest that what is valued is the personal compatibility, and in some cases the potential development of a 'friendship', rather than practical skills. It appears that personal relations between people who need personal assistance and those offering their assistance enable the very quality of the relationship which is able to offer the space for personal autonomy which Fisher (2007) suggests is found in relationships of interdependence.

What is interesting is how the financial independence and 'empowerment' of directly employing personal assistants gives way to different attempts to seek, in some ways, to mould that power so that the relationships become less about being the 'boss' and being the 'employee' towards a more collective shared life experience. Personalised funding elevates the individual, yet the employers and personal assistants in this project have sought to (within reason) reconnect

that individualism to the social. Some expressed a frustration about being the “boss” and not being recognised as such and others sought a more even relationship. Freddie and Freya are working together at a business. The rhetoric of *Valuing People* may suggest that it is Freddie’s business and the personal assistant would play a facilitative role to support him to achieve his ambition. Rather we see Freddie desiring a more combined approach – signing Freddie and Freya at the end of e-mails – which is an approach that does not feel legitimate to Freya who has compromised with “food trader” maintaining that it is “still shared a bit”. But the creation of the ‘more even’ relationship itself raises tensions. For Freddie working together on the business is unproblematic, however for Freya, whose role has been designed with the intention of placing Freddie in control, getting too involved may constitute a shifting of the power or control away from Freddie, in spite of the shift being initiated by Freddie himself.

Sharing, friendship, elements of reciprocity and the personal elements of employing and working as a personal assistant have become evident as valued aspects of the relationships between the employers and personal assistants in this project. Personal assistance at its inception was a rejection of the personal – or dependency evoking language of ‘care’ – and a heightening of the ‘empowerment’ being the employer, the boss and having control over support. Care may have been theoretically rejected by some, however it remains apparent in the development of assistance relationships. Debbie taking “overall responsibility”, working beyond the contractual relationship and integrating Daniela into her personal life shifts the contractual relationship. Freddie doing business with his personal assistant and personal assistants and employers alike negotiating boundaries and roles through small acts such as paying for drinks and Emily suggesting payment “in kind” all suggest that the ‘empowerment’ or comfortable and successful relationships are not based on sharp delineations between ‘employer’ / ‘employee’, rather they perhaps depend upon that being the absolute dichotomy when difficulties

occur. Employers (and some supporters) appear to feel uncomfortable about creating mini support agencies in their homes and seek ways of (de)commodifying or at least in-formalising the assistance relationship. The idea of empowerment lies in the assumptions of the market – that the value is a financial one, converted into self-directed hours of ‘work’ - but what direct payments and the personal assistance relationships appear to be valued for is the relationship. These relationships appear to place support or ‘care’ as an awkward commodity to be manipulated away from its contractual root to something more social, reciprocal and informal which in turn increases its value.

## Part III: Discussions and conclusion

### Chapter 8

#### Personal & Social Lives

This project has sought to further explore the new relationships that are formed through the direct employment of personal assistants by employers who have learning difficulties. Research in to this area is relatively sparse and has primarily focused on employers and their families' experiences, rather than those of the personal assistants. This project hoped to explore these relationships from both the perspective of the employer and the personal assistant premised upon the assumption that the quality of support is integral to even partial progress towards the aspirations of *Valuing People*: Independence, choice, rights and inclusion. On the basis of these values and the development of new social relations of support the research interests were:

- To explore our understandings of 'independence', 'choice', 'control' in the context of the discourses of empowerment at play in the personalisation agenda in relation to people who have learning difficulties who are employers.
- To consider the power of the ideology of 'caring' or support and the rhetoric of 'independence' and 'choice' in personal assistants' ability to make sense of their role and their ability to work within these values.
- To begin to reflect upon the implications of cash payments upon both the employer and the personal assistant.
- To consider if and in what ways direct employment using cash payments for people with learning difficulties place either the employer and/or the personal assistant in a vulnerable position.

These new social relations of support have been positioned within the current realignment of our relations with the state. Scourfield (2006: 25) argued, in relation to New Labour's modernisation agenda, that:

The power of modernization discourses lies in their capacity to construct critics not only as resistant to change but, more damagingly, as failing to having understood the need to change in the first place. The potential critic is therefore represented as not only 'anti-modern', but also 'pre-modern', a naïf in the modern world who cannot be taken seriously, someone who is not 'smart' enough for the changed times we live in.

Personalisation, like the earlier modernisation agenda is posited as something that is unquestionable, unchallengeable and unproblematic. Therefore this is the context in which the employers and the personal assistants are pursuing their 'reflexive projects' (Giddens 1994) as rational, canny, citizen-consumers (Clarke et al 2007) and emerging entrepreneurs (Scourfield 2007). As such this is the context in which this project has sought to explore the relationships and tensions within the personalisation agenda with specific interest in the tool of direct payments and the direct employment of personal assistance.

This was a small scale and explorative project, in one locality and as such does not claim to offer any wholly representative conclusions or generalisations about the experience of employing or working as a personal assistant in other areas. However, some of these people's experiences echo earlier work in this area. These echoes of previous research and new insights offered by the participants in this project were explored through a focus upon what personal assistants *do*, in chapter 5, *Roles*, the *Responsibilities* of all involved in chapter 6 and the emergent *Relationships* in chapter 7. Running throughout each of these chapters was an exploration of the experience of 'empowerment' and contingencies of that experience of 'empowerment' drawing out the

places and spaces at which tensions within the employment relationships emerged. Collectively these chapters aimed to draw attention to the diversity of experience inevitable and valuable, but equally potentially problematic, within the development of self-directed support.

Chapter 5, *Roles*, specifically sought to explore the types of 'work' and activity which may exist within the personal assistant role. Drawing upon ideas of 'doing', 'enabling' and 'supporting', this chapter explored the various elements of support and personal assistance work which have been considered by other researchers as 'diffuse' (Reynolds & Walmsley 1998), 'unorganised and particular' (Ungerson 1999) and in some disability research, purely practical, where the personal assistance role has been characterised as functional and reminiscent of a tool 'taking place of my hands' (Meyer et al 2007). In light of the experiences of the employers and personal assistants interviewed for this project, personal assistants' roles were characterised by their *practical* and *personal* nature, but critically the role was positioned within broader discourses of citizenship and agency as well as personalised, individualised self-directed support. It was argued that it is at these points, where the personal assistant role is both *personal* and *practical*, that preconceptions about *how* support *should* be used, that the personal assistant becomes a 'technology of citizenship' and the experience of empowerment within the relationship becomes contingent on the resilience (Goodley 2005) and resistance of the employer. This chapter sought to expose the tensions and challenges of personal assistant work within discourses of power which seek to shape behaviours, but which are simultaneously situated within discourses of choice, control and self-directed support.

Chapter 6 began to explore the responsibilities involved in this individualised organisation of assistance and focused upon aspects of informality in personal assistance work. This emerging informality was considered to be one of the contingencies of the empowering possibilities of direct employment of personal assistants within the context of

responsibilisation (Clarke et al 2007), the individualising of risk (Jordan 2001; Ferguson 2007; Scourfield 2007) and the analysis of dependency embedded within the personalisation agenda (Leadbeater et al 2008; Leadbeater 2004). This chapter sought to expose where direct payments, as a lever of empowerment fail and attempted to draw out the inequalities at play and unchallenged within personalisation discourses. Employers, their supporters and personal assistants spoke of feeling unsupported and access to more intense levels of support (beyond payroll and the legalities of employment) depended upon the relationship the employer had with their personal assistants, involvement in self-advocacy groups, a circle of support or the strength of their supporters. These disparities in experience fitted neatly with Fyson's (2009: 20) concerns that 'self-directed support and individual budgets appear designed to maximise inequality of outcome' which impact not only upon the employer but also has implications for personal assistants. Where the relationship has been in-formalised, this research in parallel with previous studies (Flynn 2005; Leece 2006; Leadbeater et al 2008) suggests that the work of a personal assistant may be more personally satisfying. However this relationship can, as Glendinning et al (2000) suggested, create 'boundless obligations' for these personal assistants. Critically this chapter argues that through a particular analysis of dependency and traditional welfare provision that these in-formalised or 'quasi-informal' (Flynn 2005) employment relationships may create opportunities for the creation of community support networks and types of self-reliance – as imagined in *Think Local, Act Personal* (PPPC 2011) – but equally these relationships also create opportunities for new and less secure dependencies to be created. These new and unstable dependencies are articulated through the placing of personal assistants in a relationship of tension being simultaneously responsible *to* - in line with the alteration of the social relations of support - but remain in some specific ways responsible *for* their employers through high expectations, blurry roles and boundaries and the in-formal connotations of personal assistant work. Furthermore, this chapter argued that to ignore the responsibilities *for*, through a downplaying of risks



(Glasby & Littlechild 2009), ignores the realities of working as a personal assistant with limited formal support in their role.

A concern with the personal remained in chapter 7, through further exploration of the personal assistant as a 'technology of citizenship', but also cast doubt upon the assumption that it is the practical element of the personal assistant role that is of value. Employers in this project, in line with findings from other research projects (Flynn 2005), sought personal assistants with whom they could relate on a basis of age, interests and character. Situated within an analysis of the commodification of 'care' (Ungerson 1997b), through the theoretical framework of feminist work on 'care', and disability studies rejection of 'care' as maintenance of dependency and control (Morris 1993a), this chapter suggested that the *practical* aspect of the personal assistant role and 'empowerment' through control of resources, fails to adequately reflect the feelings and actions of employers and their supporters in this project. The value of the commodified support relationship and direct hiring and firing of support appears in principle and theory to be the fulfilment of a process of tasks which enable (at times in specific ways) people with learning difficulties to live in the community and participate in the life of their communities. However, the relations between employers and personal assistants in this project shifted towards the *personal*. The *personal* and 'non-professional' nature of the work, in combination with often minimal support has lent commentators to emphasise the in-formality of the work (Leadbeater 2008; Flynn 2005). It is this in-formality that enables employers and personal assistants to shift between what is a contractual relationship and something more in-formal where boundaries are blurred through occasionally small actions - such as refusing to accept an employer paying for a drink when going out with their employer - and more systematic in-formal working - leading to consistent working above and beyond what is commissioned - representing what Wærness (1984) has defined as a subsuming of spontaneous extra work in to expected activity. This subsuming of formal (paid) work and informal (extra unpaid) work

was not evident in all situations, but for Daniela, Debbie and Diana, what Flynn's (2005) study described as 'going the extra mile' became an expected and depended upon and state endorsed aspect of Debbie's work. These processes contributed towards, what was argued to be a shift from the value of employing a personal assistant as a commodity towards a (de)commodification of the relationship and the positioning of the 'commodification' of 'care' and 'support' or assistance as an awkward commodity which does not sit comfortably with many employers. Emily and Ed exposed the awkwardness attached to the direct employment relationship questioning the intention of support and exploring payment "in kind" to alter the social relations of support. These very particular social relations of support which were reshaped with the intention of acting as a lever of 'empowerment', have been re-positioned and 'empowerment' renegotiated around more in-formalised relationships with opportunities for reciprocity in a movement away from the assumed power of contractual relationships.

These new relationships, opportunities and dependencies outlined above situate the experiences of these employers, personal assistants and supporters within the context of the body of work into these new support relations. There is a significant level of harmony between these people and work done about others who directly employ their own support and work as personal assistants. These are useful insights however this is a small project and does not presume to offer any generalisable outcomes, nevertheless it is the very variability of experience within one area and within a small group of 'active citizens', that is of interest; the contingencies which impact upon direct payments acting as a lever of 'empowerment'. Three broad themes emerged which connect the findings above and offer some analysis of the implications of these new relationships for both the employer and personal assistant, these are; Taking responsibility, Social relations of support and Working together.

## *Taking responsibility*

Personalising support has been pivotal to enabling people who were 'service users' to become the employers and managers of their own support. The personalising of support has so far often meant (although does not necessarily mean) the movement from collective provision to individualised 1:1 support. This process can be seen through (much needed) changes in social care support provision but also represents a broader shift in our relations with the state. Peters (2001: 59) observed this individualising shift:

The state has only been able to begin the process of writing itself out of its traditional responsibilities concerning the welfare state through twin strategies of a greater individualisation of society and the responsabilisation of individuals and families.

The process of individualising support and responsabilising individuals has had a knock on effect and begun the process of individualising risks (Jordan 2001; Ferguson 2007; Scourfield 2007). These risks, which in a social care context were defined by professionals' concerns around risk of harm, now become about managing a micro enterprise comprising of employed personal assistants. Baxter et al (2010) have identified this as the transfer of risk from the state to the employer and importantly the personal assistant. Personalisation at its least politically motivated and neo-liberal offers the prospect of community involvement, if not inclusion. However, the neo-liberal project equally removes possibilities of inclusion through the emphasis upon economically active citizens making active and responsible choices. However, as has often been argued these choices and responsibilities do not exist in a vacuum and are experienced differently by different people. One of the key outcomes emerging from the experiences of these employers and personal assistants

is, in line with other studies (TUC 2008), uneven levels of support. There is provision of some practical support from the Independent Living Service with regard to payroll and legal responsibilities of being an employer, however this neglects to recognise the difficulties of day-to day management of personal assistants. 'Choice' is positioned as obtainable with support:

Choice is one of the four principles on which Valuing People is based – and direct payments are a really good way of letting people choose the services they want. People with learning disabilities have told us that they want to be able to live independently and make their own decisions. Direct payments, managed properly and with appropriate support, will help make this happen

(DH 2004b: iv).

However, the role of the council in the offering of this 'appropriate' support is full of tension. Ivan (the council personalisation officer) highlighted the tentative role of the council in the development of self-directed support. Whilst it is clear that this is his role (and legal duty) to offer people the choice to take a direct payment, the role of the council in supporting that choice appears to be self limiting, as over involvement can be construed as replicating the restrictions of traditional welfare provision. Clearly the council, indirectly through the Independent Living Service and directly through care management plays a direct role in people's experience of direct payments in terms of budget allocation and remaining involved through annual reviews and problem-solving, however 'appropriate' support and opportunities to make active choices and take control, may be jeopardised by the council's aim, encouraged through government policy, to keep at arms length.

Some people, like Freddie, have well developed support structures, which work for Freddie, in terms of clear person-centred working and planning strategies, support meetings and some supervision for the personal

assistants. Others, like Georgia (employer) and Gemma (personal assistant) get little support from care management, but get informal support from the local Speaking Up group and are exploring the possibility of employing a senior personal assistant to take on a supervisory role to create a support structure. This is something that arose in many of the personal assistant's comments and was working well for Freddie. However this has implications over distancing the 'power' and autonomy of the employer by creating levels of seniority and perhaps the danger of recreating old hierarchies in different settings, namely people's homes. Critically these strategies are individually (and unevenly) developed – with limited guidance or advice – and represent either freedom to develop personalised solutions or alternatively attempts to independently (or without support) develop ways to manage what is essentially a small business (Prideaux et al 2009).

These strategies represent ways employers have sought to manage their staff, however the management of personal assistants is rarely straightforward. Many of the employers and personal assistants spoke of their relationship being, at least 'friendly' and at most crossing the line between 'formalised' paid work and more in-formalised relationships – encompassing aspects of unpaid work in their role. For some the development of these informalised arrangements worked well, for instance, for Debbie and Daniela. However, these relationships can also be viewed in a broader context of the analysis of dependency and responsibility clearly articulated in Leadbeater et al's (2008) analysis, as well as more recent government literature focusing upon 'freedom', 'fairness' and 'responsibility' (DH 2010). Daniela has successfully (with support from her care manager) developed support at home and this support has replicated, what Diana (Daniela's care manager) would expect to find within a "residential service". This service is based in part in a contractual arrangement and part in-formalised support beyond job descriptions to become something that may have been offered – what Wærness (1984) would have termed 'spontaneous care' – and now

subsumed into more routine 'care-giving work'. The drive towards 'self-reliance' and personal responsibility lends these relationships, to a greater degree to develop what Qureshi (1990) described as 'quasi-informal' and Flynn (2005: 42) described as 'neither wholly professional nor wholly informal' roles. Where the boundaries between the professional and informal have been blurred (Flynn 2005; Manthorpe & Hindes 2010), personal and work lives have blended (Davies 1990). Not only have researchers suggested that within these relationships the risk of abuse is heightened (Flynn 2005), but equally new forms of dependencies are created which are vulnerable and made fragile through high expectations.

High expectations existed on both sides. Developing relationships with personal assistants appear to lend themselves to more in-formalised working and a valuing of personal assistants who are prepared to "go the extra mile" (Flynn 2005) or take "overall responsibility" (Diana p. 178). There are also high expectations placed upon employers. The creation of small independent micro organisations combined with the assumption that support from the council stifles individual entrepreneurial spirit places those who do not have personal assistants like Debbie, strong families like Freddie or social networks, such as those involved in self advocacy groups, in a less privileged position. Building on the work of Fyson (2009) the experiences of these people would suggest that outcomes of employing your own support are based on individual support networks, peer support and family involvement. Reiterating Joanne (from the Independent Living Service) who said:

I do feel they need more support to be employers. I feel, because we are not deemed to be the employer we can't get involved too much in that side of things. I feel it does need somebody who can do that little bit more for them who's quite neutral still about it, we do get involved probably as well, but not as much as we are not supposed to. Our remit is not to get involved as much.

The complexities of the bureaucracy associated with direct payments may

in reality reflect the most straightforward part of taking a direct payment, one which can be done by an agency such as the Independent Living Service without impacting upon the employers' experience of directing their own support. Empowerment, in this context assumes a wholly individualistic interpretation which can ignore structural factors (Pollack 2010) and the context in which direct payments are taken.

The direct payment in itself is not a panacea for empowerment; rather it is contingent upon ongoing support according to the individual's needs and preferences. Concerns remain where the Independent Living Service is unable (through its local authority commissioned remit) to offer ongoing or time intensive support to employers, to be employers, and has absolutely no responsibility to support personal assistants (even though some personal assistants perceived them as a support agency) for the potential for these social relations of support to work as a lever of empowerment.

Empowerment, control, choice and taking responsibility have been equated in the discourses surrounding direct payments. Lack of appropriate support can be equally equated to dis-empowerment. Previous research has suggested that outcomes in future social care are likely to be based on 'entrepreneurial spirit' (Scourfield 2007), social capital (Fyson 2009), self advocacy (Gramlich et al 2002) or User Led Organisations (Bott 2008) and family support (Ungerson & Yeadle 2007b). Social care provision cannot be based on the goodwill of the worker or the strength of the social capital of the employer (and/or their family). There needs to be a re-appraisal of 'appropriate support' which appreciates the need for ongoing support and recognises the particular support needs of the employer (in the respect of their work involved in managing their personal assistants) and the personal assistants in managing both the *personal* and *practical* elements of their work.

## *Social relations of support: the informal and the professional*

The above discussion primarily focused on the importance of support structures to enable the activity of employing personal assistants to be an empowering experience. This section focuses upon the assumptions and values placed on support, the very support which is designed to enable and facilitate the values of the personalisation agenda. The chapters exploring *Roles, Responsibilities and Relationships* discussed the employer and personal assistant roles and relationships involved in direct employment relationships situated within the rights discourses of the Independent Living Movement (Morris 1993b) and the materialist analysis of the social model of disability (Oliver 1990) and the arguably more individualised normalisation approaches (Yates et al 2008). Central to these analyses have been critiques of traditional services and working practices which served to create dependency and restrict choice and control (Beresford 2001). In an alternative vein the chapters drew upon feminist discussions of 'care', the gendered nature of 'care work' (Graham 1991; Finch 1993) with a focus upon structural inequalities and the low pay and value attached to this form of work (Flynn 2005; Beresford 2008; TUC 2008; Hussein 2010). Any discussion of this form of work and the development of more individualised support needs to contend with these two at times contradictory areas of work. As such Kelly (2011) has argued that to avoid feminist work on care (in spite of its conflict with the aims of disability studies) in the arena of disability studies would only serve to diminish our understandings of the particular relationships that are developed in personal assistance support relationships. Kelly (2011) therefore prefers to think of care as a 'complex tension' thus enabling its use where this might be fruitful rather than discarding it completely.

To consider the role of personal assistant to be purely functional and instrumental for this group of people would be misleading. All the



employers talked about the importance of having good relations with their personal assistants, not only because it makes it easier to work together, but also because personal assistants were often employed on the basis of being an acquaintance, a friend, or at the very least a person with interests in common. Chapter 7, *Relationships* suggested that it is the nature of these 'friendly' relationships that lend themselves to slip and slide and leads to the common sense presumption that they are on some level in-formal (Leadbeater 2004; Flynn 2005; Ivan in this project p. 168) or in-formalised to the extent that talking about the role as 'work' felt awkward to some, as illustrated by Bev (Benji's personal assistant) when she said "oh this is weird because it doesn't feel like work as well it just feels like I'm going to see my friends". Bev's relationship may not be absolutely typical but these slippery boundaries were a common feature of the employment relationships. In many cases these relationships were of importance and critical to enabling a good 'working' relationship, however this very in-formality lends itself to hide the work involved and in consequence leads to the 'work' being misunderstood and devalued.

Where the social relations of care or support have been readily discussed in the development of personal assistance, the activity of personal assistance and support has been hidden (Rivas 2003) as has any significant attention to personal assistant rights. However, recent government attention has turned to personal assistants. *Working for personalised care* (DH 2011) recognises some of the concerns about the unsupported nature of the personal assistant role. The report is tentative, emphasising our lack of understanding of the personal assistant role, however it points to training and networks of personal assistants as support mechanisms to help personal assistants work effectively. Training has been a contentious area in the employment of personal assistants. Previous research studies, in common with participants in this project, have suggested that people prefer to employ people who have little training and experience enabling them to mould their personal assistants (Flynn 2005 & Faith p. 125). Previous training, as illustrated by some of

the personal assistants in this project (Cathy and Gemma) who are training in nursing and occupational therapy, needs to be forgotten when doing personal assistance work as the values of their future professions may not be those of the employer, fitting with Kelly's (2011) suggestion that personal assistants cannot be specialists as personal assistants rather they become experts in the individuals for whom they work.

Attempts to 'professionalise' personal assistant work through training may paradoxically make personal assistants less desirable employees and may not address the more critical issue of ongoing support for personal assistants. The role of personal assistant as a lever of empowerment for employers may require flexible and adaptive personal assistants, which may not be produced through current training processes. At present we have a workforce who may feel disempowered through low pay, potentially poor working conditions, few opportunities for career development, which in turn, it has been suggested, increase the risk of abuse (Carey 2008; Flynn 2005). In light of these concerns the regulation of personal assistants has been tabled in recent government literature (DH 2011). Regulation, although on the table, seems contradictory to the image of the responsible autonomous individual. It seems that to over prescribe, train, support is to undermine the very principles that are at the foundation of the personalisation agenda.

Ways of training, regulating and organising of personal assistants at present sit uncomfortably within the personalisation agenda. Worryingly it appears that the value of personal assistants can lie in their flexible, personal nature and not explicitly, but implicitly their weak labour positions. Nevertheless employers in this project wanted to be responsible and "good" employers who have concern about the wellbeing of their personal assistants, but employment set ups that effectively become 'micro enterprises' struggle to effectively offer the support that personal assistants may need. We need to explore ways of supporting personal assistants.

Kittay (2002) argued that the lives of people with learning difficulties would improve if their workers' lives were improved. The value we as a society place on 'care' work, support work and personal assistance reflects the way we perceive those they support. A disempowered workforce cannot work in empowering ways, yet we have a history of empowered workforces working in disempowering ways. It is this tension and reaction to the past that requires further exploration for the developing and expanding personal assistant workforce.

### *Working together*

*Taking responsibility and Social Relations of Support* attempted to offer some analysis of the situation of the employer and personal assistant respectively. Both groups need, at times to be treated separately, but due to the individualised and intimate nature of the social relations of support they often are not easily separable. Critiques of direct payments have often rested on concerns about inequality, be that for the uneven distribution of social capital to support in the finding and managing of personal assistants (Scourfield 2007; Flynn 2005, or the low pay, unsupported nature of personal assistant work (Ferguson 2007; Oxfam 2009) as discussed above. Direct payments are premised on quite specific analysis of independence, choice and control leading to inclusion through engagement in community in part through assuming socially valued roles of employer, employee, manager (Prideaux et al 2009) and entrepreneur (Scourfield 2007). Independence has been defined as:

Independence is not linked to the physical or intellectual capacity to care for oneself without assistance; independence is created by having assistance when and how one requires it

(Brisenden 1989: 9 in Morris 1993b: 23).

And *Valuing People* (DH 2001: 23) similarly defines independence as:

While people's individual needs will differ, the starting presumption should be one of independence, rather than dependence, with public services providing the support needed to maximise this. Independence in this context does not mean doing everything unaided.

Independence has been constructed, within a social care context, as the support that is needed rather than independence as an expression of doing everything unsupported. Chapter 5, *Roles*, explored the personal assistant role from the perspective of the employer and the personal assistant exposing tensions between the support and approach to support that the employers wanted and the support which the personal assistants and, in certain instances the care manager felt to be important. The development of independent living skills and participation in daily activities created tensions in values and raised questions about how self-directed support interacts with normalisation and the idea of the responsibilised (Peters 2001; Clarke et al 2005) and entrepreneurial citizen (Scourfield 2007).

Drawing on these interactions in combination with the importance of the personal relationship within the commodified nature of the relationship was brought to the forefront in chapter 7. When talking about the best bits about employing personal assistants Ali said: "I think when, the best bits for me is when they say they enjoy what they do" and in a similar vein Freya talked about how she supports Freddie with his food trade business:

This is very much Freddie saying this is what I do, Freddie would rather that its Freddie and Freya to give him that security, but its Freddie's food trade business and I have PAs to help me to do that

...[...]... sometimes I feel like the role is shared, or may be it would be more authentic to say that it is that but then no, no, we are not doing it like a business ...[...]... if I say to him, you're the boss Freddie, you tell me what you want to do or what you would like me [to do] and he finds that quite tricky still, scary and sometimes he wants to put my name on the form, emails and stuff because we do you know raising awareness through e-mails, but now we have substituted my name for [food] trader and that's sort of gets a bit of balance it's still shared a bit within the [food] trade title.

Ali places emphasis on shared enjoyment and Freya talks about herself and Freddie negotiating their roles. Is the business run by Freddie with the support of Freya or is it something that Freddie and Freya could do together like the good day out described by Ali. The values of *Valuing People* and the personalisation agenda, although not specifically defined, encourage a certain notion of independence; that it should be exactly what Ali wants to do – even though it may be more enjoyable when it is shared. Similarly an assumption that it should be Freddie's business even though he prefers the idea that it is a shared enterprise. Freya offers an analysis of Freddie's choice to share the responsibility as based in insecurity, rather a different reading could suggest that the value of the business is its shared nature – or the co-production involved.

The exploration of personal assistance as *practical* and *personal* once more becomes relevant. The individualised discourses of direct payments and the personalisation agenda at once marginalise the social – inferring that appropriate support would be to facilitate Freddie to run his own business – whilst drawing upon the value of co-production. Personal assistants are working through the discourses of 'independence' and the empowered individual – Freddie should want to run his own business on his own (with appropriate support – which assumes certain types of support relationships will emerge). The personal assistant, for employers with learning difficulties in this project, is rarely functional and *practical* rather they are characterised by their visibility and personal contribution

to the lives of their employer.

Understandings and discourses embedded in 'independence', through definitions such as those at the beginning of this section, do not deny and in fact imply some form of interdependency, but are equally unproblematically positioned in opposition to the perceived traditional dependencies which have, in the personalisation agenda, characterised social care users.

Kittay (1999) argued that to ignore or avoid approaching 'dependency' and 'dependency work' would diminish our ability to understand support relationships, rather she would argue, an engagement with 'dependency' re-enables a vision of how the spectrum of care is experienced and worked. Kittay (1999: xiii) drew out dependency in effect to shed light on interdependency and:

Rather than denying our interdependence, my aim is to find a knife sharp enough to cut through the fiction of our independence.

The struggle for independence to be reconstructed as not doing something alone, but with appropriate support, effectively challenged one construction of dependency. Another reconstruction or interpretation of 'independence' is necessary, this study suggests, to once again re-appraise support relationships to allow for what Scourfield (2007) termed an 'honourable dependence' and legitimise support as a collective endeavour which involves working together, rather than, as arguably is imagined in the development of direct payments, impersonal direction of personal assistance to perform practical tasks.

## *Suggestions for practice*

Managing personal assistants, with limited support, the tensions inherent in creating a workforce which is at once in-formalised and subject to a critique of expert knowledge yet simultaneously subjected to professionalising discourses, and the importance of "working together" as a legitimate and valued way of working represent some of the key interests of this study. Each has implications over how the potential 'empowering' effect of direct payments is experienced by employers and personal assistants alike. These discussions cast doubt upon a straightforward empowerment effect of direct payments and direct employment of personal assistants. What becomes interesting is how the financial 'empowerment' of direct employment of personal assistants gives way to different attempts to seek to mould that power so that the relationships become less about being the 'boss' and being the 'employee' towards a more collective, shared life experience. Personalised funding elevates the individual, yet the employers and personal assistants in this project have sought (within reason) to reconnect that individualism to the social and inter-personal. Direct payments are a product of a political analysis of disablement and it would be a terrible irony if personalisation served to remove spaces of political and collective action, the very spaces from which civil rights – the right to take control over your own life - emanated.

Drawing on these emerging themes some suggestions for practice have emerged. This is a small study and these suggestions are tentative, and could be problematic or difficult to implement in practice, but stem from the discussions above which attempted to tease out the essence of these relationships. This project therefore suggests that the experience of empowerment through employing personal assistants is uneven and dependent upon support that goes beyond the provision of help with the bureaucracy of a direct payment. The personal connection between an

employer and personal assistant is critical to empowering support, but these relationships are complex and need support to be managed. Personal assistants' needs were not readily considered in the development of direct payments and support for personal assistants (with the exception of the supervision of the employer) is largely unavailable. In light of these findings these suggestions for practice are offered attempting to recognise the importance of the social in the individual and their experience of 'empowerment'.

- *Pooling budgets*

Personal assistants often work for limited hours, rarely amounting to a full time job. Emily suggests the pooling of direct payments (now more possible with personal budgets) may be a way to maximise outcomes for Ed whilst offering personal assistants more hours and potentially a more supportive environment:

Emily: I [suggested] that a group of carers who could think about maybe pooling their resources of what they were getting and a group of parents employing four or five PAs we could actually give them full-time jobs but they would be working with different people but for the same employer as a group. People were a bit wary because it was how would it work but I'm sure there are ways it could work I really am, but that was a few years ago ...[...]... I have been approached to see about maybe pooling [with PB] pooling our resources and buying a house for 3 young men and it was something I thought wow this is interesting I hadn't thought of that and it depends upon friendships and things ...[...]... quite a tricky one cos you're looking at buying and a mortgage in 3 ways and all that sort of thing, I don't know but there could be a way of pooling resources ...[...]...it could be used more effectively and to help more people cos PAs 2 3 hours bless them but if you



can build up hours its almost like a full time job, but working with 3 or 4 people within that it would make so much sense, people are more likely to stay ...[...]... I just think families are becoming isolated, individuals are becoming isolated with their PAs ...[...]... families are isolated struggling with their PAs its about time people shared all that.

Emily found other parents to be wary of this kind of pooling, perhaps because it abstracts the personal assistant from the employer (as they would effectively become a cooperative) and dilutes the autonomy offered through the direct employment relationship. This approach does offer a way to reconnect with others, however as Emily said above it is not easily achieved in the increasingly disparate, individualised world of self-directed support. *Capable Communities and Active Citizens'* (DH 2010) suggestion of pooling budgets may maximise the benefits for the individual budget holder, and personal assistants, however there needs to be spaces for employers to connect to develop these pools.

- *Inclusive circles of support*

Only two of the participants in this project had a named circle of support or circle of friends. Camille suggested that they do offer her some advice regarding any difficulties she has with her personal assistants. In light of the individualising of support the potential of circles of support is increasing to help people maximise the opportunities available and help to reduce isolation. Although difficult to build (Mansell & Beadle-Brown 2005) the circles have potential, not only to plan support for the employer, but also the personal assistant. A circle, where a member, agreed by the employer, may take responsibility for and be a contact for the personal assistant acting as a legitimate point of contact where they feel unable to talk to their employer. If employers are creating 'micro enterprises', through the recruitment and employment of personal

assistants, then there is an obligation to offer streams of support which do not compromise the personal assistant in their role. There are several difficulties attached to this suggestion. Firstly, many people do not have access to a circle of support to begin with, and secondly there are clear conflicts of interest for the person in the circle who may take the responsibility to be a contact for the personal assistant. However, suggesting this merely looks towards a future where it is understood that personal assistants' needs have to be factored into support and that 'good' personal assistance is premised on a supported and 'empowered' workforce. This suggestion is pointing to a recognition of personal assistants' needs – alongside their employers needs – be that in a circle of support or another structure around the employer and their personal assistant.

- *Self advocacy groups / User Led Organisations*

Historic collectivity in social care provision prompted the call for individualised solutions and people organised around their collective disablement to fight for their individual and collective rights. Now we are moving towards a place where people have achieved the opportunity to create individual solutions to their needs, raising the possibility of isolation, reducing spaces for collective organisation and diminishing the potential for collective provision (for those who want it) (Spandler 2004; Scourfield 2007; Carr 2008).

The self-advocacy group in this area sprang out of a group of people and support workers from a day centre. Spaces of collective action, or just meeting friends have shifted from group environments to individuals in the community, a 'community' which offers its own challenges for people without learning difficulties. Self-advocacy groups are suffering from a lack of any core funding (Pridmore & Rose 2010) and in spite of a

government commitment to the development of User Led Organisations in *Capable Communities, Active Citizens* (DH 2010) many are struggling to survive. It is crucial that any User Led Organisation such as a Centre for Independent Living involves people with learning difficulties and that it offers space for self-organisation recognising the importance of shared experiences and opportunities for collective action.

These suggestions for practice have attempted to draw out the expressions of isolation implied by many of the participants into practical action and activity. Creating spaces for collectivity, as well as the 'community' identified in government literature, may be a starting point for disparate direct payment employers and personal assistants to connect. Through this connection individualised as well as collective analysis of social care support, resilience (Goodley 2005) and importantly resistance has the potential to occur to continue the ongoing struggle to recognise the legitimate needs and aspirations of people with learning difficulties and their personal assistants.

## Chapter 9

### Conclusion: Searching for the personal and the collective

Katrina: We have to revive that initial enthusiasm ...[...]... We need that fire in our belly, we are here, we want you to listen to what we want from our lives ...[...]... most commissioners don't have a clue about the history of learning difficulties, where we are coming from what people's dreams are. They just want to be listened to and want opportunities ...

This quote from Katrina, the self-advocacy supporter, sums up what is at risk in the personalisation agenda. The 'I' in personalisation threatens to damage the 'we' in the very social movements, of disability activists and self-advocates working collectively, which fought so hard for their rights to independent lives. New independent identities, in tandem with the collective, have been fought for by the disability movement and forged and crafted by these employers who have learning difficulties. These people are those who lived in residential care, went to day centres and now are taking advantage of some of the opportunities now available, but they are also subject to discourses which are 'confused and at times unhelpful and contradictory, mobilising elements that simultaneously 'support and confront social processes that create inequalities, oppression and exclusion' (Burton & Kagan 2006: 299). In spite of at times competing visions, the rhetoric of the personalisation agenda fits comfortably within the disability and people with learning difficulties self-advocacy movement's emancipatory discourses (Burton & Kagan 2006: 299). However, the heightening of the individual within the personalisation agenda, over the collective (mobilised within the Independent Living Movement) raises possibilities of disempowerment for those who do not want or cannot, with the limited support available, become the idealised 'responsible' (Clarke et al 2007) and 'entrepreneurial' citizen (Scourfield 2007).

The opportunities to directly employ personal assistance, for the employers in this project, reflected some of the positive outcomes of other studies; the opportunity to live independently (Hasler et al 1999), the option to employ a personal assistant of their choice and design support around their lifestyle rather than traditional services bound by fixed shift patterns. Personal assistants also spoke positively about the *personal* in personal assistant work offering the ability to work in person centred ways unrestricted by fixed shift patterns and work pressures often connected with agency support work.

Influentially Hasler et al (1999: 5) stated, direct payments are ‘...a means to an end and that end is independent living’. The aims remain clear. Nevertheless direct payments as a policy development are as much a political endeavour, responding to new global realities (Cerny & Evans 2004) as they are about individuals’ lives, their choices and their support. The localism, which appeals on the levels of user involvement and co-production is the very point at which some ‘responsible’ consumer entrepreneurs can create personalised solutions, but equally where others are not adequately supported to ‘succeed’ in developing ‘empowering’ individual solutions.

The *Roles, Responsibilities and Relationships* chapters have sought to expose social relations of support through direct payments, characterising the personal assistant role as *practical* and *personal*, but also situating support within a social context which offers ‘choice’ and ‘control’, but where choices are framed within responsible and less responsible decisions. Choice as a construct and ambition of the personalisation agenda has been problematised and positioned within the confines of the ongoing responsabilisation agenda (Clarke et al 2007). Where responsibilities have been linked to discourses of empowerment it has been argued that the relationships involved in working with a, well-documented, unsupported workforce (TUC 2008), may serve to replicate

old dependencies in new ways. The *personal* in personal assistance has been a powerful theme running through the entirety of this project. The *personal* offered numerous positives for both employer and personal assistants, but equally positioned these new support relationships as vulnerable through the development of new and unstable 1:1 dependencies and positioned support relationships as one step removed from the imagined re-arrangement of power through the new social relations of support.

Discourses of 'empowerment' within personalisation are firmly rooted within discourses of consumer capitalism and the power of the markets to respond to demand. The findings of this project suggest that the value of these new social relations of support do not necessarily lie in the (re-arranged and purposefully) unequal power relations of employer and employee, rather a negotiation between employer and personal assistant whereby the commodified aspect of their role is subtly manipulated by the different participants. This manipulation shifts the contract (which in many cases was vague) and allows for in-formalised aspects of the role to emerge. Although the in-formalising and (de)commodifying of these support relationships varies between individuals and their respective personal assistants, this process – articulated at times explicitly through "payment in kind" and at other times implicitly through high expectations beyond job descriptions - does raise a critical question mark over the fundamental assumption that power lies in the purchasing of personal assistants' time. The power to shape the support relationship relies upon the process of commodification and purchasing power, but once in place it is negotiated to such an extent that the commodification of support becomes an awkward commodity and it is the more in-formalised aspects of the support relationship which become valued. These negotiations of support relations emphasise a shift away from 'being the boss' to the value of working together and interpreting independence and control as a collective endeavour.

Duffy (2011: 12-13), in spite of his enthusiasm for self-directed support has written 'Individual Budgets like direct payments haven't transformed social care on their own and they won't'. Taking a direct payment, through a personal or individual budget is not the panacea of empowerment. Much has been gained through enabling people to direct their own support and employ their own personal assistants, but other things (and some good things) are in danger of being lost.

The rights at the foundation of the Independent Living Movement and the development of direct payments were not built upon community action, but collective autonomous organisation and mobilisation of disabled people. The process of personalisation and individualisation threatens the spaces and places where a collective analysis of individual need can be expressed and acted upon. The employers in this project relished the opportunity to manage their own support, however many equally expressed a sense of isolation and sought support from families and friends and for some the local self-advocacy group. The future of self-advocacy groups (due to funding restraints) is in doubt (Pridmore & Rose 2010) and without further inquiry into how employers with learning difficulties develop the 'resilience' (Goodley 2005) to assert their needs to their personal assistants, and in the wider community, the potential for experiencing direct employment of personal assistants as an empowering solution may be limited. The loss of the collective in the world of personalised funding has been, if not the intention then an inevitable by-product. Whilst offering the ability to be an individual, make 'socially valued friends', live and perhaps work 'independently', the potential consequences in terms of isolation and unequal outcomes requires a collective response. The inequalities inherent in any system that relies on individual ingenuity and social capital need to be addressed and there needs to be a recognition of the risks associated with an increasing number of isolated workers supporting people who may themselves be isolated in our communities.

In terms of personal assistants, specific challenges and tensions have emerged. Central to the personalisation agenda, in particular as articulated by Leadbeater et al (2008), is scepticism of the potential of state run services to adapt to individual needs and demands positioned within a critique of expert knowledge. This is a long-standing critique similarly articulated by disability activists in the development of the social model of disability (Oliver 1996) and further associated with analysis of 'reflexive modernity' (Giddens 1994). It is here that some of the challenges to the personalisation agenda become apparent. There are implicit and explicit tensions at play in the agenda which impact upon the potential for personalisation, direct payments and employing personal assistants to act as a lever of empowerment for people with learning difficulties.

Personal assistants have been positioned as largely unsupported, expected to be 'empowered' (DH 2009c) and work in 'empowering ways' (DH 2005a) – representing personal assistants' responsibilities *to* their employer. Yet, in other ways they have responsibilities *for* their employer – in terms of managing risks and taking responsibility beyond their job description. In addition personal assistants, in this project and others (Flynn 2005; Leadbeater et al 2008) have been positioned as in-formalised workers as well as subjected to professionalising discourses in the government literature (DH 2005a; DH 2011). Since the inception of direct payments employers have expressed a preference to employ inexperienced and unqualified workers as personal assistants (Morris 2004) emphasising that personal assistants do not have 'expert' knowledge. The perpetuation of personal assistance as in-formalised work - described by Kelly (2011) as an expert in their individual employer – serves to maintain support work as low skilled, low paid with few rights and often no union protection. Personal assistants are a vulnerable workforce. To approach the personal assistant workforce as a skilled qualified group of workers has so far been avoided as if a truly 'empowered' workforce would act to 'disempower' their employers. This



is one of the central tensions in the discourses surrounding direct payments and requires ways of thinking which can at once legitimise the needs of a vulnerable workforce without assuming that this will impact negatively upon the experience of employers. In fact this project would suggest that it is only by acknowledging the needs of all in these new social relations of support that either can hope to be 'empowered'.

The people in this project are the active, entrepreneurial citizens, who were early adopters of a policy, which aims to offer control and to empower. These connected, active and entrepreneurial citizens expressed positive feelings about creating the support they need to live their lives the way they choose. However, even this group of people expressed feelings of frustration, the possibility that it may all be taken away, and a sense of isolation with the challenges of becoming an employer with limited support. Personal assistants expressed similar positive feelings about how direct payments enable them to work in flexible and person centred ways for their employers. However they were equally placed in difficult support situations in a context where support is rarely solely practical, but a complex interplay of *practical, personal* and broader social pressures in their role as a 'technology of citizenship'. The daily complexity of managing and offering support will remain if the issue of support for assistants continues to be overlooked. Personal budgets are in the process of being rolled out with the expectation that the majority of social care users will take their budget as a direct payment in the future (DH 2010) and without 'appropriate' consideration of the needs of both employers and crucially their personal assistants the potential benefits of these new social relations of support will remain unevenly experienced and success limited by its in-equality of opportunity dictated by the very need for support in the first place.

## Appendix I:

Accessible information leaflet.



## **'Changing Relations': A project about people who employ their own Personal Assistants.**



You are being invited to take part in a research project about people who employ their own Personal Assistants.



And people who work as Personal Assistants.



This leaflet explains what the project is all about, why I am doing it and what will happen. This is to help you decide if you would like to take part.

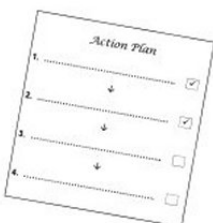
### **What is the project about?**



My name is Katie Graham. I am a student at the University of York working towards a PhD which is a course which involves doing some research and talking to people about their experiences.



I am interested in how personal budgets and direct payments can offer people who have learning difficulties more independence and choice.



I will write up the things I learn as a part of my PhD course.

I think that to understand how direct payments work, when used to employ a Personal Assistant, it is important to talk to everyone involved:



- People who employ a Personal Assistant.



- People who help you manage your budget.



- And the Personal Assistants who you employ.

## **Why have I asked you to be involved?**

I am looking for people who have a personal budget or direct payment and employ their own Personal Assistant(s) and are happy to tell me about their experiences.



I have asked you because you employ your own Personal Assistant.

## **Do I have to take part?**

No, it is your decision.



If you would like to take part and then change your mind you can leave at any point.



## What will happen if I choose to be involved?

I would like to come to chat with you about what employing your own Personal Assistant means to you. I am also interested in what independence, choice and inclusion mean to you.



I would like to speak to you about how employing a Personal Assistant has changed your experience of support. We can do this in lots of different ways and we can talk together to find the best way.



As a part of the project I would also like to talk to your Personal Assistant about what independence, choice and inclusion mean to them and how they support you to live how you want to live.



I would also like to talk to family or friend about their experiences of supporting you with your personal budget or direct payment.



## What will happen to the things I tell you?

All the information you give me will be kept confidential.



All recordings, notes and photos (if used) will be kept securely and will be deleted when the study is finished in September 2011.



All information will be used and stored in line with the Data Protection Act 1998.



I can give you a copy (in full and or an accessible version) of the project when it is completed in September 2011.

I would also like to invite you to be a part of a group to create a booklet which could help other people who are thinking about employing their own Personal Assistant.

## Who can I talk to for more information about the project?

If you have any questions or would like more information please contact Katie Graham.

**My phone number is:** 07970741632



**My address is:** Social Policy and Social Work  
Seebolm Rowntree Building  
University of York  
Heslington  
YO10 5DD

**E-mail:** [keg502@york.ac.uk](mailto:keg502@york.ac.uk)



**If you would like to get involved please let me know. I look forward to hearing from you.**

If you have any concerns or complaints about how this research is being done please contact:



Dr Robert McMurray,  
Chair Humanities and Social Sciences Ethics  
Committee  
University of York,  
Sally Baldwin Buildings Block A,  
Heslington Road,  
York, YO105DD.  
E-mail: [rm517@york.ac.uk](mailto:rm517@york.ac.uk).

## Consent Form



Everyone who takes part in any research project needs to give their consent to take part.



This is to make sure that I have given you all the information you need to make the decision that is right for you.



The next pages are the consent form for this project.



If you have any questions please feel free to ask.



## 'Changing relations' Consent Form

This form is for you to say if you agree to take part in this study.



Please read the statements below and tick to say 'yes' if you understand and agree and 'no' if you need more information or do not agree.

Please ask Katie if you have any questions.



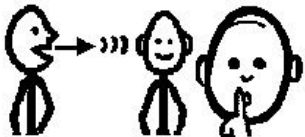
- I have read the information leaflet and understand what the research is about.

Yes  No



- I have been offered the chance to ask Katie questions about the research.

Yes  No



- I understand that all information I share will be kept confidential and all names will be changed.

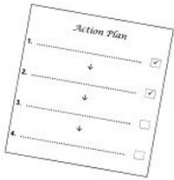
Yes  No



- I understand that I can leave the project at any time. This project will have no effect upon your personal budget or direct payment.

Yes  No





- I understand that Katie will use some of the information I share to write up the study for her PhD.

Yes  No



- I am happy for Katie to talk to the person who supports me to manage my budget.

Yes  No



- I am happy for Katie to talk to my Personal Assistant about their experiences of working as a Personal Assistant.

Yes  No



- Do you agree to your interview being recorded? You may still take part if you do not agree.

Yes  No



- I understand that Katie would like to create a booklet to help other people make the most of their personal budgets. **I would like to be involved.**

Yes  No

Your name: .....

Date: .....

Your signature: .....

Date: .....

Interviewer's name: .....

Date: .....

## Appendix II:

### Personal assistant information leaflet